Draft Code of Practice

on

Advance Healthcare Directives for Health and Social Care Professionals

March 2018

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2015 Act

Advance Healthcare Directive
An Advance Healthcare Directive is an advance expression made by a person with capacity in accordance with the requirements of the 2015 Act of the person’s will and preferences concerning healthcare treatment decisions that may arise if s/he subsequently lacks capacity.

Advance Healthcare Planning
Advance healthcare planning can be described as a process of discussion and reflection about the goals, values, will and preferences for healthcare treatment occurring in the context of an anticipated deterioration in the person’s condition. Advance healthcare plans are generally not legally enforceable (unless they are in the form of an Advance Healthcare Directive).

Applicability
Applicability refers to whether something applies, in other words, is relevant in a particular situation. This must be distinguished from applicable in the context of an Advance Healthcare Directive under the 2015 Act (see Section 4.2).

Basic Care
Basic care includes (but is not limited to) warmth, shelter, oral nutrition, oral hydration and hygiene measures but does not include artificial nutrition or artificial hydration.

Cardiac Arrest
A cardiac arrest is when a person’s heart suddenly stops pumping blood round their body, commonly because of a problem with electrical signals in their heart. When
their heart stops pumping blood, their brain is starved of oxygen. This causes them to fall unconscious and stop breathing.

**Cardiopulmonary Resuscitation (CPR)**
Cardiopulmonary resuscitation (CPR) is an attempt to restore breathing (sometimes with support) and spontaneous circulation in an individual in cardiorespiratory arrest. Cardiopulmonary resuscitation usually includes chest compressions, attempted defibrillation with electric shocks, injection of drugs and ventilation of the lungs.

**Clinician**
A clinician is a physician or other qualified person who is involved in the treatment and observation of patients.

**Clinically Indicated**
This refers to a valid reason and evidence to use a certain test, medication, procedure or surgery.

**Co-Decision-Maker**
This is a person appointed by a relevant person to jointly make decisions with him or her. This may occur where the relevant person does not have the capacity to make decision(s) even with the aid of a Decision-Making Assistant, but does have the capacity to make decision(s) with the help of a Co-Decision-Maker. A Co-Decision-Maker must be appointed in a written and witnessed agreement.

**Court**
The Circuit Court has general jurisdiction under the 2015 Act, apart from certain matters reserved for the High Court:

- a) Any decision regarding the donation of an organ from a living Donor where the Donor is a person who lacks capacity;
- b) Where an application in connection with the withdrawal of life-sustaining treatment for a person who lacks capacity comes before the courts for adjudication.
**Decision-Making Assistant**
An individual appointed by a relevant person to support him or her in making a decision, for example, by obtaining information or personal records, and ensuring that the relevant person's decisions are implemented. The Decision-Making Assistant will not make the decision on behalf of the person. All decisions are made by the relevant person.

**Decision-Making Capacity**
Decision-making capacity is defined as the person's ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time.

**Decision-Making Representative**
A person appointed by the Court when the relevant person lacks capacity to make a decision. The scope of a Decision-Making Representative’s authority will depend on the authority to make decisions specified by the court in the court order, which may include the attachment of conditions relating to the making of decisions by the Decision-Making Representative, or the period of time for which the order is to have effect.

**Decision Support Service**
The Decision Support Service is the government body set up to oversee the Assisted Decision Making (Capacity) Act 2015. It’s role is to provide information to people in relation to their options to exercise their capacity; provide information to, and provide oversight of the legally recognised persons who have authority to assist and support a relevant person; make recommendations to the Minister on any matter relating to the operation of the Act; and raise awareness of the Act.

**Designated Healthcare Representative**
Designated Healthcare Representative is the named individual designated by the Directive-Maker, in his or her Advance Healthcare Directive, to exercise the relevant powers.
Directive-Maker
The Directive-Maker is the person who made the Advance Healthcare Directive or in relation to a Designated Healthcare Representative, means the person who made the Advance Healthcare Directive under which the representative was designated as such representative.

Director of the Decision Support Service
The Director of the Decision Support Service is the head of the government body set up to oversee the Assisted Decision Making (Capacity) Act 2015.

Do Not Attempt Resuscitation (DNAR) Order
A Do Not Attempt Resuscitation (DNAR) Order is a written order stating that resuscitation should not be attempted if an individual suffers a cardiac or respiratory arrest.

Electroconvulsive Therapy (ECT)
Electroconvulsive therapy is a procedure which is occasionally used as a treatment for a mental health condition, done under a general anaesthetic in which small electric currents are passed through the brain.

Enduring Power of Attorney (EPA)
An Enduring Power of Attorney is an arrangement whereby a Donor (the person who has capacity) gives authority to an Attorney (which in the context of the 2015 Act means the person to whom authority is given) to act on their behalf in the event that the Donor lacks decision-making capacity at any time in the future. This may be in respect of all or some of the Donor’s property and affairs, or to do specified things on the Donor’s behalf, including the making of personal welfare decisions.

Functional Approach to Assessing Decision-Making Capacity
Assessing decision-making capacity on a functional basis means that the emphasis is on the specific decision to be made at the time the decision has to be made (issue-specific and time-specific).

1. Issue-specific: decision-making capacity is assessed only in relation to the decision in question. A judgement that a person lacks decision-making
capacity in relation to one issue does not have a bearing on whether decision-making capacity is present in relation to another issue.

2. Time-specific: decision-making capacity is assessed only at the time in question. A judgement that a person lacks decision-making capacity at one time does not have a bearing on whether decision-making capacity in relation to that issue is present at another time.

3. The functional approach to assessing decision-making capacity focuses on how a person makes a decision and not the nature or wisdom of that decision.

**General Practitioner (GP)**
A doctor based in the community who treats patients with minor or chronic illnesses and refers those with serious conditions to a hospital.

**Health and Social Care Professional**
Health and Social Care Professional is generally used as an umbrella term to cover all the various health and social care staff who have a designated responsibility and authority to obtain consent from persons prior to an intervention. These include, but are not limited to, doctors, dentists, psychologists, nurses, allied health professionals, social care staff, and social workers.

**Interveners**
The 2015 Act provides for legally recognised persons referred to as ‘interveners’ to support a person to maximise their decision-making capacity. An intervener can be:

(a) The Circuit Court or High Court,

(b) A decision-making assistant, co-decision-maker, decision-making representative, Attorney or Designated Healthcare Representative

(c) The Director of the Decision Support Service,

(d) A Special Visitor or a General Visitor, or

(e) A Health and Social Care Professional.

**Intervention**
An intervention in relation to a relevant person means any action taken, direction given or any order made in respect of a relevant person under the 2015 Act. The intervention may be made by the courts, by a Health and Social Care Professional,
or any person under the formal agreements set out in the Act. The intervention will reflect the level of support the person requires from an ‘intervener’ or by the Director of the Decision Support Service. This includes interventions related to health and social care made in healthcare settings, in social care settings such as nursing homes and residential settings for people with disabilities or mental health needs, in peoples’ own homes and in the community.

**Life-Sustaining Treatment**
This is any medical intervention, technology, procedure or medication that is administered to provide benefit for a person and to forestall the moment of death. These treatments may include, but are not limited to, mechanical ventilation, artificial hydration and nutrition, cardiopulmonary resuscitation (CPR), haemodialysis, chemotherapy, or certain medications including antibiotics (although antibiotics are not routinely considered to be life-sustaining treatment).

**Palliative Approach**
A palliative approach refers to the application of palliative care principles by all Health and Social Care Professionals who do not solely work in specialist palliative care. The palliative care approach aims to promote both physical and psychosocial well-being. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles.

**Palliative Care**
Palliative care improves the quality of life of persons and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual. The aim of palliative care is to enhance quality of life and, wherever possible to positively influence the course of illness. Palliative care also extends support to families to help them cope with their family member’s illness and their own experience of grief and loss.

**Presumption of Decision-Making Capacity**
This means that it shall be presumed that a person has capacity in respect of a specific matter unless otherwise shown. The onus of proving that a person lacks
capacity to make a decision is on the person who is questioning a relevant person’s ability to make a particular decision.

**Relevant person**

Relevant person means:

- A person whose capacity is in question or may shortly be in question in respect of one or more than one matter (i.e. a person who may have difficulty making a decision without the support of another person);
- A person who lacks capacity in respect of one or more than one matter (in other words, a person who may be able to make some decisions but not others); or
- A person whose capacity is in question or may shortly be in question in respect of one or more than one matter and who lacks capacity at the same time but in respect of different matters (a combination of the above – in other words, person who now, or may in the future, need support in making a decision in respect of different matters).

**Revocation**

Revocation means the cancellation of a legal document.

**Treatment**

Treatment means an intervention that is or may be done for a therapeutic, preventative, diagnostic, palliative or other purpose related to the physical or mental health of the person and includes life-sustaining treatment.

**Unwise Decision**

An unwise decision is a decision that someone makes that is different to the decision that another person would make based on the same evidence, which they perceive as being ill-advised or risky. This may reflect a difference in values, goals and preferences between the person and the person interacting with them. The decision may have adverse consequences for the person.
Validity
Validity is the state of being officially legally binding or acceptable

Wardship
Wardship is the current process whereby an application is made to the court in respect of a person who lacks decision-making capacity. The person who is the subject of such application is known as a Ward of Court.
1. Introduction

Advance Healthcare Directives have been introduced into Irish law as part of the Assisted Decision-Making (Capacity) Act 2015 (herein referred to as the 2015 Act).

A person with capacity, known as a ‘Directive-Maker’, may make an Advance Healthcare Directive that will come into effect when they lack the capacity to make healthcare treatment decisions for themselves. The purpose of an Advance Healthcare Directive is to provide Health and Social Care Professionals with important information about a person’s healthcare treatment choices and to enable a person to be treated according to his or her own ‘will and preferences’ even when he or she no longer has the capacity to make decisions. A person’s ‘will and preferences’ are their wishes, views, beliefs and values.

The goal of an Advance Healthcare Directive is to enable a person’s will and preferences to guide his or her healthcare treatment even when that person no longer has the capacity to make decisions for him or herself. This can be important because in some situations, in the absence of an Advance Healthcare Directive, a person’s will and preferences may not be known to those providing treatment or to his/her family members.

1.1 Who is this code for?

This code is for all Health and Social Care Professionals who are interacting with persons in relation to Advance Healthcare Directives. It explains what an Advance Healthcare Directive is; sets out the formalities in making, revoking and amending an Advance Healthcare Directive; and provides direction for Health and Social Care Professionals when interacting with persons who have made an Advance Healthcare Directive and their Designated Healthcare Representatives.

All Health and Social Care Professionals should familiarise themselves with this code and ensure that it is brought to the attention of relevant staff in their area of
responsibility where necessary. It is important to periodically review all of the Codes of Practice as they may be updated as developments occur.

1.2 What is an Advance Healthcare Directive?

An Advance Healthcare Directive is a legal document that sets out a person’s will and preferences in relation to their healthcare treatment decisions. It will apply if (and only if) the person lacks capacity to make those decisions for themselves.

As well as setting out their will and preference, the person may also appoint a trusted person, known as a Designated Healthcare Representative, to act on their behalf in relation to healthcare treatment decisions if they lack capacity.

1.3 What is the legal status of this code?

This code seeks to give guidance to Health and Social Care Professionals in relation to meeting their statutory obligations under Part 8 of the 2015 Act.

The provisions of this code can be used in evidence and, if relevant, may be taken into account in any civil, criminal or other proceedings before a court, tribunal or other body concerned.

1.4 Terminology used in the code

A range of terminology will be used throughout this Code of Practice:

- Advance Healthcare Directive is an advance expression made by a person with capacity in accordance with the requirements of the 2015 Act of the person’s will and preferences concerning healthcare treatment decisions that may arise if s/he subsequently lacks capacity.
The Directive-Maker is the person who has written the Advance Healthcare Directive. In some circumstances the terms patient and person will also be used.

The 2015 Act refers to the Assisted Decision-Making (Capacity) Act 2015

Decision-making capacity is the ability for people to make their own decisions. It is the ability to understand, at the time that a decision is to be made, the nature and consequences of the decision in the context of the available choices at that time.

Health and Social Care Professionals refers to the various health and social care staff who support people while they are receiving healthcare treatment. These include doctors, dentists, psychologists, nurses, allied health professionals. This term will be used throughout the document. Specific references to particular professional groups e.g. doctors, clinicians, nurses will also be used where necessary.

Designated Healthcare Representative is the person named in an Advance Healthcare Directive to ensure that the Advance Healthcare Directive is complied with when the Directive-Maker has lost capacity.

1.5 The Assisted Decision-Making (Capacity) Act 2015

The Assisted Decision Making (Capacity) Act 2015 establishes a modern legal framework to support decision-making by adults who have difficulty now, or may have difficulty in the future, in making decisions without support, and in some limited circumstances, allows for a court appointed decision-maker with legal oversight.

In addition to setting out the legal framework for the recognition and implementation of healthcare treatment decisions made in an Advance Healthcare Directive, the 2015 Act also sets out Guiding Principles which apply before and during any intervention. These Guiding Principles must be applied by everyone interacting with a person.
1.6 Functional approach to decision-making capacity

The 2015 Act requires that a person’s decision-making capacity is assessed using the functional approach. This means that a person’s decision-making capacity must be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time. In order to do this, the person must be able to:

- Understand the information relevant to the decision to be made;
- Retain this information for long enough to make a voluntary decision;
- Use and weigh up the information;
- Communicate his or her decision.

The functional approach to decision-making capacity has the benefit of facilitating people to make their own decisions whenever possible and minimises the restriction on an individual’s decision-making autonomy. ‘Blanket’ assessments of a person’s general capacity to make decisions should not be made.

Functional capacity is:

1) Issue-specific – capacity is assessed only in relation to the decision in question. A judgement that a person lacks decision-making capacity in relation to one issue does not have a bearing on whether decision-making capacity is present in relation to another issue.

2) Time-specific – capacity is assessed only at the time in question. A judgement that a person lacks decision-making capacity at one time does not have a bearing on whether decision-making capacity in relation to that issue is present at another time.

3) Context-specific – capacity is assessed in a particular context, based on choices available in that context when a particular decision is to be made.

The fact that someone is likely to make an unwise decision is not evidence that the person may lack capacity to make that decision.
1.7 Guiding principles of the Assisted Decision-Making (Capacity) Act 2015

The 2015 Act sets out a number of Guiding Principles.

**Principles of the Assisted Decision-Making (Capacity) Act 2015 include**

- The presumption of capacity
- Supporting people to maximise capacity and supporting decision-making
- Respecting people’s choices and unwise decisions
- An intervention is not always required
- Any intervention should be as limited as possible
- Essential considerations when making an intervention
- The urgency of the matter and the likelihood of the relevant person regaining capacity
- The inclusion of other people whose views may be helpful
- Respecting the privacy of the relevant person
- The use of the functional assessment of decision-making capacity

The following Guiding Principles are particularly relevant to Advance Healthcare Directives.

### 1.7.1 Presumption of Capacity

A person is presumed to have the capacity to make a specific decision at the time the decision is made unless the contrary is clearly indicated. This means that Health and Social Care Professionals must presume that the person they are providing healthcare treatment to has the capacity to make his or her own decisions. A person’s Advance Healthcare Directive only comes into effect when they do not have capacity.

Health and Social Care Professionals should always start with the presumption that the person had the capacity to make the Advance Healthcare Directive, unless there
are reasonable grounds to believe that the person did not have the capacity to make it at the time it was made. The burden of proof in showing that a person did not have capacity to make the Advance Healthcare Directive falls to the person questioning the Directive-Makers capacity.

1.7.2 Supporting people to maximise capacity and supporting decision-making

A relevant person…… shall not be considered as unable to make a decision in respect of the matter concerned unless all practicable steps have been taken, without success, to help him or her to do so.

Assisted Decision Making (Capacity) Act 2015, Section 8 (3)

Health and Social Care Professionals must take all practicable steps to help the person make the decision at the time the decision has to be made. They may only rely on the Advance Healthcare Directive when the person lacks capacity to make the decision.

1.7.3 Respecting people’s choices and unwise decisions

A relevant person…… shall not be considered as unable to make a decision in respect of the matter concerned merely by reason of making, having made, or being likely to make, an unwise decision.

Assisted Decision Making (Capacity) Act 2015, Section 8 (4)

A Health and Social Care Professional cannot decide that a person lacked decision-making capacity at the time s/he made the Advance Healthcare Directive because s/he believes that a healthcare treatment decision made in the person's Advance Healthcare Directive is unwise or not related to sound medical principles.
1.7.4 Will and preference of the relevant person

The intervener, in making an intervention in respect of a relevant person, shall: –
(a) permit, encourage and facilitate, in so far as practicable, the relevant person to participate, or to improve his or her ability to participate, as fully as possible, in the intervention,
(b) give effect, in so far as is practicable, to the past and present will and preferences of the relevant person, in so far as that will and those preferences are reasonably ascertainable,
(c) take into account
(i) the beliefs and values of the relevant person (in particular those expressed in writing), in so far as those beliefs and values are reasonably ascertainable, and
(ii) any other factors which the relevant person would be likely to consider if he or she were able to do so, in so far as those other factors are reasonably ascertainable.

Assisted Decision Making (Capacity) Act, Section 8 (7)

This principle means that even if an Advance Healthcare Directive is found not to be applicable or valid (see Section 4), it is still a very important expression of the person’s will and preferences and should, therefore, be taken into consideration as part of the decision-making process regarding that person’s healthcare treatment.
2. Advance Healthcare Directives

2.1 What is an Advance Healthcare Directive?

An Advance Healthcare Directive is a written statement made by a person who is 18 years of age or older, with capacity. It sets out their will and preferences about healthcare treatment decisions that they do not want to receive in the future, if a time comes when they lack capacity to make such decisions or cannot communicate their decision by any means.

The Advance Healthcare Directive must be in writing and must be witnessed. The person making the Advance Healthcare Directive (who is called a Directive-Maker) may set out his or her will and preferences with regard to healthcare treatment choices in an Advance Healthcare Directive and/or the Directive-Maker may appoint another individual called a Designated Healthcare Representative. The role of Designated Healthcare Representative is to ensure the terms of the Advance Healthcare Directive are complied with, or to make healthcare treatment decisions for the Directive-Maker with reference to what s/he has set out in his/her Advance Healthcare Directive. This can include decisions about refusing life-sustaining treatment, if this has been specifically provided for in the Advance Healthcare Directive.

An Advance Healthcare Directive only comes into effect when the Directive-Maker lacks capacity to consent to or to refuse healthcare treatment at the time the healthcare treatment decision has to be made.

A person is not obliged to make an Advance Healthcare Directive and it is important that an Advance Healthcare Directive is made voluntarily (see Section 4.1.1). A Directive-Maker who has capacity may cancel his or her Advance Healthcare Directive at any time. Such cancellation must be in writing (see Section 3.5).

An Advance Healthcare Directive cannot be used in the following circumstances:
• It cannot be used to give effect to an unlawful act such as euthanasia or assisted suicide. These are still criminal acts under Irish law.
• It cannot be used to authorise a non-therapeutic sterilisation procedure.
• It cannot be used to make any decision regarding organ donation from a person lacking capacity. However, people can make their will and preference known in their Advance Healthcare Directive regarding organ donation after death.
• There are also restrictions in the use of an Advance Healthcare Directive for a person who is involuntary detained under the Mental Health Act 2001 or the Criminal Law (Insanity) Act 2006 (see Section 6.2.2).

An Advance Healthcare Directive does not need to be written by, or witnessed by a solicitor.

2.2 Role of an Advance Healthcare Directive

There is a general legal principle that an adult has the right to consent to and the right to refuse healthcare treatment. An Advance Healthcare Directive means that a person can rely on this legal principle even if s/he lacks capacity. If the person has made a valid and applicable Advance Healthcare Directive to refuse healthcare treatment then that refusal is a valid legal refusal and must be respected. While advance requests for healthcare treatment are not legally binding they represent a valuable source of information to Health and Social Care Professionals about the healthcare treatment decisions of the person which may assist with the clinical decision that has to be made (see Section 2.3.2).

The following vignette demonstrates how an Advance Healthcare Directive can work in practice:
Mr Atkins has severe heart failure and has been admitted to hospital with increased shortness of breath for the third time in six months. He is aware of the seriousness of his condition. He has a discussion with his doctor, Dr Brody, who agrees that in accordance with Mr Atkins wishes that while all other healthcare treatment will be provided, cardiopulmonary resuscitation (CPR) and ventilation will not be performed in the event of cardiac arrest. This discussion is documented by Dr Brody and a ‘Do Not Attempt Resuscitation’ (DNAR) order is recorded in Mr Atkins notes.

Mr Atkins responds to treatment. Before returning home, Dr Brody asks Mr Atkins if he would like to discuss Mr Atkins’s future will and preferences which would apply if Mr Atkins no longer had capacity to makes decisions about his healthcare treatment. Mr Atkins says that he would wish, if he were to have a cardiac arrest at any stage, to be allowed to die peacefully rather than receiving cardiopulmonary resuscitation. Dr Brody suggests that he make an Advance Healthcare Directive to ensure that his will and preferences are made known to those who will be treating him, whether at home or during any subsequent hospital admission. Dr Brody and Mr Atkins work together to draw up an Advance Healthcare Directive reflecting Mr Atkins’ will and preferences, including the appointment of his daughter as his Designated Healthcare Representative. This is subsequently signed and witnessed. Copies of the Advance Healthcare Directive are placed in the hospital chart and sent to Mr Atkins general practitioner.

This vignette demonstrates the ways in which a person can use an Advance Healthcare Directive to direct future healthcare treatment decisions so as to ensure that his or her will and preferences are respected. It also shows the important contribution of Health and Social Care Professionals in working with patients in developing an Advance Healthcare Directive.
2.3 The implications of an Advance Healthcare Directive

Both a request and a refusal of healthcare treatment can be set out in an Advance Healthcare Directive.

2.3.1 Refusal of healthcare treatment

A refusal of healthcare treatment in an Advance Healthcare Directive is legally binding provided the Advance Healthcare Directive is valid and applicable (validity and applicability are described in Section 4). This means that a Health and Social Care Professional is legally required to comply with a refusal of healthcare treatment set out in an Advance Healthcare Directive even if he or she disagrees with it. The legal obligation to comply with an Advance Healthcare Directive arises once the following conditions are met:

- At the time in question, the Directive-Maker lacks capacity to give consent to the healthcare treatment;
- The healthcare treatment to be refused is materially the same as that in the Advance Healthcare Directive; and
- The circumstances in which the refusal of healthcare treatment is intended to apply are materially the same as those in the Advance Healthcare Directive.

If there are ambiguities in relation to the Advance Healthcare Directive, there are procedures that should be followed (see Section 4.3).

If the Advance Healthcare Directive does not meet the statutory criteria, it is still important because it conveys significant important information in relation to the person’s healthcare treatment will and preferences (see Section 4.4).

2.3.2 Request for healthcare treatment

An Advance Healthcare Directive may include a request for a specific healthcare treatment. This request is not legally binding. A person cannot insist upon a healthcare treatment that is, for example, not available in the service in question or is
not clinically indicated. Situations where a healthcare treatment may not be clinically indicated include those where the Health and Social Care Professional judges that a healthcare treatment:

- Is unlikely to work; or
- Might cause the patient more harm than benefit; or
- Is likely to cause the patient pain, discomfort or distress that will outweigh the benefits it may bring.

However, a request for healthcare treatment is an indication of the will and preferences of the individual. Respect for the individual’s rights of autonomy and dignity requires that it be afforded serious consideration. Any request for healthcare treatment must be taken into consideration during any decision-making process if, at a time when the Directive-Maker lacks capacity to participate in such a process, the specific healthcare treatment is potentially relevant to the Directive-Maker’s medical condition. If the reason that the Health and Social Care Professional does not comply with the request is because s/he has a conscientious objection to providing the healthcare treatment in question, s/he must abide by the requirements as set out in Section 2.4.5.

Where a request for a specific healthcare treatment set out in an Advance Healthcare Directive is not complied with, the Health and Social Care Professional involved in that decision-making process must:

1. Record the reasons for not complying with the request in the Directive-Maker’s healthcare record, and
2. Give a copy of those reasons to the person’s Designated Healthcare Representative (if any) as soon as possible and not later than 7 working days after they have been recorded.

An example of a response to a request for healthcare treatment in an Advance Healthcare Directive can be seen in the following vignette:
Vignette 2: Request for healthcare treatment

Mr Fogarty, who is aged 75 years, has strong views about the value of life. He has some communication difficulties after a stroke and is keen that Health and Social Care Professionals will know his will and preferences if he ever requires emergency healthcare treatment. He makes an Advance Healthcare Directive saying that he wants cardiopulmonary resuscitation and immediate transfer to hospital where he wishes to avail of any possible life-saving treatment if he is ever seriously unwell and unable to express his own views.

When Mr Fogarty presents his Advance Healthcare Directive to his GP, she thanks him and tells him that although a request for healthcare treatment in an Advance Healthcare Directive is not legally binding, it is very helpful to have such a clear guide to his will and preferences and that she will take this into account in making clinical decisions. She also tells him that, while his Advance Healthcare Directive will always be taken into account in decision-making if he subsequently lacks capacity, she and/or hospital staff may not be able to respect his will and preferences for life-sustaining treatment if such treatment is not believed to be clinically indicated. She notes that some individuals may become so unwell that death is considered to be imminent and unavoidable. For such individuals, cardiorespiratory arrest may represent the terminal event in their illness and the provision of cardiopulmonary resuscitation would not be clinically indicated as it would not restart the heart and maintain breathing for a sustained period. Attempting cardiopulmonary resuscitation in such circumstances may cause harm to the individual, increase his/her suffering and/or result in a traumatic and undignified death.

This vignette demonstrates a number of aspects of the legal framework for Advance Healthcare Directives. First, it shows that while a request for healthcare treatment in an Advance Healthcare Directive is not legally binding, it is important and must be taken into account in making healthcare treatment decisions if the healthcare treatment in question is relevant to the condition. Secondly, it shows that a Health and Social Care Professional cannot be required in an Advance Healthcare Directive to provide a healthcare treatment which s/he does not consider to be clinically
indicated. It also shows the kind of factors which would indicate that a healthcare treatment is not clinically indicated.

2.4 Professional responsibilities

Health and Social Care Professionals have a number of professional responsibilities arising from the 2015 Act. These are set out as follows:

2.4.1 Determine if the person lacks capacity

An Advance Healthcare Directive is relevant only in situations where a person lacks capacity to make the specific healthcare treatment decision required at the time in question. It is presumed that a person has capacity to make the decision unless otherwise shown. The burden of proof in demonstrating that the person lacks the capacity to make a decision regarding their healthcare treatment is on the Health and Social Care Professional providing the healthcare treatment. The assessment of capacity should be in accordance with the Guiding Principles of the 2015 Act (see Section 1.6 and 1.7) and the necessary support should be provided to the person to maximise decision-making capacity before deeming the person to lack capacity.

2.4.2 Take steps to ascertain if there is an Advance Healthcare Directive

Where a Health and Social Care Professional has decided that a person lacks the capacity to make a healthcare treatment decision in accordance with the Guiding Principles of the 2015 Act, s/he should take all reasonably practicable steps to ascertain if that person has made an Advance Healthcare Directive.

The 2015 Act allows for the establishment of a Register of Advance Healthcare Directives to be maintained by the Director of Decision Support Service. When this Register is established, a Health and Social Care Professional should take all reasonably practicable steps to consult this Register. Health and Social Care
Professionals should also ask any person accompanying / supporting the person lacking capacity if that person has an Advance Healthcare Directive.

Until such a Register of Advance Healthcare Directives is established, the Health and Social Care Professional should ask any person accompanying / supporting the person lacking capacity if that person has an Advance Healthcare Directive.

It is prudent for Health and Social Care Professionals who are involved in the ongoing treatment of a person to ascertain if the person s/he is treating has made an Advance Healthcare Directive. This is particularly relevant where a person has a deteriorating chronic condition such as motor neurone disease, severe heart failure or in advance of a major clinical intervention such as surgery. In these instances it is advisable to have a discussion with the person as to their healthcare treatment choices which would apply now or in the future.

The Health and Social Care Professional should also take active steps to ensure that other Health and Social Care Professionals are made aware of the existence of the Advance Healthcare Directive. Once a Health and Social Care Professional is made aware of the existence of an Advance Healthcare Directive, s/he should ensure that this is accurately recorded on all relevant medical records, for example medical and nursing notes, healthcare provider administration system, admission chart, healthcare record, National Ambulance Administration System.

2.4.3 Requirement to read the Advance Healthcare Directive

If a Health and Social Care Professional ascertains that there is an Advance Healthcare Directive, s/he should take all reasonably practicable steps to view the Advance Healthcare Directive and to familiarise him or herself with the content of the Advance Healthcare Directive.

It is not possible for a Health and Social Care Professional to make a judgement on the validity and applicability of an Advance Healthcare Directive without accessing
the Advance Healthcare Directive itself, verbal reports of the content of an Advance Healthcare Directive are insufficient.

The Health and Social Care Professional should check the following:

1. Whether the **formalities** for the making of the Advance Healthcare Directive have been complied with – that is, it is signed by the Directive-Maker, by the Designated Healthcare Representative (if such has been appointed) and by two witnesses on the same date (at least one of whom should not be a family member).

2. The **content and applicability** of the Advance Healthcare Directive – is there a specific refusal of healthcare treatment or request for a specific healthcare treatment and in what circumstances; if so, are the healthcare treatment and the circumstances set out in the Advance Healthcare Directive essentially the same as those applying to the Directive-Maker at present.

3. Whether a **Designated Healthcare Representative** has been appointed.

**2.4.4 Response to an Advance Healthcare Directive**

Having read the Advance Healthcare Directive, the Health and Social Care Professional must determine if the Advance Healthcare Directive is valid and applicable (see Section 4).

If the Advance Healthcare Directive is valid and applicable, the Health and Social Care Professional must comply with any refusal of healthcare treatment in the Advance Healthcare Directive (see Section 2.3.1) and must take into consideration any request for healthcare treatment (see Section 2.3.2).

**2.4.5 Conscientious objection**

A situation may arise where a Health and Social Care Professional disagrees in principle with a person’s healthcare treatment will and preferences as set out in a valid and applicable Advance Healthcare Directive and raises a conscientious objection to complying with it.
Conscientious objection is a limited right and cannot lead to the restriction of the rights and freedoms of another person. Therefore, if a Health and Social Care Professional has a conscientious objection, s/he should take the following steps:

- S/he should make their objection clear when the matter initially arises and when he or she realises that the person’s Advance Healthcare Directive conflicts with his or her own held values.
- S/he must inform the Designated Healthcare Representative (if there is one) and also inform colleagues of the conscientious objection.
- S/he must then make arrangements to transfer the care of the person to another Health and Social Care Professional who does not have a conscientious objection. Arrangements to transfer a person for care or healthcare treatment should not be delayed or impeded in any way. The transfer arrangements should be noted on the person’s file.
- If it is not possible to make arrangements to transfer the person, then the person must be treated in accordance with the valid and applicable Advance Healthcare Directive.

### 2.5 Liability Issues

A Health and Social Care Professional who provides treatment to a person contrary to his or her valid and applicable Advance Healthcare Directive may be found to have committed an assault for which s/he may be made liable at civil law, i.e. through a legal action taken by the Directive-Maker or a person acting on behalf of the Directive-Maker, and/or criminal law, i.e. through a prosecution for assault/battery.

However, Health and Social Care Professionals are not liable where:

- S/he did not comply with a refusal of healthcare treatment provided that, at the time in question, s/he had reasonable grounds to believe, and did believe, that the Advance Healthcare Directive was not valid or applicable, or both.
• S/he complied with a refusal of healthcare treatment set out in an Advance Healthcare Directive provided that, at the time in question, s/he had reasonable grounds to believe, and did believe, that the Advance Healthcare Directive was valid and applicable. This is the case even where the Health and Social Care Professional considers that the decision in the Advance Healthcare Directive is unwise.

• At the time in question, s/he had no grounds to believe that an Advance Healthcare Directive existed.

• S/he had grounds to believe that an Advance Healthcare Directive existed but had no immediate access to the Advance Healthcare Directive or its contents and the medical condition was sufficiently urgent that s/he could not reasonably delay taking appropriate medical action until s/he had access to the Advance Healthcare Directive.
3. Formalities for Making, Revoking and Amending an Advance Healthcare

3.1 Making an Advance Healthcare Directive

A person who is 18 years or over and who has capacity may make an Advance Healthcare Directive.

There is no required format for making an Advance Healthcare Directive although the 2015 Act states that the Minister for Health may publish forms of directives that may be used or adapted in making an Advance Healthcare Directive. The legal formalities for the making of the Advance Healthcare Directive are:

- An Advance Healthcare Directive must be in writing and must contain the following:
  (i) The name, date of birth and contact details of the Directive-Maker;
  (ii) The signature of the Directive-Maker, and the date that the Directive-Maker signed the directive;
  (iii) The name, date of birth and contact details of the Designated Healthcare Representative (if any);
  (iv) The signature of the Designated Healthcare Representative (if any) and the date that the representative signed the directive; and
  (v) The signatures of two witnesses.

While a Directive-Maker can record his/her Advance Healthcare Directive in a non-written format, for example voice and video recording and speech recognition technologies, s/he is advised to make his/her Advance Healthcare Directive in a format which can be accessed by Health and Social Care Professionals and his/her Designated Healthcare Representative (if s/he has one appointed) in order for his/her will and preferences to be respected.

• Where a person is signing on behalf of the Directive-Maker, they must not be a witness to the Advance Healthcare Directive and can only sign if -
  (i) The Directive-Maker is unable to sign the directive,
  (ii) The Directive-Maker is present and directs that the directive be signed on his or her behalf by that person, and
  (iii) The signature of the person signing on behalf of the Directive-Maker is witnessed.

• The Advance Healthcare Directive must have two witnesses each of whom must be 18 years or over and at least one of whom must not be an immediate family member of the Directive-Maker. Each of the witnesses must witness the signature of the Directive-Maker (or the person signing on his or her behalf) and the signature of the Designated Healthcare Representative (if any) by signing his or her own signature to the Advance Healthcare Directive.

• The Directive-Maker (or the person signing on his or her behalf) and the Designated Healthcare Representative (if there is one) must sign the Advance Healthcare Directive in the presence of each other and in the presence of the two witnesses.

If the formalities have not been complied with, the Advance Healthcare Directive is not legally binding. However, if the intention of the Directive-Maker is clear and the Advance Healthcare Directive is otherwise valid and applicable, the will and preferences of the Directive-Maker should be respected.

In order for an Advance Healthcare Directive to be valid and applicable, it does not have to be witnessed by a solicitor.
3.2 Making an Advance Healthcare Directive: the role of the Health and Social Care Professional

A person does not need to consult with a Health and Social Care Professional before making an Advance Healthcare Directive. If a person wishes to discuss the details of his/her Advance Healthcare Directive, the Health and Social Care Professional should support this. The Health and Social Care Professional should discuss the implications of the person’s known medical condition and assist with whatever information is requested. He or she should explain available healthcare treatment options and risks to the Directive-Maker, including which forms of healthcare treatment may be life-sustaining treatment and the consequences of the refusal of such treatment.

If a Health and Social Care Professional does not agree with the views of the person making an Advance Healthcare Directive, s/he may state this but s/he should give objective information to the person and should ensure that s/he does not unduly influence the person’s decisions.

A Health and Social Care Professional may be asked to be a witness to an Advance Healthcare Directive. It is a matter for each Health and Social Care Professional to decide whether or not to agree to act as a witness. If they do agree to act as a witness, the Health and Social Care Professionals function is solely to witness the signature. In other words, their role is to confirm that the Directive-Maker signed the Advance Healthcare Directive. The mere act of witnessing an Advance Healthcare Directive by a Health and Social Care Professional does not require the Health and Social Care Professional to undertake a capacity assessment to determine whether the person has the capacity to make an Advance Healthcare Directive. Nor does it imply that s/he has done so. However, if a Health and Social Care Professional, notwithstanding the presumption of capacity, is concerned that a person may not have the capacity to make an Advance Healthcare Directive, s/he should not witness the Advance Healthcare Directive.

Acting as a witness does not require that the Health and Social Care Professional agrees with the content of the Advance Healthcare Directive.
3.3 Support in making an Advance Healthcare Directive

Some people may require support in making an Advance Healthcare Directive. This may be provided informally, or formally where a person has appointed a Decision-Making Assistant in accordance with the 2015 Act. The Decision-Making Assistant may support the person in making an Advance Healthcare Directive by obtaining or interpreting information about Advance Healthcare Directives for the Directive-Maker. The fact that a person needs support in making an Advance Healthcare Directive does not impact on the legally binding nature of the Advance Healthcare Directive.

This is illustrated in the following vignette.

**Vignette 3: Intellectual disability and Advance Healthcare Directives**

Ms Clarke is a 45 year old woman with a moderate learning disability. She lives at home with her parents and sister while attending a day service during the week. She communicates verbally reasonably well and has limited writing skills. She manages most personal care with some prompting. Ms Clarke makes daily decisions around activities. She requires support with more complex decisions particularly around her healthcare and this is provided by her family, especially her sister, as well as her Health and Social Care Professional. Ms Clarke requires ongoing medical input for heart disease, chronic lung disease and epilepsy. She does not like healthcare interventions and attending hospital appointments and is upset by this. As her medical condition progresses, she says she does not want to attend hospital appointments and undergo medical procedures. Following an admission to acute hospital for treatment of pneumonia (including a short period requiring ventilation in the intensive care unit) Ms Clarke makes it very clear in talking to staff in the day service that she does not want to return to the intensive care unit “ever again”. A discussion between Ms Clarke, her Health and Social Care Professionals, her sister and the rest of her family confirms that her physical condition is deteriorating. Ms Clarke is supported in understanding what this means. She is clear that she wants to make sure that she is not admitted to intensive care for ventilation again.
An Advance Healthcare Directive is drawn up on a video clip which is transcribed and signed by two witnesses. Ms Clarke formally nominates her sister as her Designated Healthcare Representative. In the Advance Healthcare Directive Ms Clarke makes it clear that she understands that she may die as a result of refusing treatment and says that she does not want treatment in this situation. Five months later Ms Clarke becomes acutely unwell again and is transferred to hospital; at this stage she is drowsy and unresponsive. Ms Clarke’s parents feel strongly that Ms Clarke has been doing well since her previous hospital admission and would like her to be transferred to intensive care if needed. Ms Clarke’s sister is of the view that Ms Clarke herself does not want this and as her Designated Healthcare Representative requests that Ms Clarke should not be admitted to intensive care. The treating clinician reviews the Advance Healthcare Directive and following discussion with Ms Clarke, her parents and sister, he does not admit Ms Clarke to intensive care but instead prescribes palliative care including oxygen and pain relief. Ms Clarke died peacefully three days later.

This vignette shows that a person who has an intellectual disability or needs support to make decisions is not a barrier to that person making a legally binding Advance Healthcare Directive. It also shows how support can operate and ways in which technology can be used to assist in the drawing up of an Advance Healthcare Directive. The vignette also shows that the Advance Healthcare Directive is legally binding even where some family members do not wish it to be given effect.

### 3.4 Amending an Advance Healthcare Directive

A Directive-Maker who has capacity may, in writing, alter his or her Advance Healthcare Directive. An alteration to an Advance Healthcare Directive is of no effect unless it is signed and has two witnesses.

If consulted by the Directive-Maker about whether to amend an Advance Healthcare Directive, a Health and Social Care Professional should provide all necessary up-to-date information regarding the amendments.
3.5 Revoking an Advance Healthcare Directive

A Directive-Maker who has capacity may cancel his or her Advance Healthcare Directive. In accordance with the presumption of capacity, it must be presumed that the Directive-Maker has capacity to do this unless the contrary has been established (see Section 1.7.1).

The cancellation must be in writing. There are no further formalities. However, it is good practice that the cancellation clearly identifies that the Advance Healthcare Directive is being cancelled and that the date of cancellation is included. The Directive-Maker should also inform any Designated Healthcare Representative of the cancellation. As per Section 2.4.2, where a Health and Social Care Professional is aware of a cancellation of an Advance Healthcare Directive, they should ensure that this is recorded on the person’s file. It is the responsibility of the Directive-Maker to ensure that the cancellation of the Advance Healthcare Directive is brought to the attention of Health and Social Care Professionals.

In some exceptional circumstances, the Directive-Maker may, while s/he has capacity, have verbally stated to the Health and Social Care Professional that s/he wishes to cancel his/her Advance Healthcare Directive but does not have the opportunity to put this in writing. In such circumstances, the Directive-Maker’s change of mind should be respected. As in all situations, a Health and Social Care Professional should be very careful to ensure that they do not exert any pressure on a Directive-Maker to cancel/change his or her Advance Healthcare Directive. The Directive-Maker’s verbal statement and surrounding circumstance should be formally documented by the Health and Social Care Professional and if possible this should be signed by the Directive-Maker (and witnessed). It is generally the responsibility of the Directive-Maker to inform his or her Designated Healthcare Representative of the change. However, if the Directive-Maker is unable to do this, the Health and Social Care Professional should inform the Designated Healthcare Representative of the Directive-Maker’s change of mind.
3.6 Advance Healthcare Directives outside the 2015 Act

3.6.1 Advance Healthcare Directives made prior to the commencement of the 2015 Act

Advance Healthcare Directives made before the 2015 Act comes into force may still be valid and applicable provided they substantially comply with the requirements set out in the 2015 Act (see Section 4).

3.6.2 Advance Healthcare Directives made outside Ireland

An Advance Healthcare Directive made outside Ireland which ‘substantially complies’ with the 2015 Act has the same legal status as if it had been made in this country.

In order to substantially comply with the requirements of the 2015 Act, the Advance Healthcare Directive must comply with the formalities (in other words, be in writing and witnessed) and must identify the healthcare treatment to be refused and the circumstances in which it is to apply. If the Advance Healthcare Directive is to apply to life-sustaining treatment, this must be clearly identified within the Advance Healthcare Directive.

In the Code on How to Make an Advance Healthcare Directive, people are advised that where an Advance Healthcare Directive is made in a language other than English or Irish, arrangements should be made by the Directive-Maker or the Designated Healthcare Representative to have this translated. However, if this has not happened, Health and Social Care Professionals should make all reasonable efforts to have the Advance Healthcare Directive translated by appropriate professionals in accordance with the Equal Status Acts 2000-2015.
4. Validity and Applicability of Advance Healthcare Directives

In order for an Advance Healthcare Directive to apply, the Health and Social Care Professional responsible for providing the healthcare treatment must have determined that the Directive-Maker lacks capacity to make the decision at that time and the Advance Healthcare Directive must be valid and applicable.

In making a decision as to the validity or applicability of an Advance Healthcare Directive, Health and Social Care Professionals should follow the guidance provided in this code.

Where a Health and Social Care Professional considers that the Advance Healthcare Directive is not valid and applicable, s/he should set down in writing the grounds for this belief and also confirm this belief to the Designated Healthcare Representative (if any). If there is uncertainty about the validity and applicability of an Advance Healthcare Directive, see Section 4.3.

Where a Health and Social Care Professional considers that the Advance Healthcare Directive is valid and applicable, it is good practice to document confirmation of the belief as to validity and applicability. The Health and Social Care Professional should also document the reasons why they believe that it is not a valid and applicable Advance Healthcare Directive.

4.1 Validity

In order to give rise to the obligation to comply with a refusal of healthcare treatment or take into consideration a request for healthcare treatment, the Advance Healthcare Directive must be valid and applicable. A valid and applicable Advance Healthcare Directive to refuse healthcare treatment has the same legal status as a decision to refuse healthcare treatment made by a person with capacity at the time of the treatment.
An Advance Healthcare Directive is not valid if:

(a) The Directive-Maker did not make the directive voluntarily; or
(b) The Directive-Maker, while he or she had capacity to do so, has done anything clearly inconsistent with the relevant decisions in the directive.

In an emergency situation, there may not be time or it may not be possible to ascertain the validity of an Advance Healthcare Directive, in which case the urgency of the medical condition requires the Health and Social Care Professional to take appropriate action (see Section 6.1).

4.1.1 Voluntariness

All decisions regarding healthcare treatment must be voluntary and made without undue influence or coercion (whether by a Health and Social Care Professional, family member/friend, advocate/trusted person or other person). This principle applies whether the decision was made contemporaneously or contained in an Advance Healthcare Directive.

During the course of healthcare treatment, a person may discuss different healthcare treatment options and the risks associated with each option with Health and Social Care Professionals, as well as with family and friends, advocates or other trusted person/s. It is a legitimate and normal part of a person’s decision-making process to consult with trusted people close to him or her. It is also often reasonable for Health and Social Care Professionals and others to try to advise a person of the merits and demerits of particular choices (although Health and Social Care Professionals should always remain particularly conscious of the potential for undue influence in discussing Advance Healthcare Directive preferences). Pressure or influence will only be ‘undue’ if, as a result, the decision no longer represents the will and preference of the person.

It is reasonable for Health and Social Care Professionals to presume that an Advance Healthcare Directive was made voluntarily unless there are good grounds for concern, based on evidence, that this may not have been the case.
4.1.2 Doing something inconsistent with the Advance Healthcare Directive while having capacity

An Advance Healthcare Directive is not valid where the Directive-Maker acts in a manner or makes decisions that clearly are inconsistent with the relevant decisions in his or her Advance Healthcare Directive. This would include, for example, a situation where a person, subsequent to making an Advance Healthcare Directive but while s/he has capacity, consents to a healthcare treatment in the same circumstances in which s/he has refused that healthcare treatment in the Advance Healthcare Directive.

This ground for invalidity applies only to inconsistent acts of the Directive-Maker while s/he has capacity. It ceases to apply once the Directive-Maker lacks capacity. However, it is important to remember that the Directive-Maker must be presumed to have capacity until it has been established that s/he lacks capacity. This means that, if a person acts inconsistently, in other words consents to or requests treatment which s/he has refused in the Advance Healthcare Directive, this should be presumed to invalidate the Advance Healthcare Directive unless the person is shown to lack capacity.

An inconsistent act will only invalidate those aspects of the Advance Healthcare Directive which are inconsistent with the act. All other aspects of the Advance Healthcare Directive remain valid.

The impact of inconsistent acts may be seen in the following vignette:

**Vignette 4: Inconsistent acts**

Ms Daniels, a retired woman with severe chronic lung disease and recurrent hospital admissions, made a signed and witnessed Advance Healthcare Directive refusing ventilation to keep her alive in the event of admission to hospital with an exacerbation of her lung condition. She appointed her husband as her Designated
Healthcare Representative, including giving him power to advise and interpret her will and preferences as specified in her Advance Healthcare Directive.

A few months later, she was admitted to hospital with pneumonia. She consented to non-invasive ventilation on the ward and, when this was insufficient to relieve her shortness of breath, agreed to full ventilation and admission to the intensive care unit.

She returned home after two months but was readmitted a few days later with impaired level of consciousness due to recurrent infection and marked worsening of her lung function. This time, staff were aware that Ms Daniels had agreed to ventilation the last time she was admitted even though she had made an Advance Healthcare Directive refusing ventilation. Staff therefore considered that Ms Daniels had acted inconsistently with her Advance Healthcare Directive while she had capacity. For this reason, they decided that this aspect of her Advance Healthcare Directive was no longer valid.

Staff discussed the matter with Ms Daniels' husband who was her Designated Healthcare Representative. When they explained Ms Daniels' current medical situation to him, he said that even though Ms Daniels had accepted ventilation previously, Ms Daniels would not wish to be ventilated in the circumstances which now arose. On this basis, ventilation was not provided and Ms Daniels died peacefully shortly after admission.

This vignette gives an example of an inconsistent act in operation. Because Ms Daniels had capacity at the time of her first admission, her Advance Healthcare Directive had no legal effect but her decision to consent to ventilation was inconsistent with what she had stated in her Advance Healthcare Directive. Ideally, Ms Daniels should have been invited to consider her Advance Healthcare Directive in light of her inconsistent act and asked whether she intended her Advance Healthcare Directive to apply to decisions made after the inconsistent act. Because this was not made clear, the Health and Social Care Professionals here correctly found that Ms Daniels' act invalidates her refusal of ventilation in her Advance
Healthcare Directive. However the vignette also shows that Ms Daniels’ will and preference is still the decisive factor with respect to the proposed treatment. As her Designated Healthcare Representative, her husband was able to advise on her will and preferences with reference to her Advance Healthcare Directive in the situation which arose.

4.1.3 Matters which do not affect the validity of an Advance Healthcare Directive

A person who is 18 years and over and has decision-making capacity is legally entitled to refuse treatment for any reason including a reason based on his or her religious beliefs. This includes decisions which:

a) Appear to be unwise;

b) Appear not to be based on sound medical principles; or

c) May result in his or her death.

A Directive-Maker must include a statement in his/her Advance Healthcare Directive stating that the refusal is to apply to the treatment identified even if his or her life is at risk.

A healthcare treatment refusal which:

a) Appears to be an unwise decision;

b) Appears not to be based on sound medical principles;

c) May result in the death of the directive maker;

cannot be used by Health and Social Care Professionals or others (including family and friends of the Directive-Maker and persons appointed under the 2015 Act) to justify not complying with the treatment refusal set out in the Advance Healthcare Directive even if his or her life is at risk.
4.2 Applicability of an Advance Healthcare Directive

An Advance Healthcare Directive is not applicable if:

a) At the time in question the Directive-Maker still has capacity to give or refuse consent to the healthcare treatment in question.

b) The treatment proposed is not materially the same as the specific healthcare treatment in the Advance Healthcare Directive.

c) The circumstances in which the Advance Healthcare Directive is stated to apply are absent or not materially the same.

d) Where the healthcare treatment in question is life-sustaining, the Advance Healthcare Directive does not contain a statement that the Advance Healthcare Directive is to apply even if the Directive-Maker’s life is at risk.

e) The refusal in the Advance Healthcare Directive relates to the administration of ‘basic care’.

4.2.1 Decision-making capacity

It should be presumed that at the time the Advance Healthcare Directive was made that the Directive-Maker had the requisite decision-making capacity. Therefore, at the time the Advance Healthcare Directive is to take effect, it is not necessary to make enquiries as to the capacity of the Directive-Maker at the time the Advance Healthcare Directive was made.

4.2.2 Materially the same healthcare treatment

A healthcare treatment is materially the same as treatment in the Advance Healthcare Directive if the core elements of the healthcare treatment are the same. Minor differences such as different terms being used or minor variations in modes of delivery should not prevent the Advance Healthcare Directive being applicable.

Specific healthcare treatments covered by an Advance Healthcare Directive might include:

- Resuscitation
Mechanical ventilation
Tube feeding
Dialysis
Antibiotics or antiviral medications.

If there is a doubt as to whether healthcare treatment proposed is materially the same as that in the Advance Healthcare Directive, the Health and Social Care Professional should consult with another Health and Social Care Professional of the same specialisation. Where a Health and Social Care Professional reaches a conclusion having consulted with a second Health and Social Care Professional, s/he should document the consultation; the views of the second Health and Social Care Professional; their decision; and their reasons for the decision.

4.2.3 Materially the same circumstances

Whether an Advance Healthcare Directive comes into effect in the particular circumstances depends first on whether the person lacks capacity to make the decision at the time in question and secondly on the contents of the Advance Healthcare Directive.

Some Directive-Makers may wish their Advance Healthcare Directive to apply even if they have no health problems. An example of this is a Directive-Maker who for religious, or other reasons, does not wish to have a blood transfusion or to receive blood products.

Health and Social Care Professionals should determine whether the circumstances identified in the Advance Healthcare Directive are materially the same as those which arise at the time when the Advance Healthcare Directive is to come into effect.

Where healthcare treatment or circumstances are set out precisely in the Advance Healthcare Directive, minor variations between the circumstances set out and the circumstances now arising will not prevent the Advance Healthcare Directive from being applicable.
Particular care should be taken where the Advance Healthcare Directive refers to ‘all circumstances’. The circumstances in which the refusal of the healthcare treatment identified is intended to apply must be specified. If the circumstances detailed in the Advance Healthcare Directive are clear and unambiguous, then the Advance Healthcare Directive must be respected and followed. So, for example, where a person had stated that on religious grounds they do not wish to have a transfusion of blood or primary blood components under any circumstances, the Advance Healthcare Directive will be applicable (except in cases of pregnancy see Section 6.4).

However, in other situations it is necessary that the Directive-Maker clarifies specifically the circumstance in which the healthcare treatment is being refused. A person who refuses in their Advance Healthcare Directive an identified healthcare treatment in one circumstance cannot be taken to be providing a blanket refusal of healthcare treatments that may arise in different circumstances, for example a person who advance refuses antibiotic treatment in one specified context cannot be presumed to be refusing antibiotics in other contexts.

Some circumstances may refer to specific conditions. Examples of possible conditions are set out in the box below:

The Directive-Maker has:
- A specified level or severity of disability;
- A terminal illness;
- An end-stage irreversible life limiting condition;
- A prolonged disorder of consciousness.

‘Terminally ill’ can be taken to mean that a person is suffering from advanced, progressive, and irreversible disease, and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months; and the application of life-sustaining treatment would only serve to postpone the moment of death.
‘End-stage irreversible life limiting condition’ can be taken to mean that a person is suffering from an advanced, progressive, and irreversible condition and has reached the end-stage of the condition, limiting survival of the person. Examples include those with end-stage renal failure, end-stage motor neuron disease, or end-stage chronic obstructive pulmonary disease (such people may not fall into the definition of terminal illness because their survival may be prolonged by dialysis or assisted ventilation). Other examples include people with irreversible loss of major cerebral function and extremely poor functional status such as those with severe stroke or advanced dementia.

‘Prolonged disorder of consciousness’ can mean one or more of:

1. Coma (absent wakefulness and absent awareness): A state of unarousable unresponsiveness, lasting >6 hours in which a person cannot be awakened, fails to respond normally to painful stimuli, light or sound, lacks a normal sleep-wake cycle and does not initiate voluntary actions.

2. Vegetative state (VS) (wakefulness with absent awareness): A state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus-induced arousal, evidenced by sleep-wake cycles and a range of reflexive and spontaneous behaviours. Vegetative state is characterised by complete absence of behavioural evidence for self-awareness or environmental awareness.

3. Minimally conscious state (MCS) (wakefulness with minimal awareness): A state of severely altered consciousness in which there is evidence of minimal but clearly discernible behavioural evidence of responses above the level of spontaneous or reflexive behaviour, which indicates some degree of interaction with the person’s surroundings.
4.2.4 Applicability of an Advance Healthcare Directive to life-sustaining treatment

An Advance Healthcare Directive is not applicable to life-sustaining treatment unless this is substantiated by a statement in the directive by the Directive-Maker to the effect that the directive is to apply to that treatment even if his or her life is at risk.

Assisted Decision Making (Capacity) Act 2015, Section 85 (3)

Treatment can be regarded as life-sustaining where failure to provide that treatment at that time would result in a significant risk of death. There must be a statement in the Advance Healthcare Directive that the Directive-Maker understands that s/he may die as a result of refusing that treatment.

The Advance Healthcare Directive is not applicable if there is no statement to the effect that the Advance Healthcare Directive is to apply to that healthcare treatment even if the Directive-Maker’s life is at risk. However, the Advance Healthcare Directive still gives important information as to the will and preferences of the Directive-Maker.

The operation of an Advance Healthcare Directive in respect of refusal of life-sustaining treatment may be seen in the following vignette:

**Vignette 5: Life-sustaining treatment**

Ms Anderson, who was 35 years old, suffered severe brain damage as a result of a head injury and despite all rehabilitative efforts was left lacking decision-making capacity and had difficulty swallowing. She had previously made an Advance Healthcare Directive stating that she would not want specified healthcare treatments, including tube feeding or intravenous hydration, even if she died as a result, or that it would result in severe brain damage and poor functional status. She appointed her partner Ms Byrne as her Designated Healthcare Representative.
Ms Anderson was admitted to a nursing home where staff noted that, despite assistance from dietetic staff, her nutritional intake was poor and that she was losing weight. They were concerned that she would develop a pressure sore and that they would be criticised as a result. They asked the general practitioner, Dr O'Neill, if he could persuade Ms Byrne as her Designated Healthcare Representative to allow tube feeding. Dr O'Neill reviewed the Advance Healthcare Directive and noted that it was clear about the healthcare treatments to be refused and about the circumstances in which these refusals were to apply. He informed staff that the refusal of tube feeding was legally binding even if it resulted in Ms Anderson’s decline and death and that it wasn’t possible for anyone, including Ms Byrne, to override Ms Anderson’s clear will and preferences as outlined in her Advance Healthcare Directive. He also noted the importance of providing basic care, including whatever oral nutrition and hydration that Ms Anderson could tolerate, and measures to minimise the risk of pressure sores.

This vignette shows that a person can make a legally binding refusal of life-sustaining treatment in an Advance Healthcare Directive and that in order to do so, the Directive-Maker must expressly state that the refusal of treatment in the Advance Healthcare Directive is to apply even if his or her life is at risk. It also shows that basic care cannot be refused and gives an example of what constitutes basic care in the situation in question.

4.2.5 Basic Care

‘Basic care’ is defined in the 2015 Act as including warmth, shelter, food and liquids provided orally and hygiene measures. Basic care also includes some, but not all, measures taken to relieve a person’s pain, for example, positioning a person to alleviate discomfort or breathlessness, bandaging and other wound care measures and administration of non-prescription medicinal products for example, laxatives, analgesic, antacids for heartburn, to alleviate pain or other symptoms.

An Advance Healthcare Directive is not applicable to the administration of basic care to the Directive-Maker, and basic care cannot be refused in an Advance Healthcare Directive.
Directive. In contrast, an Advance Healthcare Directive is applicable to the administration of *treatment* - an intervention for a therapeutic, preventative, diagnostic, palliative or other purpose related to the physical or mental health of the person.

Basic care includes care that can be provided by someone who is not a Health and Social Care Professional in order to promote the comfort and dignity of a person.

Basic care does not include artificial nutrition or artificial hydration (for example, tube feeding). These can be refused in an Advance Healthcare Directive.

**4.2.6 Relief of pain and other distressing symptoms**

Measures to relieve pain and other potentially distressing symptoms range from relatively simple interventions, such as positioning the person or providing mouth care, to invasive procedures including use of infusion pumps to administer medications and even surgical procedures. While some low level measures to relieve pain might be categorised as basic care, many interventions aimed at providing pain relief represent treatment for a palliative purpose (that is serving to alleviate and provide temporary relief from symptoms or suffering without effecting a cure) do not come within the definition of basic care. Although many Health and Social Care Professionals may regard providing such treatment as a fundamental part of healthcare treatment, the 2015 Act is explicit that such treatment can be refused in an Advance Healthcare Directive.

If the Health and Social Care Professional is unsure whether the intervention represents basic care or a healthcare treatment they should seek the opinion of another colleague.

In a situation where a Health and Social Care Professional considers that the refusal of clinically indicated treatment for pain relief may result in severe, otherwise untreatable distress and hence infringe on the essential human right of that person to
be protected from inhuman and degrading treatment s/he should refer the matter to the Court (see Section 4.3.1).

If immediate healthcare treatment is essential to relieve unbearable distress while awaiting the outcome of the court application, this should be provided.

**Vignette 6: Pain relief and basic care regarding an Advance Healthcare Directive**

Mrs Murphy has advanced dementia and lives in a nursing home. She has a history of bowel disease and has undergone multiple abdominal operations over the years as a result. Five years earlier, Mrs Murphy made an Advance Healthcare Directive stating that she would not want specific healthcare treatments including surgery and cardiopulmonary resuscitation if she no longer has capacity to make decisions for herself even if her life were at risk as a result. Mrs Murphy has now fallen and sustained an unstable (displaced) hip fracture. Mrs Murphy did not appoint a Designated Healthcare Representative in her Advance Healthcare Directive. She is in pain as a result and every movement to provide nursing care exacerbates that pain.

Her doctor, Mr Walsh, considers that her Advance Healthcare Directive is valid and applicable in this case. However, Mr Walsh is aware that the pain from Mrs Murphy’s displaced hip fracture cannot be relieved with medication alone but requires hip fracture repair.

Therefore an ambiguity remains between Mrs Murphy’s Advance Healthcare Directive and whether her instructions are intended to apply to refusal of surgery for pain relief. An application is made to the Court for a decision as to the applicability of her Advance Healthcare Directive in this instance.

*This vignette provides an example of refusal of treatment which is clinically indicated as necessary for pain relief but which does not fit within the definition of ‘basic care’ in the 2015 Act. Mrs Murphy’s refusal of surgery and cardiopulmonary resuscitation*
in a valid and applicable Advanced Healthcare Directive means that it is not legally permissible to provide the treatment. However, because the refusal would leave Mrs Murphy in severe and unbearable pain, her human right to protection for inhuman and degrading treatment arises. The Health and Social Care Professional is therefore required to refer the matter to the Court for resolution.

Vignette 7: Basic care and pain relief

Mr English has metastatic cancer. He is aware that he is likely to die shortly and has made an Advance Healthcare Directive refusing life-sustaining treatment when his condition deteriorates as anticipated and appointing his partner Mr Flynn as his Designated Healthcare Representative. In his Advance Healthcare Directive Mr English requested that he would not receive opioid medication for pain relief if at all possible. Mr English described experiencing distressing delirium due to the use of opioid medication on a previous admission.

Mr English is now close to death in hospital and is unable to speak for himself. He is in great pain and significant distress due to bony metastases, the pain from which is not adequately controlled by his current medications. His doctors speak to Mr Flynn and recommend that the use of a strong opioid is now required to try and control his partner’s severe pain. Mr Flynn agrees that although his partner wished to avoid opioids if at all possible, he would not have wished to die in pain. It is agreed to give Mr English an appropriate dose of an opioid medication to reduce his pain with careful monitoring for and treatment of side effects to minimise the risk of delirium.

This vignette shows how a Designated Healthcare Representative can play an important role in ensuring that appropriate treatment in accordance with the will and preferences of the Directive-Maker is provided. It is clear that the doctors here attempted to act in conformity with Mr English’s wishes to avoid opioids if at all possible but that when they were no longer able to control Mr English’s pain, they discussed the matter with Mr English’s Designated Healthcare Representative and following this discussion provided stronger pain relief. In doing this, the doctors continued to act in accordance with Mr English’s will and preferences and took all
steps possible to ensure that Mr English’s level of alertness was maintained as far as possible.

If Mr English’s Designated Healthcare Representative had not agreed with the delivery of appropriate pain relief, it could have been necessary for the Health and Social Care Professionals to refer the matter to the court.

4.3 Uncertainty regarding validity and applicability of an Advance Healthcare Directive

Situations may arise where Health and Social Care Professionals are uncertain regarding whether an Advance Healthcare Directive is valid or applicable because of an ambiguity in the Advance Healthcare Directive.

In such situations, the Health and Social Care Professional must:

(i) Consult with the Directive-Maker’s Designated Healthcare Representative (if any) or, if there is no Designated Healthcare Representative, the Directive-Maker’s family and friends, and

(ii) Seek the opinion of a second Health and Social Care Professional.

If the Health and Social Care Professional has complied with the consultation process above, but the ambiguity still has not been resolved, the Health and Social Care Professional must resolve the ambiguity in favour of the preservation of the Directive-Maker’s life, if this is the issue at stake.

All of the steps taken should be documented in the Directive-Maker’s records.

Ultimately, questions about uncertainty or ambiguity may have to be resolved by the court (see Section 4.3.1).

The operation of the required procedure can be seen in the following vignette:
Mrs Dunne, who is 25 years old, is unconscious following a major haemorrhage a few hours after the delivery of her baby. A blood transfusion is urgently clinically indicated and there is a substantial risk that without this transfusion, Mrs Dunne will die. Mrs Dunne is a Jehovah’s Witness and an Advance Healthcare Directive drawn up shortly after her 18th birthday states that she should never be given blood or blood products even if her life were at risk as a result. She appointed her husband as her Designated Healthcare Representative.

Mrs Dunne’s treating Health and Social Care Professional is uncertain about whether the Advance Healthcare Directive applies in the circumstances which now arise. As required where there is uncertainty regarding the validity or applicability of an Advance Healthcare Directive, the Health and Social Care Professionals consult with Mrs Dunne’s Designated Healthcare Representative - in this case, her husband - explaining to him that a blood transfusion is now urgently required. Mr Dunne says he honestly does not know what his wife’s will and preferences would be as they did not have a discussion about what she would want in these circumstances. He says that she took her religion very seriously but that she also took being a mother very seriously and she would want to be alive for her baby. Mrs Dunne’s treating Health and Social Care Professional also seeks the opinion of a second Health and Social Care Professional as is required under the 2015 Act.

After this Mrs Dunne’s Health and Social Care Professional is still uncertain. In these circumstances, and in light of the urgency of the matter, he decides to give the transfusion. This is because in a situation where, after the procedures set down in the 2015 Act have been followed, there is still an ambiguity, the 2015 Act requires that the ambiguity must be resolved in favour of preserving the Directive-Maker’s life.

This vignette shows the application of the procedures required under the 2015 Act to resolve uncertainty about whether an Advance Healthcare Directive is applicable in a particular set of circumstances. As this vignette shows, a Designated Healthcare Representative must always act on the basis of the will and preferences of the
Directive-Maker and if the Designated Healthcare Representative does not know what the Directive-Maker's will and preferences would be, s/he should state this. In this situation, the uncertainty was resolved because the 2015 Act includes a specific provision that, in circumstances where there is uncertainty as to the validity or applicability of an Advance Healthcare Directive, the ambiguity must be resolved in favour of preserving of the Directive-Maker's life.

4.3.1 Referral to Court

Ultimately, if there is doubt about the validity and applicability of an Advance Healthcare Directive and, in particular, disagreement about the correct course of action, a determination may be obtained from the court. Any interested person may make an application to court for a declaration as to whether an Advance Healthcare Directive is valid and/or applicable or whether a Designated Healthcare Representative is acting in accordance with the powers contained in the Advance Healthcare Directive.

A court application relating to life-sustaining treatment must be made to the High Court. Other applications are made to the Circuit Court.

Where an application has been made to the High Court and the decision of the Court is awaited, the Advance Healthcare Directive does not prevent a Health and Social Care Professional from administering life-sustaining treatment or doing any act which s/he believes to be necessary to prevent a serious deterioration in the health of the Directive-Maker or, if the Directive-Maker is pregnant, from having a deleterious effect on the ‘unborn’.
4.4 Relevance of Advance Healthcare Directive which is not valid or applicable

An Advance Healthcare Directive does not have any effect and should be disregarded:

- If the Directive-Maker has capacity to make his or her own decisions at the time in question.
- There is evidence that an Advance Healthcare Directive was not made voluntarily, under undue influence or coercion.

In other circumstances, an Advance Healthcare Directive which is not applicable because it does not apply to a particular healthcare treatment or circumstance may provide important guidance and evidence of the person’s will and preferences and as such should be taken into consideration.
5. Designated Healthcare Representative

In an Advance Healthcare Directive, a person may appoint a Designated Healthcare Representative who is given powers to ensure that the terms of the Advance Healthcare Directive are complied with. S/he may also appoint an alternate Designated Healthcare Representative who may act if the original Designated Healthcare Representative dies or is unable to exercise his or her powers. A Designated Healthcare Representative should be a person that the Directive-Maker trusts and is aware of the Directive-Maker’s will and preferences. A person may appoint more than one Designated Healthcare Representative for different aspects of his or her healthcare treatment, for example, one for mental health and one for all other aspects of healthcare treatment.

A Designated Healthcare Representative may only exercise their powers under the Advance Healthcare Directive in circumstances where the Directive-Maker lacks capacity.

A Designated Healthcare Representative cannot delegate any of the powers given to him or her and may only exercise the powers when and for so long as the Directive-Maker lacks capacity.

Further details on the operations of Designated Healthcare Representatives may be found in the Code of Practice for Designated Healthcare Representatives.

5.1 Role of the Designated Healthcare Representative

The Designated Healthcare Representative has the power to ensure that the terms of an Advance Healthcare Directive are complied with. This means that s/he can provide direction to Health and Social Care Professionals in relation to the healthcare treatment decisions and take steps to ensure that the directive maker’s will and preferences are respected.
The appointed Designated Healthcare Representative can be given specific power/s as follows:

- To advise and interpret what would be the Directive-Maker’s will and preferences in relation to treatment. This must be done with reference to the Directive-Maker’s Advance Healthcare Directive.
- To consent to or refuse treatment based on the Directive-Maker’s known will and preferences. This must be done with reference to the Directive-Maker’s Advance Healthcare Directive. This can include consent to and refusal of life-sustaining treatment only if the Advance Healthcare Directive expressly gives this power to the Designated Healthcare Representative.

If the Directive-Maker wishes to give either or both of these powers to the Designated Healthcare Representative, s/he must state this clearly in their Advance Healthcare Directive. S/he should also state clearly any limits on the power of the Designated Healthcare Representative, including whether the power to consent to or refuse treatment extends to life-sustaining treatment.

The Designated Healthcare Representative must sign the Advance Healthcare Directive to confirm that s/he will act in accordance with the Directive-Maker’s known will and preferences and in accordance with their Advance Healthcare Directive.

A Directive-Maker may change his/her Designated Healthcare Representative at any time while s/he has capacity.

Where a Directive-Maker has appointed a person as his/her Designated Healthcare Representative, their Health and Social Care Professional must consult with them. The views of the Designated Healthcare Representative (who s/he has given legal authority to) will take priority over views of any other person, including family members.

The scope of the Designated Healthcare Representative’s powers depends on what has been conferred in the Advance Healthcare Directive. Where a person presents
as a Designated Healthcare Representative, the Health and Social Care Professional must check the terms of the Advance Healthcare Directive to establish:

- That the person has been appointed as the Designated Healthcare Representative.
- The scope of that person’s powers as the Designated Healthcare Representative.

In general, it is reasonable for Health and Social Care Professionals to assume that the Designated Healthcare Representative is accurately representing the will and preferences of the Directive-Maker as specified in their Advance Healthcare Directive.

However, in exceptional circumstances, a Health and Social Care Professional may have reason, based on evidence, to believe that the Designated Healthcare Representative is not acting in accordance with the powers which s/he has been given under the Advance Healthcare Directive or in accordance with the Directive-Maker’s known will and preferences.

In such circumstances, the Health and Social Care Professional should first discuss the matter with the Designated Healthcare Representative and express his or her concerns about the action that the Designated Healthcare Representative proposes to take.

Ultimately, if the Health and Social Care Professional continues to have concerns, s/he should make a complaint in respect of the conduct of the Designated Healthcare Representative to the Director of the Decision Support Service, who must review this complaint and, if satisfied that it has substance, undertake an investigation. The Director may, on completion of an investigation refer the matter to the court and if the court is satisfied that the Designated Healthcare Representative is acting or is proposing to act outside the scope of his or her powers, the court may make an order prohibiting the Designated Healthcare Representative from exercising those powers.
In some situations, for example an emergency situation, referral to the Director of the Decision Support Service may not be sufficient to resolve the matter and it may be necessary to make an immediate application to court for a declaration.

In addition to the Designated Healthcare Representative’s general powers to ensure the Advance Healthcare Directive is complied with, the Health and Social Care Professional must:

- Provide the Designated Healthcare Representative with a copy of the reasons why s/he did not comply with a request in the Directive-Maker’s Advance Healthcare Directive. This must be done as soon as practicable after the decision not to comply was made and recorded no later than 7 days after the request was not fulfilled.
- Consult with the Designated Healthcare Representative in order to resolve any uncertainty as to the validity or applicability of the Advance Healthcare Directive.

The Designated Healthcare Representative must record any decision made in relation to the Advance Healthcare Directive. The Designated Healthcare Representative is obliged at the request of either the Directive-Maker if s/he has regained capacity, or the Director of the Decision Support Service, to produce the record for inspection so it is important the detail of why the Advance Healthcare Directive was not complied with is accurately recorded.

The requirement to consult with the Designated Healthcare Representative can be seen in operation in the following vignette:

**Vignette 9: Consultation with Designated Healthcare Representative**

Mrs Graham is admitted to the Emergency Department with a one hour history of right-sided limb weakness and with marked difficulty understanding and producing speech such that she is unable to discuss her care. A brain scan confirms a large recent stroke. Having tried to support and communicate with Mrs Graham without success, it is clear that Mrs Graham lacks capacity. Her husband is present and has
a copy of an Advance Healthcare Directive drawn up by Mrs Graham. This states that she would not want ‘aggressive measures if I ever have a severe stroke’ including resuscitation, ventilation or tube feeding, even if her life is at risk as a result. Mr Graham, who was appointed as the Designated Healthcare Representative with the power to advise and interpret her will and preferences and to consent to or refuse treatment (which explicitly includes decisions relating to life-sustaining treatment) as specified in her Advance Healthcare Directive, explains that his wife’s mother had died in hospital a few weeks after a stroke having had a lot of medical interventions and that one of his wife’s great fears was dying in a similar manner.

Dr Browne explains that the circumstances in which the Advance Healthcare Directive is to apply is not entirely clear in her view. For many people, a ‘severe stroke’ refers to the ultimate functional outcome following a stroke, and this is difficult to judge in the immediate period after a stroke. Furthermore, Mrs Graham is within the time frame where she might benefit from thrombolysis (clot-busting therapy) and, if this were successful, Mrs Graham might have little if any residual consequences of her stroke. Mr Graham says that he doesn’t know if his wife would have wanted thrombolysis. Having discussed the matter fully with Mr Graham, Dr Browne then obtains a second opinion from Dr Kelly. Following this Dr Browne judges that there is still ambiguity regarding Mrs Graham’s will and preferences as specified in her Advance Healthcare Directives and that the potentially life- and brain-saving thrombolysis should be given.

Unfortunately, Mrs Graham develops a major brain haemorrhage following thrombolysis. She has impaired consciousness and a dense right sided stroke. She is unable to communicate. Dr Browne explains to Mr Graham that, while not zero, the likelihood of Mrs Graham’s situation improving is now extremely low. Mr Graham states that her current status corresponds to what his wife would have regarded as a severe stroke and that she would not have wanted the specified healthcare treatments in this circumstance. Dr Browne accepts this and a palliative approach to care is taken in the next few days before Mrs Graham’s death.
This vignette shows the benefits of having a Designated Healthcare Representative to assist in reaching conclusions as to the will and preferences of the Directive-Maker where there is an ambiguity in the Advance Healthcare Directive. It demonstrates also that the decision of the Designated Healthcare Representative must always be in accordance with what s/he believes to be the will and preferences of the Directive-Maker with reference to what has been stated in the Advance Healthcare Directive.

The vignette also reflects the dynamic and changing environment in which decisions about healthcare treatment are made and the need for on-going engagement with Designated Healthcare Representatives.

In a situation where the Directive-Maker has given his or her Designated Healthcare Representative the power to advise on the Directive-Maker’s will and preference as specified in the Advance Healthcare Directive, the Designated Healthcare Representative is the only person with legal authority to interpret the will and preferences of the Directive-Maker as specified in the Advance Healthcare Directive. This can be seen in the following vignette:

**Vignette 10: Designated Healthcare Representative's interpretation of the expressed will and preferences with reference to the Advance Healthcare Directive**

Mr Doyle had a severe stroke due to cardiac disease which left him with significant disability. He made an Advance Healthcare Directive noting that he would not want life-saving treatment, including treatment with antibiotics, if he is ever seriously unwell and unable to express his own views even if his life was at risk. He appointed his nephew as his Designated Healthcare Representative and gave him specific power to advise on his will and preferences as specified in his Advance Healthcare Directive and to provide or refuse consent on his behalf. Subsequently Mr Doyle was admitted to a nursing home, and staff in the nursing home were made aware of the Advance Healthcare Directive.
In the last week, Mr Doyle has developed a severe chest infection. At this stage, he is still capable of expressing his own will and preferences and he declines admission to hospital for antibiotics and rehydration and agrees to a purely palliative approach (i.e. pain relief and comfort care only). He slips gradually into a coma and his nephew reiterates to staff in the nursing home his uncle’s wish to avoid admission to hospital or the administration of antibiotics.

Mr Doyle’s only child, Ms Ryan, lives in Australia and has been informed that he is gravely ill. She has just arrived home to see him in the nursing home. She demands that he immediately commences intravenous fluids and that he be treated with antibiotics. The senior nurse present tells her of her father’s Advance Healthcare Directive. She also tells her that Mr Doyle’s nephew is Mr Doyle’s Designated Healthcare Representative. Ms Ryan protests that she was unaware of the Advance Healthcare Directive and that she is Mr Doyle’s closest relative. The nurse states that she is legally obliged to comply with the Advance Healthcare Directive.

Mr Doyle dies without receiving antibiotics.

This vignette reflects the tensions that may sometimes arise among families. It also demonstrates the very clear guidance which the 2015 Act provides in such situations. Absolute priority is given to compliance with a valid and applicable Advance Healthcare Directive and where a Designated Healthcare Representative has been appointed and given power to advise on the Directive-Maker’s will and preferences with reference to the Advance Healthcare Directive, the views of this Designated Representative are determinative. The vignette reinforces that it is the will and preference of the person, as expressed in his Advance Healthcare Directive and not ‘next-of-kin’ views that determine treatment decisions. A next of kin has no legal status when it comes to healthcare treatment decision-making.
6. Advance Healthcare Directives in Specific Circumstances

6.1 Advance Healthcare Directives in emergency situations

Emergency situations are those in which immediate or urgent action by Health and Social Care Professionals is needed to avoid significant harm, injury, or death to an individual.

Advance Healthcare Directives are applicable in emergency situations and an advance refusal of healthcare treatment required in an emergency should be respected where:

(1) The person lacks capacity to make the decision at the time in question; and
(2) The existence and content of that person’s Advance Healthcare Directive is known or accessible to the Health and Social Care Professional; and
(3) The healthcare treatment required in the emergency has been refused in a valid and applicable Advance Healthcare Directive, including, if relevant, an explicit instruction that the Directive-Maker intends the directive to apply to that healthcare treatment even if his or her life is at risk.

In some emergency situations (including, for example, when Health and Social Care Professionals who are not familiar with the person are asked to respond to an emergency in the community):

- Health and social care professionals may not be aware of or have had an opportunity to examine the content of an Advance Healthcare Directive; or
- The Advance Healthcare Directive may not be immediately accessible; or
- The nature or site of the emergency may be such that a Health and Social Care Professional cannot both provide the care necessary and read an Advance Healthcare Directive; or
- There may be an ambiguity or lack of clarity in the Advance Healthcare Directive that cannot be immediately resolved.
In these circumstances, the Health and Social Care Professional should take all reasonably practicable steps, bearing in mind the emergency situation, to find out if the person has an Advance Healthcare Directive and to access the Advance Healthcare Directive. For example if the situation allows, check with the person accompanying the patient. In some cases where an Advance Healthcare Directive refers to a common healthcare treatment, such as a refusal of cardiopulmonary resuscitation, and the circumstances of the refusal are clearly set out, a Health and Social Care Professional may be able to evaluate the applicability of the Advance Healthcare Directive quickly and respond appropriately. In other situations, this may be more difficult. If it is not possible to evaluate the applicability of the Advance Healthcare Directive, Health and Social Care Professionals should act reasonably within the constraints of the emergency. This means that emergency treatment immediately necessary to avoid harm, injury, or death to the person should, should be provided pending review of the Advance Healthcare Directive. In such circumstances, Health and Social Care Professionals should not provide treatment other than that immediately necessary in the circumstances of the emergency.

When the emergency is over, Health and Social Care Professionals should document the circumstances, the steps taken to review the Advance Healthcare Directive and the basis upon which healthcare treatment was provided or not provided.

The following vignette provides an example of a reasonable response in an emergency situation:

**Vignette 11: Emergency treatment**

An emergency call is received for a man who has become unconscious at home. On arrival, the ambulance crew find Mr Thompson, a very emaciated 62-year old man, lying in bed: he is unconscious and his breathing is irregular and shallow. His wife Mrs Thompson is tearful and apologetic. She says that her husband has terminal cancer and that the priority for both of them, following discussion with the palliative care team, is that he should die at home but that she panicked when he became
unconscious. She reports that her husband has an Advance Healthcare Directive stating that he doesn’t want measures such as cardiopulmonary resuscitation but that she doesn’t know where she has put the document. She asks that the ambulance crew not provide any treatment. The ambulance crew assess the situation; they note that Mr Thompson is not in any discomfort and they agree to Mrs Thompson’s request and wait with her until a friend arrives. The ambulance crew subsequently documents the events and the basis for their decision not to provide treatment.

This vignette reflects a reality which may emerge in emergency situations. Sometimes an Advance Healthcare Directive may not be to hand and an immediate decision may have to be made. In such situations, Health and Social Care Professionals should assess the situation, as the ambulance crew did here, and should reach their best assessment of the most appropriate course to take in the circumstances.

In situations such as these, the importance of recording the basis for decisions taken is especially important and healthcare professionals should take the time to detail all the circumstances.

6.2 Advance Healthcare Directives and mental health

A person with a mental health condition makes an Advance Healthcare Directive in the same way that a person with physical illness or no illness does.

6.2.1 Advance Healthcare Directives and mental health treatment

If the Advance Healthcare Directive relates to mental health treatment, and the person has been admitted to an approved centre as a ‘voluntary patient’, then it is fully enforceable once the conditions outlined in Section 4 are fulfilled (subject to two limits discussed in Section 6.2.2).
The legally binding status of an Advance Healthcare Directive for voluntary patients may be seen in the following vignette:

**Vignette 12: Advance Healthcare Directives and voluntary patients**

Ms Lopes is a young woman who has been admitted to hospital on a number of occasions on a voluntary and involuntary basis with bipolar episodes. She suffered unforeseen side effects from a psychotropic medication she was prescribed on her previous hospitalisation, and would prefer to be treated with an alternative medication if she is hospitalised again in the future. She would also like a neighbour to be notified if she becomes unwell, so that a person looks after her pets while she is in hospital. While she is well, she makes an Advance Healthcare Directive appointing a close friend as her Designated Healthcare Representative, and includes instructions in relation to her medication, and the care of her pets.

After a stressful period at work, she is hospitalised again. On this occasion, she is admitted to hospital on a voluntary basis. After her admission, she does not have the capacity to make decisions, and the treatment team consult with her Designated Healthcare Representative, and her Advance Healthcare Directive instructions in order to determine a course of treatment in accordance with her will and preferences. On this occasion, her Advance Healthcare Directive, refusing the psychotropic medication due to the unwanted side effects, is binding because she is a voluntary patient, and must be respected. Now that she has an Advance Healthcare Directive outlining her treatment will and preferences, her doctors are aware of her request to be treated with an alternative medication, which suits her better, and she is not treated with the medication she was given on her last hospitalisation. She is recovering well, engaging with the treatment team, and is happy to take the alternative medication now that her treatment will and preferences have been respected.

*This vignette shows the potential of Advance Healthcare Directives in building trust in treatment decision-making in a mental health context. It also reinforces that Advance Healthcare Directives are fully legally binding for patients who have been*
voluntarily admitted to psychiatric unit and that they must be complied with in exactly the same way as an Advance Healthcare Directive in respect of treatment for a physical health issue.

6.2.2 Limits on enforceability of Advance Healthcare Directives in mental health treatment

There are two limits on the enforceability of Advance Healthcare Directives in the context of mental health. These apply where the Directive-Maker is subject to involuntary detention under the Mental Health Act 2001 or is the subject of a conditional discharge order under the Criminal Law (Insanity) Act 2006 at the time the relevant treatment decision needs to be made.

The limits apply to treatment for a ‘mental disorder’ (as the term is currently defined in the Mental Health Act 2001). This includes ‘the administration of physical, psychological and other remedies relating to the care and rehabilitation of a patient under medical supervision, intended for the purposes of ameliorating a mental disorder’ (Mental Health Act (2001), Section 2(1).

Where the Directive-Maker is subject to the Mental Health Act 2001 or the Criminal Law (Insanity) Act 2006, the Advance Healthcare Directive (like all Advance Healthcare Directives) is only applicable if the person lacks capacity to make a treatment decision at the time the decision needs to be made. If the person does not lack capacity, the requirements for consent to treatment under these Acts apply.

Where the Directive-Maker lacks capacity, decisions about treatment for the Directive-Maker’s mental disorder are made in accordance with Part IV of the Mental Health Act 2001 or Section 13A of the Criminal Law (Insanity) Act 2006. This means that the Advance Healthcare Directive is not legally binding in respect of these decisions. However, the Advance Healthcare Directive remains binding in respect of physical illness.
Even though the Advance Healthcare Directive is not legally binding in respect of treatment for a mental disorder in these situations, a valid and applicable Advance Healthcare Directive still represents an important expression of an individual’s will and preferences regarding treatment, and should be taken into consideration by Health and Social Care Professionals. This is critical for promoting recovery, and giving people a sense of control over their mental health treatment.

The role of an Advance Healthcare Directive in the context of an admission under the Mental Health Act 2001 can be seen in the following vignette:

**Vignette 13: Advance Healthcare Directive in admission under Mental Health Act 2001**

Ms Collins is a 77-year-old woman, who experienced severe depression after retiring from her job in adult education. During her previous involuntary hospitalisation, it was decided that she lacked capacity and was treated with electroconvulsive therapy, and another medication from which she suffered serious side effects. She has since recovered, and regained full capacity. As an older woman living alone, she lives in fear of becoming unwell again, being involuntarily detained, found to be lacking in capacity, and being treated with electroconvulsive therapy or the medication she reacted badly to in the past.

She has since made an Advance Healthcare Directive clearly stating that she does not want to be treated with electroconvulsive therapy or the medication she reacted to, and her will and preference is to be treated with an alternative medication which has worked well for her in the past, and counselling. She appoints a trusted friend as her Designated Healthcare Representative to interpret and communicate her mental health treatment will and preferences.

A few months after making her Advance Healthcare Directive, Ms Collins becomes unwell again, is admitted to hospital under the Mental Health Act 2001, and is found to lack capacity. It is proposed to treat her with the medication and electroconvulsive therapy she refused in her Advance Healthcare Directive. However, after consulting
her Advance Healthcare Directive, and her Designated Healthcare Representative, the treatment team are now aware of her will and preferences, and take her will and preferences into consideration. The treatment team respect her wish not to be treated with the medication specified in her Advance Healthcare Directive, or with electroconvulsive therapy, even though her Advance Healthcare Directive is not legally binding (due to the fact that she is an involuntary patient under the Mental Health Act 2001). Instead she is treated with the medication she has requested, and counselling. Ms Collins is recovering well from her crisis, and is engaging with her treatment. She feels less fearful about becoming unwell again and more in control of her life now that her will and preferences in relation to her treatment as outlined in her Advance Healthcare Directive treatment have been respected.

Ms Collins’ Advance Healthcare Directive acted as an important communication tool, and helped the treatment team to determine a course of treatment in accordance with her will and preferences as specified in her Advance Healthcare Directives when she was unwell, and her decision-making capacity became impaired. Respect for Ms Collins’ Advance Healthcare Directive was central to promoting person-centred recovery, during her involuntary detention under the Mental Health Act 2001.

*This vignette illustrates the on-going relevance of an Advance Healthcare Directive even where a person has been involuntarily admitted under the Mental Health Act 2001. Although Ms Collins’ Advance Healthcare Directive was no longer legally binding following her admission, it still played a crucial role in clinical decision-making by her treatment team. This reflects the importance of an Advance Healthcare Directive as an expression of a person’s will and preferences even where the Advance Healthcare Directive is not legally binding.*

### 6.2.3 Advance Healthcare Directives and treatment for a physical illness

If a person with a mental health condition makes an Advance Healthcare Directive that relates to the treatment of physical illness, it is fully enforceable once the conditions outlined in Sections 3 and 4 are fulfilled. This is the case regardless of whether the Directive-Maker has a mental health condition at the time of making the

The on-going enforceability of an Advance Healthcare Directive in respect of a physical disorder may be seen in the following vignette:

**Vignette 14: Enforceability of an Advance Healthcare Directive in respect of a physical disorder where the person has been admitted under the Mental Health Act 2001**

Mr Nolan is a young man with schizophrenia. He was admitted to hospital because he had secondary cancer and needed to begin treatment for it right away. During the first day in the hospital, his thinking became impaired and he became extremely agitated. He believed that the doctors and nurses wanted to poison him, and he was subsequently detained under the Mental Health Act 2001 on the basis that because of the severity of his illness, his judgment is so impaired that failure to admit him would lead to a serious deterioration in his condition.

Mr Nolan had made an Advance Healthcare Directive a few months earlier when he was presumed to have had capacity in which he refused any further treatment for his cancer, and appointed a Designated Healthcare Representative to communicate his will and preferences.

Following his admission, staff tried to talk to Mr Nolan to gain his trust, and gave him time and space to think about proceeding with the cancer treatment. They also consulted with the Designated Healthcare Representative and other people Mr Nolan trusted, to ensure that the Advance Healthcare Directive was a true reflection of his will and preferences, and that he had capacity when he made it.

The staff involved, advocates and people that Mr Nolan trusted discuss the treatment options with him, but it was clear that he now lacked capacity to decide about
treatment; i.e. could not understand, retain or weigh up the relevant information. After giving him appropriate support, Mr Nolan’s Advance Healthcare Directive in relation to his cancer treatment was upheld, and he was not given any further treatment for his cancer.

This vignette reinforces that an Advance Healthcare Directive in respect of treatment for a physical condition continues to be legally binding even where a person has been involuntarily admitted under the Mental Health Act 2001. The staff here made all efforts to confirm that the Advance Healthcare Directive represented Mr Nolan’s will and preferences in respect of treatment for his cancer. They also took steps to facilitate Mr Nolan in expressing his current will and preferences. All of these steps were appropriate (and they should be documented). However, once the staff had satisfied that the Advance Healthcare Directive was valid and applicable, it was legally binding and they were legally obliged to comply with it.

6.3 Attempted suicide and Advance Healthcare Directives

The 2015 Act does not distinguish between the enforceability of an Advance Healthcare Directive in a situation of deliberate self-harm and its enforceability in any other situation. However, it states that nothing in the 2015 Act shall be taken to affect Section 2 of the Criminal Justice (Suicide) Act 1993. This states that any person who ‘aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be guilty of an offence’. This means that where a person with an Advance Healthcare Directive presents in a situation of possible attempted suicide, it is necessary to ask whether the action of the Health and Social Care Professional constitutes aiding or abetting suicide.

Aiding and abetting means facilitating, assisting, promoting or encouraging a person to die by suicide. In order to aid and abet, the healthcare professional must know that the person has attempted to die by suicide.
**Vignette 15: Refusal to eat**

Mrs Young, an 89-year woman, made an Advance Healthcare Directive refusing life sustaining treatment, including artificial hydration and nutrition, in circumstances including her current state of health. She had been increasingly immobile due to arthritis and felt she could no longer live in her own home as result. She told those close to her that she prayed every day for death. She voluntarily stopped eating and drinking, reminding those close to her, who were upset by this, that she would be happy to die.

After a week, Mrs Young slipped into a coma. Her family called her doctor who found that she was severely dehydrated and would die without intravenous fluids. He was aware of the Advance Healthcare Directive and of Mrs Young’s expressed statement that she prayed for her death. He concluded that in giving effect to Mrs Young’s Advance Healthcare Directive, he would not be aiding or abetting in her suicide. Accordingly, he respected her will and preferences as expressed in her Advance Healthcare Directive.

*This vignette shows the kinds of difficult decisions which must be made around attempted suicide. Mrs Young’s doctor concluded that while Mrs Young had said that she would be happy to die, her decision to stop eating did not constitute an attempt to die by suicide. On this basis, he concluded that complying with her valid and applicable Advance Healthcare Directive did not constitute aiding or abetting suicide. Accordingly, in light of her legally binding Advance Healthcare Directive, he did not attempt to administer intravenous fluids contrary to her expressed will and preference.*

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**Vignette 16: Refusal of dialysis**

Mr Ahmed, a 72-year-old man, had been on dialysis several times a week for decades. His wife had died a few weeks earlier and, although his doctor didn’t feel he was depressed, Mr Ahmed had been feeling very lonely. He told family and
friends that he hoped that his own death would occur soon. He decided not to continue with dialysis and then called in to the dialysis unit to explain his decision and to say goodbye to the staff and other patients with whom he had become very close over the years. He then made an Advance Healthcare Directive refusing dialysis and stated that this was to apply even if his life was at risk. He discussed his Advance Healthcare Directive with his daughter and appointed her as his Designated Healthcare Representative.

Subsequently, Mr Ahmed’s daughter contacted Mr Ahmed’s general practitioner, Dr James who makes a home visit to Mr Ahmed. He confirmed that Mr Ahmed was unconscious and in acute kidney failure which could only be treated with dialysis in the hospital. Mr Ahmed’s daughter confirmed that Mr Ahmed had been entirely clear in his wish to decline treatment in this specific circumstance and, in her view, this was a clear expression of his wishes regarding treatment. Dr James reviewed Mr Ahmed’s Advance Healthcare Directive and confirmed this was his expressed wish. He arranged that palliative care was provided to Mr Ahmed in his own home and he died peacefully the following day.

The vignette reinforces the requirement that a valid and applicable Advance Healthcare Directive applies even if the effect is the death of the Directive-Maker (provided that the Advance Healthcare Directive states that it is to apply in these circumstances). The fact that a person has expressed a wish to die does not mean that his or her refusal of treatment constitutes suicide. The General Practitioner took steps to confirm with Mr Ahmed’s Designated Healthcare Representative that declining treatment was in accordance with his wishes. Having had this confirmed, he was legally required to comply with his refusal of treatment in his Advance Healthcare Directive.

Vignette 17: Possible overdose

Mr Bell, a 49-year old man with a history of depression, including two previous deliberate overdoses, and had significant disability due to a stroke, was brought to
the emergency department having been found unconscious at home. Some months earlier Mr Bell had made an Advance Healthcare Directive noting his poor quality of life and stating that he did not want to be investigated and treated if he were to become acutely ill for any reason, including cardiac, respiratory or neurological disease, even if that choice placed his life at risk.

Mr Bell's consultant, Dr Palmer, was aware of the Advance Healthcare Directive but was uncertain why Mr Bell had become unexpectedly unwell. She noted that investigations to exclude an overdose would always be performed in anyone presenting with an unexplained reduction in consciousness, as in Mr Bell’s case. The diagnosis of a possible overdose could be confirmed or refuted by a blood test. However, it would take half an hour for the test result to return and Mr Bell’s breathing was becoming shallow and his life was at immediate risk. She decided to perform the blood test and to ventilate Mr Bell in the meantime, with a plan to discontinue ventilation if the blood result did not confirm an overdose. The test results show that Mr Bell had not taken an overdose and Dr Palmer discontinued the ventilation. Mr Bell dies according to his will and preference as expressed in his Advance Healthcare Directive.

This vignette indicates a real possibility that Mr Bell's acute life-threatening condition was due to attempted suicide. This gave rise to uncertainty as to whether Mr Bell's refusal of treatment could be observed or whether this would constitute aiding and abetting suicide. The decision to test for an overdose is reasonable given Dr Palmer’s knowledge of Mr Bell’s background. If there was no evidence of attempted suicide, Mr Bell’s refusal of treatment in his Advance Healthcare Directive would be observed. If there was evidence of attempted suicide, Section 2 of the Criminal Law (Suicide) Act 1993 may apply.

6.4 Advance Healthcare Directives and Pregnancy

There are restrictions on the enforceability of an advance refusal of treatment where a Directive-Maker lacks capacity and is pregnant. These restrictions apply only
where the Health and Social Care Professional concerned considers that the refusal of treatment ‘would have a deleterious effect on the unborn’.

A ‘deleterious effect’ means that the refusal would be harmful to the ‘unborn’.

In order to conclude that a refusal ‘would have a deleterious effect’, the Health and Social Care Professional must consider that it is more likely than not that the refusal would have such an effect. This consideration must be based on clinical evidence and the Health and Social Care Professional should consult with an expert in obstetrics (if s/he is not such an expert) and must provide details in writing of the basis on which s/he reached the conclusion.

In these circumstances if:

- The Directive-Maker has not specifically stated whether a specific refusal of treatment is intended to apply if she is pregnant, and it is considered by the Health and Social Care Professional concerned that complying with the refusal of treatment would have a deleterious effect on the unborn, there is a presumption that the treatment should be provided or continued.
- The Directive-Maker has stated that a specific refusal of treatment is to apply even if she were pregnant, and it is considered by the Health and Social Care Professional concerned that a refusal of treatment would have a deleterious effect on the unborn, an application must be made to the High Court to determine whether or not the refusal of treatment should apply.

The factors which the High Court must consider in deciding whether the refusal should apply are:

- The potential impact of the refusal of treatment on the unborn;
- The invasiveness and duration of the treatment and the risk of harm to the Directive-Maker;
- Any other matter which the High Court considers relevant.
6.5 Advance Healthcare Directives and ‘Do Not Attempt Resuscitation (DNAR)’ Orders

Cardiopulmonary resuscitation (CPR), which can include chest compressions, defibrillation (with electric shocks), the injection of drugs, the provision of oxygen and fluids and ventilation of the lungs, is often a potentially life-saving intervention for victims of sudden cardiorespiratory arrest.

However, cardiopulmonary resuscitation is not always an appropriate or potentially life-saving intervention. Some individuals may be so unwell that death is considered to be imminent and unavoidable. For such individuals, cardiorespiratory arrest may represent the terminal event in their illness and the provision of cardiopulmonary resuscitation would not be clinically indicated (i.e. would not restart the heart and maintain breathing for a sustained period).

6.5.1. Do Not Attempt Resuscitation Orders and Advance Healthcare Directives

This code deals with Do Not Attempt Resuscitation Orders only in the context of an Advance Healthcare Directive.

A Do Not Attempt Resuscitation (DNAR) Order is a written order, made by the clinician involved in a person’s care that resuscitation should not be attempted if an individual suffers a cardiac or respiratory arrest. They are used when it is thought that performing cardiopulmonary resuscitation on a person who has a cardiac or respiratory arrest would not restart the heart and maintain breathing, or when the person themselves has expressed a wish not to have cardiopulmonary resuscitation. They are made in consultation with the person, or with regard to the will and preference of the person where s/he no longer has decision-making capacity.

There is a statutory obligation on Health and Social Care Professionals to respect a valid and applicable Advance Healthcare Directive refusing cardiopulmonary resuscitation irrespective of whether or not a Do Not Attempt Resuscitation Order is
documented in a person’s healthcare record. A valid and applicable Advance Healthcare Directive takes precedence over all national and hospital/healthcare policies with respect to Do Not Attempt Resuscitation Orders.

A valid and applicable Advance Healthcare Directive refusing cardiopulmonary resuscitation is legally binding. In clinical situations where cardiopulmonary resuscitation would be a potentially life-saving intervention, it should be regarded as a ‘life-sustaining treatment’. This means that an Advance Healthcare Directive is applicable to the refusal of cardiopulmonary resuscitation where it is substantiated by a statement by the Directive-Maker that the directive is to apply to that treatment even if his or her life is at risk.

This legal status of an Advance Healthcare Directive refusing cardiopulmonary resuscitation is evident in the following vignette:

**Vignette 18: Advance Healthcare Directive refusing cardiopulmonary resuscitation**

Mrs Stewart has end-stage heart failure and a life-threatening cardiac arrhythmia (irregular heartbeat) is an imminent risk. She, after consultation with her doctors and family, makes an Advance Healthcare Directive refusing cardiopulmonary resuscitation (CPR) in the event of a cardiac arrest even if her life is at risk. The existence of the Advance Healthcare Directive is noted when Mrs Stewart is admitted to hospital with a urinary tract infection and a copy is placed in her hospital chart. The doctor caring for Mrs Stewart also completes the hospital's standard form for documenting ‘Do Not Attempt Resuscitation’ (DNAR) decisions following consultation with Mrs Stewart.

Mrs Stewart remains in hospital for the next 6 weeks. It is hospital policy that the Do Not Attempt Resuscitation decision is re-documented every month but that is not done in this case. When Mrs Stewart has a cardiopulmonary arrest, the lack of an up to date Do Not Attempt Resuscitation decision is noticed by nursing staff and a cardiac arrest call is made and cardiopulmonary resuscitation is commenced. This is
successful in restarting the heart and Mrs Stewart is ventilated and admitted to the Intensive Care Unit.

On review of the notes, the presence of a valid and applicable Advance Healthcare Directive refusing cardiopulmonary resuscitation is noted. It is clear that Mrs Stewart should not have been resuscitated – her Advance Healthcare Directive was legally binding and the local hospital policy regarding Do Not Attempt Resuscitation documentation was of no relevance. Ventilation is discontinued in accordance with her Advance Healthcare Directive and Mrs Stewart dies.

The circumstances surrounding Mrs Stewart’s death are reported to the Coroner. Hospital management and staff meet Mrs Stewart’s family to apologise for failure to respect her Advance Healthcare Directive.

This vignette shows the importance of clear documentation and re-documentation and the need for effective procedures in this regard. It also shows that where there has been a failure to observe a valid and applicable Advance Healthcare Directive and treatment has been provided in error, this treatment must be discontinued so as to ensure that the Advance Healthcare Directive is complied with.

6.5.2 Choking (asphyxiation) and advance refusal of cardiopulmonary resuscitation

If it is recognized that a person with an Advance Healthcare Directive refusing cardiopulmonary resuscitation is choking on a foreign body, such as a bolus of food, every reasonable effort should be made to relieve the obstruction of the airway.

Choking on a foreign body can lead to a cardiac arrest if not treated promptly. If it is suspected that choking is the cause of cardiac arrest, it is appropriate to provide cardiopulmonary resuscitation while efforts are made to clear the blockage of the airway unless the Advance Healthcare Directive specifically states that cardiopulmonary resuscitation should not be provided in such a circumstance.
6.5.3 Pre-surgical care and advance refusal of cardiopulmonary resuscitation

Where a Directive-Maker is going to have a surgical procedure involving the administration of anaesthesia, the implications of an Advance Healthcare Directive refusing cardiopulmonary resuscitation should be considered and discussed with the person, if s/he has capacity. The clinical implications of refusal of cardiopulmonary resuscitation should be explained to the person in the context of surgery and the person should be asked if they wish to modify their Advance Healthcare Directive accordingly. This is because:

- Surgery and anaesthesia, whether regional or general, can promote cardiopulmonary instability including cardiac arrest, due for example to heart rhythm disturbances that will require support.
- Advance decisions regarding refusal of cardiopulmonary resuscitation may have been based on the often poor survival rates following cardiopulmonary resuscitation in most settings. However, survival rates following anaesthetic-related cardiac arrest in the operating theatre are much greater than in ward or residential settings.
- Many of the interventions used during a surgical procedure would be considered routine when giving an anaesthetic but would be regarded as resuscitative measures in other settings. These include intravenous cannulation, administration of intravenous fluids, insertion of an artificial airway, delivery of oxygen, provision of respiratory assistance, cardiac monitoring and administration of drugs to maintain blood pressure.

If the person does not have capacity and has refused cardiopulmonary resuscitation in a valid and applicable Advance Healthcare Directive and surgery is clinically indicated, the matter should be referred to the Court.
7. Dual Arrangements

7.1 Introduction

The 2015 Act allows a person to enter into a number of different decision-support arrangements where a person appoints a person of their choosing to support them to make decisions in relation to personal welfare (to include healthcare) and property and affairs. A person can have a number of different arrangements, at differing levels of support and also for different decisions.

The making of an Advance Healthcare Directive and the creation of an Enduring Power of Attorney (EPA) are two of the mechanisms provided for in the 2015 Act where a person who has capacity may appoint another to make general or specified decisions on their behalf to come into effect when he or she subsequently lacks capacity. The making of an Advance Healthcare Directive is confined to healthcare treatment decisions and the Directive-Maker can state their will and preferences in writing (subject to complying with formalities) or appoint a Designated Healthcare Representative to provide direction on what is set out in the Advance Healthcare Directive or to consent to or refuse treatment.

An Enduring Power of Attorney is an arrangement whereby a person, who is known as a Donor, appoints another person known as an Attorney to act for him or her in the future and gives the Attorney authority to make decisions on his or her behalf.

The authority which a Donor may give to an Attorney in an Enduring Power of Attorney may be either or both of the following:

(a) General authority to act on the Donor’s behalf in relation to all or a specified part of the Donor’s property and affairs; or

(b) Authority to do specified things on the Donor’s behalf in relation to the Donor’s personal welfare (which includes healthcare decisions, but not relating to the refusal of life sustaining treatment or treatment that is included in and
Advance Healthcare Directive) or property and affairs, or both which authority may, in either case, be conferred subject to conditions and restrictions.

It is therefore possible for a person to set out their will and preferences with regard to healthcare decisions in both an Advance Healthcare Directive and an Enduring Power of Attorney.

### 7.2 Interface between healthcare decision in an Enduring Power of Attorney and an Advance Healthcare Directive

The scope of the authority given to an Attorney in an Enduring Power of Attorney in relation to healthcare decisions cannot include authority relating to the refusal of life-sustaining treatment. The refusal of life-sustaining treatment can only be provided for in an Advance Healthcare Directive.

If a person has made an Enduring Power of Attorney and it has come into effect (that is that the person now lacks capacity and the Enduring Power of Attorney has been registered), the Health and Social Care Professional should find out whether a person has made a healthcare treatment decision in an Enduring Power of Attorney, as distinct from, or in addition to, setting out their treatment choices in an Advance Healthcare Directive. It is also necessary for the Health and Social Care Professional to ascertain what authority has the Attorney in relation to specific healthcare decision and if there are any conditions or restrictions imposed on the Attorney in relation to the exercise of his or her authority in relation to the specific decision.

In addition, if a person purports to give authority to an Attorney in relation to a healthcare decision which is already contained in or subsequently provided for in an Advance Healthcare Directive made by him or her, the provisions contained in the Enduring Power of Attorney shall be null and void and the directions contained in the Advance Healthcare Directive shall prevail.

If there is ambiguity in the Advance Healthcare Directive, the contents of a healthcare treatment decision in an Enduring Power of Attorney may provide useful
information to a Health and Social Care Professional to interpret the will and preferences of the Directive-Maker.

While the 2015 Act does not provide for a particular process to be followed in the event of there being ambiguity in relation to a healthcare decision set out in an Enduring Power of Attorney, it is suggested that the Health and Social Care Professional follows the process set out in Section 4.3 of this Code of Practice for an Advance Healthcare Directive and that the views of the Attorney be obtained.

7.3 Interface between an Advance Healthcare Directive and the appointment of a Decision-Making Representative

A Decision-Making Representative is appointed where the court has declared that a person (called a relevant person in the 2015 Act) lacks capacity to make one or more than one decision specified in the declaration relating to his or her personal welfare or property and affairs or both. The Decision-Making Representative is given authority by the court to make specified decisions on behalf of the relevant person.

The court must have regard to the terms of any Advance Healthcare Directive and/or Enduring Power of Attorney made by the person and must ensure that the terms of any order it makes is not inconsistent with theAdvance Healthcare Directive and/or Enduring Power of Attorney. Where it makes an order to appoint a Decision-Making Representative, it must ensure that the functions of the Decision-Making Representative are not inconsistent with

- An Advance Healthcare Directive made by the Directive-Maker or inconsistent with the relevant powers exercisable by any Designated Healthcare Representative under the terms of the Advance Healthcare Directive; or
- The terms of an Enduring Power of Attorney are inconsistent with the functions of an Attorney under an Enduring Power of Attorney.
It is therefore possible that a Health and Social Care Professional may have to interact with a Designated Healthcare Representative/Attorney with regard to some healthcare treatment choices contained in an Advance Healthcare Directive or Enduring Power of Attorney but also deal with a Decision-Making Representative appointed by the court in relation to healthcare treatment matters not included in the Advance Healthcare Directive or Enduring Power of Attorney. It is important that verification of the authority of the Decision-Making Representative to make healthcare treatment decisions is clarified by reference to the obtaining of the court order.
8. No Advance Healthcare Directive

Every adult is presumed to have capacity to make decisions about their treatment choices and consent to their treatment as required. However, a person who does not have the capacity to make a decision and who has not made an Advance Healthcare Directive is entitled to the same respect for his/her dignity and personal integrity as a person with capacity. Health and Social Care Professionals should follow the steps in Section 1 to ascertain what healthcare treatment decisions a person has or lacks the capacity to make. The fact that a person lacks capacity to make a particular decision at a particular time does not mean that s/he lacks capacity to make other decisions or to make the particular decision at another time.

If a person lacks capacity to make a healthcare treatment decision and there is no one with legal authority to make decisions, the Guiding Principles in the 2015 Act should be followed:

- Which treatment option would give the best clinical benefit to the person;
- Give effect, in so far as practicable, to the person’s past and present will and preferences, in so far as they are reasonably ascertainable;
- Take into account, the beliefs and values of the person, in so far as reasonably ascertainable;
- Unless the Health and Social Care Professional reasonably considers that it is not appropriate or practicable to do so, consider the views of any person named by the person to be consulted with regard to her healthcare treatment decisions;
- Seek the opinion of other Health and Social Care Professionals;
- Act at all times in good faith and for the benefit of the person.

In making the decision, it is necessary for the Health and Social Care Professional to follow the provisions outlined in this code and relevant principles of professional practice and conduct. Health and social care professionals should also ensure that there are no disputes in respect of the will and preferences of the person and no other doubts or concerns arise. In cases where the treatment decision is especially complex or there are disputes among the family and friends of the person as to what
the person’s will and preferences would be, the matter may have to be referred to
court to be resolved. If the decision involves the donation of an organ from a living
Donor or the withdrawal of life-sustaining treatment, the relevant court is the High
Court. For all other matters, the relevant court is the Circuit Court.
Appendix 1 – Group Membership

Advance Healthcare Directives Multidisciplinary Working Group

Prof Deirdre Madden (Chair) Director of BCL International, School of Law, University College Cork
Ms June Boulger National Lead for Patient and Public Partnership, HSE Acute Hospital Division
Ms Barbara Bolger National Specialist, Primary Care Operations, HSE Primary Care Division
Mr Derek Chambers Mental Health Lead on Connecting for Life, HSE Mental Health Division
Ms Ina Crowley Project Officer for Public Health Nursing Services, Office for Nursing and Midwifery Services Director (until February 2017)
Ms Audry Deane Health Policy Officer, Age Action, National Patient Forum Representative
Prof Mary Donnelly Vice-Dean for Student Affairs, School of Law, University College Cork
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**Advance Healthcare Directives Subgroup**

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