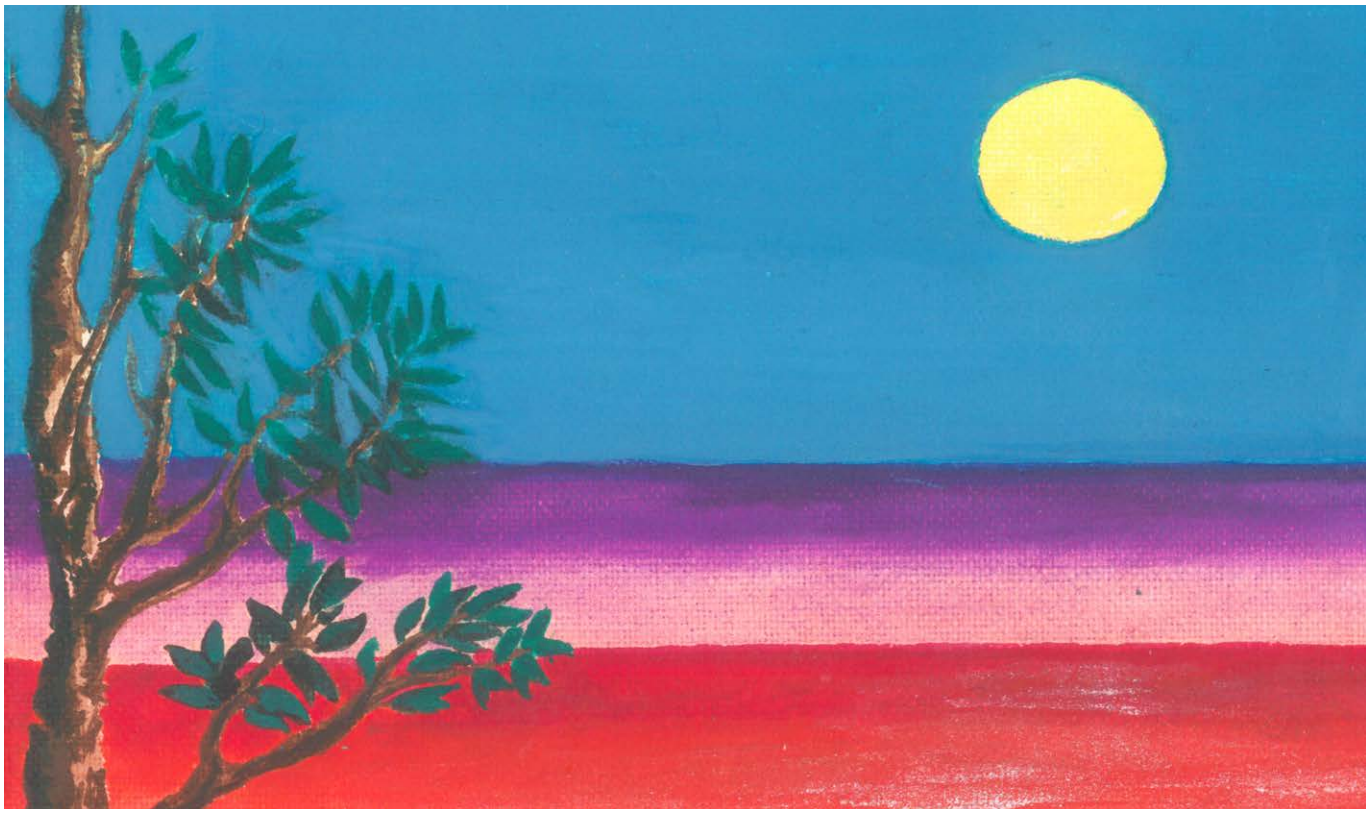
Making and implementing Advance Decision to Refuse Treatment:

A toolkit for healthcare professionals



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States of Jersey

Introduction

What is this toolkit for?

The purpose of this toolkit is to support healthcare professionals' understanding of Advance Decision to Refuse Treatment (ADRT). It looks at:

- the legal framework for ADRTs and explaining healthcare professionals' obligations when caring for someone who lacks capacity;
- what an ADRT is and the criteria one needs to meet;
- how to support someone to make an ADRT;
- what steps should be followed if a person lacks capacity and has an ADRT;
- challenges that healthcare professionals may face when acting on an ADRT and offering practical guidance to help overcome them; and
- the relationship between ADRTs and Lasting Power of Attorney for health and welfare.

It consolidates guidance from the Capacity and Self-Determination Law (Jersey) 2016, General Medical Council and British Medical Association.

This toolkit should be read in conjunction with the Capacity and Self-Determination Law (Jersey) 2016 and its accompanying Code of Practice. Throughout this toolkit the law will be referred to as the CSDL.

Who is this toolkit for?

The toolkit aims to support anyone who is engaging someone in discussions about advance care planning. This could be prompted by a direct question about an ADRT or a broader discussion about a person's wider goals of care. It is also for anyone involved in implementing an ADRT. This could include health and social care professionals.

What is the scope of this toolkit?

The information in this toolkit applies to Jersey.

Making an ADRT can form part of Advance Care Planning, a process of discussing and/or formally documenting a person's wishes for their future care. This toolkit focuses on ADRT and does not discuss other ways to plan ahead.

How do I use this toolkit?

We recommend that you read this entire toolkit. However, each part can also be read independently if you feel there are some sections that are more relevant to you than others.

Contents

Acknowledgements

This Advance Decision to Refuse Treatment toolkit was initially developed by Compassion in Dying (charity number 1120203) for use in the UK. Compassion in Dying have generously shared their work to help with the creation of this resource for use in Jersey.

Part A: The law

Any person over the age of 16 has the right to refuse medical treatment as long as they have capacity to make the decision.[1] This is the case even if that refusal will result in their death.[2]

Adults with capacity also have the legal right to refuse medical treatment in advance in an ADRT.[3] This allows their wishes to be known should they lose capacity to make or communicate decisions in the future. The right to refuse treatment in an ADRT is written into statutory law in the Capacity and Self-Determination Law (Jersey) 2016 (CSDL).

The Capacity and Self-Determination Law (Jersey) 2016

The CSDL sets out in law a framework that must be followed when making decisions on behalf of someone who cannot make a decision for themselves. The CSDL applies to everyone, including family members and friends as well as healthcare professionals.[4]

The Law is based on 5 core principles. These principles must underpin everyone's approach to decision-making:[5]

1. a person, aged 16 and over, must be assumed to have capacity, unless it is shown that the person lacks capacity in relation to the decision
2. a person in not to be treated as unable to make a decision unless all practicable steps to enable that person to make the decision have been taken without success
3. a person is not to be treated as unable to make a decision merely because the person makes an unwise decision
4. an act done, or a decision made, on behalf of a person lacking capacity must be done or made in the person's best interests
5. before an act is done, or a decision is made which is restrictive of the person's rights and freedom of action, regard must be had to whether the purpose for the which it is needed can be achieved as effectively in a less restrictive way

What is 'capacity'?

Capacity is the ability to make a decision. It is time and decision-specific.[6] This means that whether or not a person has capacity depends on when the decision needs to be made and what the decision is. For example, a person may lack capacity to make a decision on one day but be able to make that decision at a later date. This might be if, for example, they have dementia and their capacity is fluctuating. A person might also have capacity to make some decisions but not others. For example, they could be able to decide what they want to eat but not have capacity to understand what will happen if they refuse life-sustaining treatment. Healthcare professionals should not make a blanket statement that a person 'lacks capacity'.

The CSDL states that a person has capacity if they can:

a) understand the information relevant to the decision

b) retain that information for a period, however short, to make the decision

c) use or weigh up that information as part of the process of making the decision

d) communicate the decision by any means[7]

A person only has to be unable to do one of these things to lack capacity to make that particular decision.

Part B: What is an ADRT?

Key facts:

An ADRT:

- allows a person to record any medical treatments that they do not want to be given in the future, in case they later lose capacity and cannot make or communicate that decision themselves[8]
- can be used to refuse any medical treatment, including life-sustaining treatment such as cardiopulmonary resuscitation (CPR), mechanical ventilation and clinically assisted nutrition and hydration
- is legally binding if it is 'valid' and 'applicable' to the situation the person is in (see page 13 for more information)[9]
- only comes into effect once the person has lost capacity[10]

The legal term is Advance Decision to Refuse Treatment, however it is commonly abbreviated to ADRT, and this is the term used throughout this toolkit. Refusals of treatment contained in a valid and applicable ADRT must be given the same weight as those given by a patient with capacity. Healthcare professionals who ignore a valid and applicable ADRT may face a criminal charge or civil liability.[11]

ADRTs are not solely for people who are nearing the end of life or who have been given a diagnosis of a specific condition. Any adult with capacity has the right to make an ADRT.[12] Advance care planning is valuable at any time and making an ADRT can form an important part of planning for a person's future care and treatment.

What are the requirements for an ADRT?

The requirements for an ADRT depend on whether or not it contains a refusal of life-sustaining treatment. The CSDL defines life-sustaining treatment for the purpose of ADRTs as "any treatment necessary, in the view of a person providing health care for a person lacking capacity, to sustain the latter person's life".[13]

An ADRT that does not refuse life-sustaining treatment:

- can be made verbally
- must state precisely what treatment is to be refused – it is not enough to give a general wish not to be treated
- must set out the circumstances when the refusal should apply – it is helpful to include as much detail as possible[14]

An ADRT that refuses life-sustaining treatment must:

- be in writing
- specify the treatment(s) that is to be refused. Although this may be expressed in layman's terms it must state precisely what treatment is to be refused – a statement giving a general desire not to be treated is not sufficient – it is however possible to make a blanket refusal of 'all life-sustaining treatment'
- specify the circumstances in which the refusals of treatment should apply
- be made only by someone who is 16 years or older
- be made only by someone who had capacity at the time it was written
- be signed by the person (or, if they are unable to sign it, by another person in the their presence) in the presence of a witness
- be signed by the witness, in the presence of the person and
- contain a statement to the effect that the ADRT should apply even if the person's life is at risk as a result[15]

It is not a requirement that an ADRT be endorsed or written by a solicitor.

What can an ADRT not be used for?

A person cannot demand specific treatment in an ADRT, just as a person with capacity cannot demand to be given specific treatment. Although a person can express their preferences for particular treatments, healthcare professionals are not legally obliged to give them.

An ADRT cannot be used to request anything unlawful, such as an assisted death.

An ADRT cannot be used to refuse care that meets essential needs. The British Medical Association defines this as "any procedures designed to alleviate a patient's pain, symptoms or distress" and includes pain relief, personal care and the offer of food and water by mouth.[16]

An ADRT cannot be used to refuse treatment for a mental disorder if a person has been detained under the Mental Health (Jersey) Law 2016.[17]

The benefits of ADRTs

An ADRT allows a person to maintain autonomy and control over their medical treatment, especially at the end of their life.[18]

An ADRT can prevent a situation where a doctor provides more treatment than the person themselves would actually want.

An ADRT can help clarify a person's wishes for medical treatment and their wider goals for care. This is particularly helpful in a situation where those close to a person who lacks capacity have differing views about what that person would have wanted.

Making an ADRT can form a useful starting point for difficult conversations. There is evidence that the vast majority of seriously ill patients would like to discuss their care, but healthcare professionals are sometimes reluctant to initiate these discussions.[19]

ADRTs can help to alleviate some of the anxiety that family members experience when consulted by healthcare professionals about treatment decisions at the end of a loved one's life. This can lead to a more positive bereavement process.

Older ADRTs

ADRTs made before the CSDL was introduced still have legal effect. If a person made an ADRT before the introduction of the CSDL, it may not meet the criteria for an ADRT that refuses life-sustaining treatment to be legally binding. See page 7 for more information on these criteria.

Part C: ADRTs in practice – helping a person to make an ADRT

"Ideally an ADRT should be drafted with appropriate discussion with a healthcare professional rather than by the patient in isolation. Medical advice can lead to a better informed decision, but it is important for any adviser to help the patient clarify their own wishes rather than influence them." BMA[20]

A person may approach you wishing to make an ADRT or wanting to find out more about what one is. Good communication is essential in medical decision-making and this discussion can act as the starting point to an open dialogue about the person's wishes and goals for treatment and care.[21] A good discussion can help the person to clarify their wishes and understand their decisions as well as help them feel more confident that their wishes will be respected in the future.[22]

There are many reasons a person may want to make an ADRT. Some people may be in good health but have been motivated to plan ahead after witnessing the death of a loved one. Others may be prompted to make an ADRT following a diagnosis where a loss of capacity is likely. Whatever the reason you should encourage the person to consider what they would want if they could no longer make decisions for themselves.

The Content

An ADRT must detail both the treatment that is to be refused and the circumstances in which this refusal is to take effect.[23] Some people may find this challenging because it can be difficult to envisage the medical scenarios they may find themselves in. This can be especially hard if they do not have a specific diagnosis.

When specifying the treatments to be refused it is possible to make a general refusal of all life-sustaining treatments, which would include things such as clinically assisted nutrition and hydration, CPR, mechanical ventilation and antibiotics for life-threatening infections.

Ultimately, the content of the ADRT should reflect the person's individual wishes.

The Discussion

When discussing a person's ADRT it may be necessary to clarify exactly what their wishes are. The starting point should be what they, as an individual, want or, conversely, what they would like to avoid by making an ADRT. They may need support to understand their diagnosis and prognosis, the available treatment options, and the implications of consenting to or refusing a treatment.

If a person does have a specific diagnosis, you can explain the effectiveness of different treatments and their impact on prognosis, and the impact of a refusal in the context of their condition. You can explain the different types of life-sustaining treatments which may be given should they lose capacity in the future. Your role is to provide factual and understandable information with which the person can assess the benefits and burdens of different treatments.

It may be possible to work backwards – instead of starting with the treatments that the person wants to refuse, they could begin by talking about what is important to them or what they are trying to avoid. For example, they may have seen a relative given life-sustaining treatment following a stroke and be keen to avoid being in that situation themselves. You could then ask them what it was about their relative's situation they feared most. It may be that they themselves want to avoid a situation where they are unable to communicate or recognise loved ones, in which case they could write in their ADRT that they refuse life-sustaining treatment in such a situation.

Such discussions may need to be ongoing or periodically revisited to reflect changes in the person's condition or changes in their wishes.[24]

It is not a legal requirement that people discuss their wishes or decisions with a healthcare professional. An ADRT will not be invalid if the person completing it has not done so.

Clarifying the person's wishes

It is very important that an ADRT is clear so that it can be easily understood and implemented at the time it is needed. A person may wish to include language that is ambiguous or vague and you should support them to clarify what they mean by these words. For example, they may wish to include terms such as 'severe', 'serious', or 'unbearable'. This type of language can be particularly difficult to interpret because each person may have different ideas about what constitutes 'severe', 'serious', or 'unbearable'. You should therefore try to establish what situation they envisage when they consider these words, and help them to use language which is less open to interpretation.

Whilst an ADRT can be written in layman's terms, you may need to check that a person has not included a description of a treatment that is medically unclear. For example they might have stated that they want to refuse 'nutrition' in certain circumstances, which could mean food by mouth, which is not a medical treatment. In this situation you could ask them if they actually meant clinically assisted nutrition, such as through a PEG feed, intravenous drip or nasogastric tube, and if so check if they also want to refuse clinically assisted hydration.

Another point that may need clarifying is whether or not the person has fully considered the situations in which they want to refuse treatment. For example, they might have stated that they wish to refuse life-sustaining treatment if they lose capacity to make decisions about their care following a stroke. It could be helpful to ask if they have considered whether or not they would also want to refuse life-sustaining treatment in other situations, such as if they have dementia or are in a continuing vegetative state.

Recording the person's wishes

It is very important that the person's ADRT is recorded on their medical records.[25] This helps to ensure that it is known about and can be communicated to others when it is needed. People may also ask that you add a note of the fact that they have an ADRT with other health professionals. If the patient is receiving hospital treatment, this should be added as an alert on TrakCare. As there is currently no centralised system of registration for ADRTs, it is up to the individual themselves to make sure that the people who need to know are aware of their ADRT.

Part D: ADRTs in practice – implementing ADRTs

The decision-making pathway explained in this section is summarised in the pull-out flowchart at the back of this toolkit.

When there is a decision to be made about medical treatment, the first thing that must be done is an assessment of whether or not that person has capacity to make the decision in question. See page 5 for more information on assessing capacity.

Remember: You must always start by presuming that the person has capacity to make the decision in question.[26] A lack of capacity about one particular issue does not automatically indicate a lack of capacity to make a decision on a different issue.

Has the person made an ADRT?

If it is decided that a person lacks capacity to make a decision about their medical treatment, you should check whether they have made an ADRT.[27]

You should make reasonable efforts to check if they have made an ADRT by:

- contacting anyone the person has nominated to be consulted in decisions about their care or by consulting anyone else close to them
- checking their medical records
- contacting their GP and
- checking for a MedicAlert emblem – MedicAlert is an international charity specialising in the transfer of medical data to healthcare professionals in emergency situations. People can register their ADRTs with MedicAlert, and will wear a piece of jewellery containing the international medical symbol and the words 'has ADRT', as well as MedicAlert's 24-hour telephone number[28]

Is the ADRT valid and applicable?

If it is established that an ADRT exists, once a copy is obtained, the next step is to check whether it is valid and applicable. Remember that if it refuses life-sustaining treatment, it must meet certain additional requirements to be valid.

"If the patient lacks capacity and a refusal of treatment is recorded in their notes or is otherwise brought to your attention, you must bear in mind that valid and applicable ADRTs must be respected." GMC[29]

An ADRT refusing life-sustaining treatment, is valid if:

- the person was over 16 when they made the ADRT
- they had capacity at the time they made the ADRT
- they were not subject to coercion or undue influence at the time of making the ADRT
- it includes an explicit statement which states that the ADRT is to apply even if their life is at risk
- it is in writing
- it has been signed by the person in the presence of a witness, and the witness has in turn signed the ADRT
- the person who made the ADRT has not withdrawn it at a time when they had capacity to do so
- the person has not made an LPA for health and welfare after the ADRT (see page 16 for more information on LPAs) and
- since making the ADRT, the person has not acted in a way that is clearly inconsistent with the content of the ADRT[30]

An ADRT is applicable if:

- the person does not have capacity to give or refuse consent to the treatment in question
- the treatment in question is the treatment specified in the ADRT
- the circumstances in question are the circumstances set out in the ADRT and
- there are no reasonable grounds to believe that circumstances exist that the person did not or could not have anticipated at the time of making the ADRT, which would have affected their decision[31]

If you decide an ADRT is not valid or applicable

If the ADRT does not meet the criteria needed to be valid and applicable, it should still be taken into account as evidence of the person's wishes, values, beliefs and feelings.[32] This information has to be considered as part of the best interests decision-making process when any action is being taken on behalf of someone who lacks capacity.[33]

Potential challenges in implementing an ADRT

An ADRT may be worded too ambiguously

A person may have little knowledge of end-of-life conditions and treatments and subsequently write an ADRT that does not provide clinically useful or clear instructions. If there is any ambiguity in the way an ADRT is worded and the person has already lost capacity, they will not be able to clarify the content.

Under the CSDL, ambiguous ADRTs may not be applicable. If the refusal is not clear and cannot be followed it may still provide an indication of the person's wishes, in which case it should be taken into account as part of a best interests decision-making process.

The ADRT may be worded too specifically

Conversely, if an ADRT describes a treatment or situation different to that which has arisen, it may be unclear whether or not the decision should still apply. For example, a person may refuse clinically assisted nutrition and hydration in the event that they have dementia, but give no preference in the event that they have a stroke. In these circumstances, the ADRT may not be applicable to the situation in question but again it may provide an indication of the person's wishes and if this is the case it should therefore be taken into account as part of the best interests decision-making process.

The ADRT may not follow the person to other wards, departments or care setting

People can be transferred to different wards or care settings many times during their care, for example, between an emergency department, an intensive care unit, a hospital ward and then to a care home. If communication between the various professionals responsible for their care is not carefully co-ordinated, then the existence of an ADRT may not be transferred between settings. To avoid this happening it is crucial that there is an effective transfer and communication of a person's medical needs, including whether or not they have an ADRT. Practitioners have a duty of care to ensure that knowledge of an ADRT is shared at any transfer point.

Family members may object to the content of the ADRT

Faced with the illness of someone close to them, family members may urge healthcare professionals to ignore an ADRT refusing life-sustaining treatment and act to sustain the person's life. However, under the CSDL, a valid and applicable ADRT is legally binding and must be followed, even if family members object. Family members in this scenario should have this explained to them, and should be offered support in dealing with the situation.

Healthcare professionals may have a conscientious objection to following the person's instructions

Healthcare professionals with a conscientious objection to withholding or withdrawing treatment as directed in a person's ADRT do not have to act contrary to their beliefs.[34] However, they must not simply abandon their patients and have a duty to find another doctor who will comply with their wishes.

The CSDL Code of Practice advises that healthcare professionals with a conscientious objection should make their views clear when the matter of the ADRT is initially raised.[35] Where feasible, people with capacity should immediately be given the option of having their care transferred to another healthcare professional. If the person lacks capacity, the healthcare professional should make arrangements for their care to be transferred. If transferral of their care cannot be agreed, the Royal Court has the power to direct that a different healthcare professional takes responsibility for them.[36]

There may be disputes over the ADRT

There is potential for disagreement about the validity and applicability of an ADRT. Members of a multi-disciplinary team may interpret the person's wishes, or the severity of their condition, in different ways.

It is ultimately for the healthcare professional with overall responsibility for the patient's care when the treatment is required to decide whether the ADRT is valid and applicable.[37] In the event of a disagreement about the validity and applicability of an ADRT, either between healthcare professionals themselves or between healthcare professionals and those close to the person, all available evidence must be considered. All staff involved in the person's care and those close to the patient should be given the opportunity to express their views.[38]

The purpose of such discussions should not be to overrule the person's ADRT but rather to seek evidence concerning its validity and to confirm its scope and its applicability to the current circumstances. Details of these discussions should be recorded in the patient's medical notes.[39]

As a last resort, where there continues to be genuine doubt or disagreement about the existence, validity or applicability of an ADRT, a decision can be sought from the Royal Court.[40]

The Royal Court does not have the power to overturn a valid and applicable ADRT.[41] It does, however, have the power to make declarations as to:

- whether an ADRT exists
- whether an ADRT is valid
- whether an ADRT is applicable to the proposed treatment[42]

Whilst awaiting a declaration of the Royal Court, you can provide treatment without incurring liability as long as the treatment is life sustaining or to prevent any serious deterioration in the person's condition.

Part E: ADRTs and Lasting Power of Attorney for health and welfare

The CSDL also created a new legal tool called Lasting Power of Attorney (LPA).[43] An LPA allows a person to give someone they trust the legal power to make decisions on their behalf if they lack capacity.[44] The person who makes the LPA is known as the 'donor' and the person given the power to make decisions is known as the 'attorney'.[45]

There are two different types of LPA:

- an LPA for health and welfare covers decisions about health and personal welfare[46]
- an LPA for property and affairs covers decisions about money and property[47]

The type of LPA that is relevant in the context of ADRTs is the LPA for health and welfare. Within this LPA the donor has to choose whether or not to give their attorneys the power to give or refuse consent to life-sustaining treatment on their behalf.[48]

The relationship between an ADRT and an LPA depends on the order in which the documents were made. Whichever was made more recently takes priority for dealing with the decision in question. If a person made their ADRT after they made an LPA, then their attorney cannot override the ADRT.

If, however, the person has made an LPA after the ADRT, then the LPA will take precedence and the attorney could choose to override the ADRT. In this circumstance, if the decision in question concerns life-sustaining treatment, then you should look at the LPA document to ensure that the donor had given their attorney power to make such decisions. You should also check the document to see whether or not there is an instruction that states the attorneys must follow the ADRT.

It is important to note that attorneys must also always act in a person's best interests.

Case study:

Miss Hart appointed her brother, George, to be her attorney for health and welfare. A few weeks later she also made an ADRT to refuse resuscitation if she had a heart attack, as she was worried that George would not be comfortable carrying out her wishes. If she becomes ill in the future, healthcare professionals should follow George's decisions in almost all circumstances because he is her attorney. However, if she has a heart attack, healthcare professionals must follow her ADRT because this was made more recently. George cannot tell a healthcare professional not to follow his sister's ADRT.

If Miss Hart had appointed George to be her attorney AFTER making her ADRT, and she had given him the power to make decisions about life-sustaining treatment, he would have the power to tell the doctor not to follow her ADRT, as long as he was making this decision in her best interests.

Further guidance and support

Below is a summary of the guidance most relevant to ADRT making and implementation. Healthcare professionals should also refer to this guidance to ensure they act within the CSDL and in accordance with best practice.

GMC Guidance on Treatment and Care towards the End of Life[49]

The GMC Guidance is designed as a framework to support healthcare professionals to address issues at the end of life in a way that helps the needs of individual patients. It acknowledges that the decision whether to withhold or withdraw treatment that may prolong a person's life is one of the most challenging decisions faced by healthcare professionals and is based on long-established medical principles including respect for human life and care and respect for patients.

BMA Guidance on ADRTs[50]

The BMA Medical Ethics Department has produced guidance on ADRTs including advice for healthcare professionals involved in the making of an ADRT, and in assessing their validity and applicability. The Guidance covers the reasons that patients may wish to make an ADRT and any practicalities that need to be considered.

CSDL Code of Practice[51]

The Code of Practice provides practical guidance on implementing the CSDL for anyone that must have regard to its provisions including professionals and carers.

Decision-Making Flowchart

Person needs medical treatment

Does the person have capacity to give or refuse consent to the medical treatment?

Can they do all of these things?

- understand the relevant information
- retain the relevant information
- use and weigh up that information as part of the process of making the decision

YES

The patient can give or refuse consent to the medical treatment themselves.

NO

Has the patient made an ADRT to Refuse Treatment?

To find out you should consult people close to the patient, check the patient's medical records, contact the patient's GP, check for a MedicAlert emblem.

YES

Is it valid?
Is it applicable?
(See overleaf)

YES

Follow the ADRT

NO

Document why the ADRT is not valid or applicable in the person's notes

NO

Has the patient made a LPA for health and welfare?

YES

Discuss the treatment with the attorney and follow their decision (as long as they are acting in the persons best interests).

If the decision that needs to be made concerns life-sustaining treatment, check the LPA document to ensure the attorney has the authority to make decisions about life-sustaining treatment.

Decide whether or not giving the treatment is in the patient's best interests. This includes considering any expressed wishes of the patient, their values and beliefs and the views of any other relevant people.

Is the ADRT valid and applicable?

Once it is established that a person who lacks capacity has an ADRT, the next step is to check whether it is valid and applicable. If it refuses life-sustaining treatment, it must meet certain requirements to be valid.

An ADRT refusing life-sustaining treatment, is valid if:

- the person was over 16 when they made the ADRT
- they had capacity at the time they made the ADRT
- they were not subject to coercion or undue influence at the time of making the ADRT
- it includes an explicit statement which states that the ADRT is to apply even if their life is at risk
- it is in writing
- it has been signed by the person in the presence of a witness, and the witness has in turn signed the ADRT
- the person who made the ADRT has not withdrawn it at a time when they had capacity to do so
- the person has not made a LPA for health and welfare after the ADRT
  (see page 16 for more information on LPAs) and
- since making the ADRT, the person has not acted in a way that is clearly inconsistent with the content of the ADRT

An ADRT is applicable if:

- the person does not have capacity to give or refuse consent to the treatment in question
- the treatment in question is the treatment specified in the ADRT
- the circumstances in question are the circumstances set out in the ADRT and
- there are no reasonable grounds to believe that circumstances exist that the person did not or could not have anticipated at the time of making the ADRT, which would have affected their decision

References

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2 S v St George's Healthcare NHS Trust [1998] 2 WLR 936

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5 Capacity & Self-Determination (Jersey) Law 2016, Article 3

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8 Capacity & Self-Determination (Jersey) Law 2016, Article 21

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