seirbhís tacaíochta cinnteoireachta
decision support service

Code of Practice for

Designated Healthcare Representatives

April 2023

This code should be read in conjunction with the Assisted Decision-Making (Capacity) Act 2015 (as amended). For the avoidance of doubt, in the event of any conflict or inconsistency, the legislative provisions in the Act prevail.

Contents

1 Introduction

1.0 Context and purpose of this code of practice

The Assisted Decision-Making (Capacity) Act 2015 (as amended) (the Act) establishes a modern legal framework for adults who require, or may require, support in exercising their decision-making capacity, either now or in the future.

One of the ways in which the Act provides for advance planning is through an advance healthcare directive. The person who makes an advance healthcare directive is known as a directive-maker.

A designated healthcare representative is a person chosen by the directive-maker to ensure that the terms of the advance healthcare directive are complied with.

The purpose of this code of practice is to provide guidance to you, as a designated healthcare representative, so that any functions and duties you carry out are in accordance with the Act.

In reading this code of practice, any reference to particular sections and chapters should be understood as referring to those included within this code and not to the Act.

1.1 Advance healthcare directive

In an advance healthcare directive, the directive-maker sets out their will and preferences regarding healthcare treatment decisions, including treatment refusals, in case they are unable to make those decisions in the future.

1.1.1 Making an advance healthcare directive

Any person aged 18 or older with capacity can make an advance healthcare directive that will come into effect if they lack capacity to make treatment decisions for themselves in the future.

The purpose of an advance healthcare directive is to enable a person's will and preferences to guide their treatment even when they lack capacity to give or refuse consent to the treatment in question. This helps to ensure that the directive maker's rights remain at the centre of their treatment decisions.

The advance healthcare directive must be in writing. Under the Act, 'in writing' may include voice and video recording, and speech recognition technologies.

1.1.2 Matters addressed in an advance healthcare directive

A directive-maker has a legal right to consent to or refuse treatment, including life-sustaining treatment, once addressed in the advance healthcare directive.

A treatment decision within an advance healthcare directive includes any intervention that is made or may be carried out for therapeutic, preventative, diagnostic, palliative, or other purposes related to the physical or mental health of the directive-maker. This includes life-sustaining treatment.

Some examples of treatments which may be found in an advance healthcare directive include:

- emergency treatments such as cardiopulmonary resuscitation (CPR);
- diagnostic tests such as blood samples or biopsies; and
- therapeutic interventions such as for treatment of cancer.

1.2 Designated healthcare representative

A designated healthcare representative is a person chosen by the directive-maker to act as their agent to ensure that the terms of the advance healthcare directive are complied with. The advance healthcare directive may also include an alternate designated healthcare representative, should the first named person be unable to take up this position if required to do so. This code of practice applies to an alternate designated healthcare representative in the same way as it does for the main designated healthcare representative.

Your role as a designated healthcare representative is to provide direction to healthcare professionals and take steps to ensure that the will and preferences of the directive-maker are considered and respected in relevant treatment decisions.

Where explicitly provided for in the advance healthcare directive, the designated healthcare representative can advise the healthcare professional on their interpretation of the directive-maker's will and preferences for a treatment decision and may consent to or refuse treatment by reference to the advance healthcare directive.

An advance healthcare directive can be made without appointing a designated healthcare representative.

1.3 Further guidance

Further information and guidance is available on our website Decision Support Service or by contacting us.

1.3.1 Other codes of practice

Other codes of practice contain information that can support you as a designated healthcare representative.

You must read the code of practice on supporting decision-making and assessing capacity. This describes how to support decision-making through applying the guiding principles of the Act. As an intervener under the Act, you are required to comply with the provisions of that code of practice.

In addition, you may wish to read codes of practice for other decision supporters and healthcare professionals to help you better understand their roles when you are interacting with such people.

2 Your functions and duties on appointment

2.0 Introduction

This chapter provides guidance on your functions and duties as a designated healthcare representative while the directive-maker still has capacity to make their own treatment decisions.

2.1 No authority until advance healthcare directive comes into effect

Following your appointment as a designated healthcare representative, you are not automatically authorised to represent the directive-maker on any decisions included in the advance healthcare directive.

This is because an advance healthcare directive is only applicable when the directive-maker lacks capacity to give or refuse consent to treatment, even after all necessary supports have been provided to maximise their capacity.

In addition, it is important to note that even where the advance healthcare directive has come into effect for a specific decision, you must presume the directive maker has capacity on each subsequent decision, or the same decision at a different time, before exercising your authority.

The process for determining whether an advance healthcare directive applies in a specific situation is further described in section 3.1.

2.2 Read the advance healthcare directive

2.2.1 Understand the scope of your authority

When making the advance healthcare directive, the directive-maker may give you one or both of two powers. These are:

- the power to advise and interpret what the directive-maker's will and preferences are regarding treatment decisions in the advance healthcare directive; and
- the power to consent to or refuse treatment, including life-sustaining treatment, based on the known will and preferences of the directive-maker.

You must read and understand the advance healthcare directive as this is the legal basis for actions you take. You must always act within the scope of the advance healthcare directive.

As the designated healthcare representative, you cannot delegate your responsibilities to any other person.

2.2.2 Be aware of content of the advance healthcare directive (treatment decisions)

You must be aware of the potential implications of treatment decisions included in the advance healthcare directive. You should discuss treatment decisions within the scope of the advance healthcare directive with the directive-maker while they have capacity. You should obtain information on the potential implications of such decisions and ensure you know how to get further information if needed.

Any person aged 18 and over with capacity can consent to or refuse treatment, including life-sustaining treatment. In an advance healthcare directive, the directive-maker can request or refuse specific treatments, including refusal of life-sustaining treatment.

Where a directive-maker wishes to refuse life-sustaining treatment, the advance healthcare directive must contain a statement by the directive-maker that this refusal applies even where their life is at risk.

2.2.3 Role of an alternate designated healthcare representative

In addition to appointing a designated healthcare representative, a directive-maker may name an alternate designated healthcare representative in the advance healthcare directive.

This alternate designated healthcare representative only has authority to represent the directive-maker if you are unable to represent the directive-maker.

In this situation, the alternate designated healthcare representative replaces you and assumes your responsibilities. Where possible and appropriate, you may be required to provide the alternate designated healthcare representative with relevant information and documentation about any actions you undertook on behalf of the directive-maker.

2.2.4 More than one advance healthcare directive

A directive-maker can make more than one advance healthcare directive and can appoint a different designated healthcare representative in each one. For example, the directive-maker can make one advance healthcare directive for a mental health condition and a second for a physical health condition.

There is no obligation for a directive-maker to disclose to you the existence of any other advance healthcare directives to which you are not appointed as designated healthcare representative.

However, where you are aware of the existence of another designated healthcare representative you may need to consult with them, as set out in the guiding principles of the Act.

2.3 Understand the directive-maker's will and preferences

It is important that you have a clear understanding of the directive-maker's will and preferences in relation to treatment decisions included in the advance healthcare directive.

2.3.1 Treatment decisions within the advance healthcare directive

In taking on the role of designated healthcare representative, you have agreed to respect and give effect to the known will and preferences of the directive-maker for all treatment decisions specified in the advance healthcare directive in relation to which you have been appointed.

Even if you know the directive-maker well, it may be useful to document and maintain a record of the directive-maker's will and preferences in relation to the decisions you may be required to make in the future. This is especially important if you have been given specific powers in the advance healthcare directive to interpret the directive-maker's will and preferences.

It may be useful to revisit the directive-maker's will and preferences regarding treatment decisions in the advance healthcare directive, especially if the directive-maker has experienced a change in circumstances, for example, if they have been diagnosed with a serious illness.

If you disagree with the directive-maker's will and preferences, you may continue to be a designated healthcare representative so long as you can commit to representing their wishes in accordance with their advance healthcare directive. If you cannot commit to this, you must inform the directive-maker that you are unable to be their designated healthcare representative. This may apply to a specific treatment decision or the full advance healthcare directive.

2.3.2 Treatment decisions in other decision support arrangements

A directive-maker may also have, or have had, a decision-making assistance agreement or a co-decision-making agreement in place to support them in making decisions.

Where such agreements include treatment decisions, it is important to engage with these decision supporters, with the permission of the directive-maker, to better understand the directive-maker's will and preferences with regard to relevant decisions.

Where a directive-maker has a decision-making representation order in place, any treatment decisions should be made with regard to the advance healthcare directive. This is further described in section 3.2.2.

2.3.3 Permission to discuss will and preferences with other people

Where appropriate, you may consult with the directive-maker to identify other trusted people that may know the directive-maker well, and who can help you to interpret the directive-maker's will and preferences.

This may also help to clarify any people that the directive-maker does not wish to be consulted with.

2.4 Keep a copy of the advance healthcare directive

You should keep a copy of the advance healthcare directive in a secure but convenient and accessible place. Any records of relevant conversations, as described in section 2.3.1, should be kept with the advance healthcare directive.

If the directive-maker amends their advance healthcare directive, you must keep a copy of the most up-to-date version, noting any amendments made. Changes to the advance healthcare directive are further described in section 2.6.

2.5 Your role in informing other people

While the directive-maker has capacity to do so, it remains their decision who they advise about the existence of their advance healthcare directive. For example, they may inform their healthcare service providers and family members.

At this stage, your role may include assisting the directive-maker when requested to do so, for example by providing a copy of the advance healthcare directive to relevant service providers. In doing so, you must make it clear that the directive-maker is still responsible for making treatment decisions.

Where the directive-maker does not wish service providers to be advised about the advance healthcare directive, it may still be useful for you to be aware of services the directive-maker is receiving and key contacts within those services. This will enable you to inform relevant services quickly if the advance healthcare directive comes into effect.

2.6 Amending or revoking the advance healthcare directive

A directive-maker may amend or revoke, in writing, their advance healthcare directive so long as they have capacity to do so.

In order to be effective, any amendments to the advance healthcare directive must be signed and witnessed following the same process as applied when making the advance healthcare directive. This means that if you want to continue to act as the designated healthcare representative, you must sign and date any amendment in the presence of two witnesses.

Where the directive-maker revokes the advance healthcare directive, this is effective so long as it is in writing. There is no requirement for the revocation to be signed or witnessed.

3 Acting as a designated healthcare representative

3.0 Introduction

This chapter provides guidance on your functions and duties as a designated healthcare representative when the directive-maker does not have capacity to make their own treatment decisions, or when their capacity is being called into question.

It describes your role when interacting with healthcare professionals in the context of a treatment decision. This includes representing the directive-maker and ensuring their will and preferences are taken into consideration with regard to requests for and refusal of treatment, as set out in the advance healthcare directive.

3.1 Applicability of the advance healthcare directive

An advance healthcare directive is only applicable when the directive-maker lacks capacity to give or refuse consent to a treatment decision specified in it, at the time the decision needs to be made, even after all necessary supports have been provided to maximise their capacity.

3.1.1 Determining the directive-maker's capacity

As a designated healthcare representative, you are not required to determine the directive-maker's capacity.

The most appropriate person to undertake the capacity assessment should be considered on a case-by-case basis in the context of the decision that needs to be made. In the case of a treatment decision, this will usually be the healthcare professional with the best understanding of the decision that needs to be made.

The capacity assessment must use a functional approach. This means it focuses on how the directive-maker makes a decision and the steps they take in the decision-making process.

It also means that the assessor must limit the assessment to the directive-maker's capacity to make a specific decision at the time and in the circumstances in which the decision is being made.

3.1.2 Make service providers aware of the advance healthcare directive

If the directive-maker's capacity has been called into question, or an assessment has been made that the directive-maker lacks capacity to make a specific decision, you should make reasonable efforts to ensure relevant service providers are aware of the advance healthcare directive and of your role.

3.1.3 Changes in capacity over time

The directive-maker's capacity may change during your appointment as a designated healthcare representative. This may include lacking capacity as well as gaining capacity to make decisions in one or more areas covered by the advance healthcare directive. Changes in capacity may also be temporary or fluctuating.

While it is useful for you to be aware of any such changes in capacity, this will only be applicable when a specific treatment decision, or one that is materially the same as what is included in the advance healthcare directive, needs to be made.

3.1.4 Ambiguity regarding validity and applicability

Where there is ambiguity regarding the validity and applicability of an advance healthcare directive, the healthcare professional involved in administering the proposed treatment must seek to resolve the ambiguity by:

- consulting with you, as the designated healthcare representative; and
- seeking the opinion of a second healthcare professional.

Where consulted, you should advise and interpret the directive-maker's will and preferences as set out in the advance healthcare directive, in so far as it is applicable to the decision that needs to be made.

Where ambiguity remains, the healthcare professional must resolve the ambiguity in favour of the preservation of the directive-maker's life.

Where the directive-maker is pregnant, the healthcare professional must resolve the ambiguity in favour of preventing a deleterious effect on the directive-maker's pregnancy.

3.1.5 Court proceedings

The directive-maker may be the subject of a court application to:

- determine or review their capacity to make a specific treatment decision;
- determine validity or applicability of an advance healthcare directive in relation to a non-life-sustaining treatment decision; or
- determine validity or applicability of an advance healthcare directive in relation to a life-sustaining treatment decision.

In such circumstances, you may be requested or permitted by the court to support the directive-maker.

3.2 Act within the scope of your authority

As the designated healthcare representative, you are deemed to be the agent of the directive-maker when you exercise the relevant powers set out in the advance healthcare directive. You must always act within the scope of your authority as set out in the advance healthcare directive.

3.2.1 Check your authority regarding the treatment decision in question

You must ensure you have the appropriate authority before taking an action as a designated healthcare representative. When a treatment decision needs to be made, you should review the advance healthcare directive to ensure the specific decision comes within the scope of your authority. In addition, you should review the extent of your authority with regard to the decision, as described in section 2.2.1.

3.2.2 Authority to act where a decision-making representation order is in place

The directive-maker may also have a decision-making representation order in place, made after the advance healthcare directive.

Where the decision-making representation order includes healthcare treatment decisions, the court must ensure these are consistent with treatment decisions in the advance healthcare directive.

In addition, the functions of a decision-making representative appointed to support the relevant person in making a treatment decision must be consistent with the functions of the designated healthcare representative for that same treatment decision in the advance healthcare directive.

The purpose of this is to minimise the risk of different interpretations of the will and preferences of the directive-maker with regard to treatment decisions.

While you should endeavour to work with the decision-making representative, where applicable, to act consistently for the benefit of the directive-maker, a valid and applicable advance healthcare directive takes precedence over a decision-making representation order.

3.2.3 Authority to act where other decision support arrangements are in place

The directive-maker may also have a decision-making assistance agreement or a co-decision-making agreement in place. A valid and applicable advance healthcare directive takes precedence over any treatment decisions included in such arrangements.

However, a decision-making assistance agreement or co-decision-making agreement will only be effective and in place while the directive-maker (known as the appointer in these agreements) has capacity to make the decisions contained in the agreement. Accordingly, the advance healthcare directive would not be applicable while the directive-maker has capacity.

Where the directive-maker has an enduring power of attorney in place, it may be useful to engage with any attorney appointed. However, treatment decisions are not included in this type of decision support arrangement.

3.2.4 Providing evidence of your authority on request

You may be requested to provide evidence of your legal authority to act as a designated healthcare representative. A copy of the advance healthcare directive is evidence of your authority.

3.2.5 Do not delegate your authority

As a designated healthcare representative, your authority to act on behalf of the directive-maker cannot be delegated to any other person. Section 2.2.3 describes the function of an alternate designated healthcare representative.

3.2.6 Interacting with family members and others

Unless a family member, friend or any other person has been given specific authority by the directive-maker in a decision-making support arrangement, they do not have any authority in relation to the directive-maker's decisions, nor are they permitted to access the directive-maker's information.

However, it may be useful to interact with such people in gathering information to make a decision, as described in section 3.3.1.

3.3 Understand context for the treatment decision

3.3.1 Gather all relevant information

When gathering information, you must ensure that you include information on any factors that would have been considered important to the directive-maker if they were making the decision themselves.

You should gather relevant information on the options available, and the risks and benefits of these options. You must ensure, as much as possible, that you understand the short-term and long-term consequences of the options available.

3.3.2 Consider necessity of the treatment decision

Before consenting to or refusing treatment in line with the directive-maker's will and preferences, you must consider whether the decision is necessary at this time. Decisions should not be made in advance.

3.4 Act in accordance with known will and preferences

Where the directive-maker has expressed clear will and preferences in relation to the decision that needs to be made, or a decision that is materially the same, you must act in accordance with their known will and preferences, by reference to the advance healthcare directive.

3.4.1 Consider previous discussions with the directive-maker

If you have kept a record of previous discussions with the directive-maker in regard to their will and preferences, as described in section 2.3.1, you should consult these.

3.4.2 Consult the views of others where appropriate

Other people may be able to provide you with useful information on the directive-maker's will and preferences in relation to the specific treatment decision. This may include:

- other decision supporters, as described in sections 3.2.2 and 3.2.3;
- a person providing care to the directive-maker;
- a person providing other relevant services to the directive-maker; and
- healthcare professionals.

At the same time, you should bear in mind that the directive-maker may not wish some people to be consulted about their will and preferences, as described in section 2.3.3.

You must ensure that you only disclose information as provided for in the advance healthcare directive when discussing the directive-maker's will and preferences with another person. You should make a record of any person you consulted as part of the decision-making process, including why you consulted them and the information they provided you with. Section 3.5 provides further guidance on record keeping.

Even after consulting with others, authority to interpret will and preferences remains with you, as the designated healthcare representative.

3.5 Record keeping

3.5.1 Maintaining records

As a designated healthcare representative, you are required to make clear and accurate records of any treatment decision you make on behalf of the directive-maker, within seven working days of making the decision. This record must be in writing.

When making a written record of a treatment decision, you should ensure it includes the date of the record and enough detail to enable you to answer questions about the decision, if necessary. This may include information you gathered and other people you have consulted in reaching your decision. You must be able to demonstrate how your decision was made with reference to the advance healthcare directive. The level of detail should be proportionate to the significance and complexity of the decision.

You must be able to produce that record for inspection at the request of the directive-maker if they regain capacity, or the Decision Support Service.

In addition, a court may seek a record of the decision made if a complaint is filed in court about you.

3.5.2 Retention and storage of information

You must only retain information about the directive-maker that is relevant to the scope of your authority in the advance healthcare directive.

You must ensure this information is stored securely, to prevent unauthorised access, use or disclosure. For example, if you store information or records on a shared device (e.g., a personal computer, tablet or other device that is used by other members of your family), you must ensure you have sufficient security settings so that the information cannot be accessed by others. If you store information or records electronically, you must ensure that the information is backed up to prevent unintended loss.

3.5.3 Destruction or disposal of information

If your appointment ends for any reason, you must ensure documentation is either returned to the directive-maker or disposed of securely.

4 Complaints and investigations

4.0 Introduction

This chapter provides information on how complaints about you, acting as a designated healthcare representative, may be investigated and possible outcomes of any such investigations.

4.1 Acting outside the scope of your authority

Any person may make a complaint to the Decision Support Service about you in your role as a designated healthcare representative.

4.1.1 Consideration by the Decision Support Service

Following receipt of a complaint, the Decision Support Service will consider whether it is within remit. If it is, the Decision Support Service will inform you of the complaint and how it will proceed.

Further information on complaints procedures is available from the Decision Support Service.

4.1.2 Where no external complaint has been received

The Decision Support Service does not need to receive a complaint from a third party in order to carry out an investigation. The Decision Support Service may investigate a matter on its own initiative.

4.1.3 Referral to court

Following investigation, the Decision Support Service may decide to take no further action or may make an application to the court. If the court is satisfied that you have acted, or propose to act, in a manner outside the scope of your authority under the advance healthcare directive, the court may make an order prohibiting you from exercising those powers.

The court will decide:

- that you are no longer permitted to act as a designated healthcare representative because you have acted, or propose to act, outside the scope of your authority; or
- that you can continue to act as a designated healthcare representative.

4.1.4 Interacting with general and special visitors

The Decision Support Service maintains a panel of general visitors and special visitors to assist with the investigation of complaints.

The Decision Support Service may instruct a general or special visitor to visit you, the directive-maker and other people as necessary to investigate any complaints received.

A special visitor will only be sent where an assessment of the directive-maker's capacity is required as part of the visit. Both general and special visitors are authorised to request specific information from you, including documentation relating to specific decisions you have made on behalf of the directive-maker.

You must facilitate the visitor and their requests for information. You must not obstruct a general visitor or special visitor in carrying out their visit. You must facilitate the visitor and their requests for information. As set out in section 4.3.4, it is an offence for any person to fail to comply with or hinder or obstruct the exercise of the Decision Support Service's investigative functions.

Further information on the role of general visitors and special visitors can be found in the code of practice for general visitors and the code of practice for special visitors.

4.2 Grounds for disqualification

You are not eligible to continue acting in your role if, at any time following your appointment, you:

- are convicted of an offence in relation to the person or property of the directive-maker, or the person or property of a child of the directive-maker;
- become the subject of a safety or barring order in relation to the directive-maker or a child of the directive-maker;
- become the owner, or registered provider, of a designated centre or mental health facility where the directive-maker lives, unless you are the spouse, civil partner, co-habitant, parent, child or sibling of the directive-maker;
- live with, work at, or become an agent for a designated centre or mental health facility where the directive-maker lives, unless you are the spouse, civil partner, co-habitant, parent, child or sibling of the directive-maker;
- provide paid personal care or healthcare services to the directive-maker, unless you are the spouse, civil partner, co-habitant, parent, child, sibling or the primary carer of the directive-maker; or
- become unable, for whatever reason, to exercise relevant powers.

Unless the advance healthcare directive provides otherwise, where you are in a relationship with the directive-maker, you will be disqualified from acting as designated healthcare representative at any time following your appointment, if you:

- are the spouse or civil partner of the directive-maker, and the marriage or civil partnership is annulled or dissolved, or there is a judicial separation or written agreement to separate; or

- are the spouse, civil partner or cohabitant of the directive-maker and you have separated and have not lived together for a continuous 12-month period. However, if the reason you are not living together is because one or both of you had to move to a health or residential facility or an institution (including prison), you will not be regarded as having separated.

4.3 Offences

There are a number of offences created under the Act relating to the role of designated healthcare representative.

4.3.1 Fraud, coercion or undue influence

Any person who uses fraud, coercion or undue pressure to force a directive-maker to make, vary or revoke an advance healthcare directive commits an offence with penalties of up to five years imprisonment or a fine of up to €50,000, or both.

This includes any instance where fraud, coercion or undue influence is used to make the directive-maker believe their access to a designated centre or mental health facility depends on them creating, varying or revoking an advance healthcare directive.

4.3.2 Making a false statement

Any person who makes, falsifies, alters or purports to revoke an advance healthcare directive on behalf of another person, without that person's consent, commits an offence with penalties of up to five years imprisonment or a fine of up to €50,000, or both.

4.3.3 Ill-treatment or neglect

A designated healthcare representative who ill-treats or wilfully neglects a relevant person commits an offence, with up to five years imprisonment or a fine of up to €50,000, or both.

4.3.4 Not co-operating with an investigation or obstruction

It is an offence to not co-operate with an investigation carried out by the Decision Support Service or to hinder or obstruct a member of staff of the Decision Support Service in carrying out their functions. In such a case, you may be subject to a fine of up to €5,000.

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