



Capacity and Self-Determination (Jersey) Law 2016
Code of Practice

The cover and associated artwork comes from 'Arts Exploration' and 'The Art Group'. These groups support individuals affected by both capacity and mental health issues. Thank you to the group members who shared their work.

The cover was chosen from a selection of works by public focus groups and professionals. A selection of the submitted artworks are showcased at the end of the Code of Practice.

Thank you to the artists who have allowed us to use their creativity and personal interpretation of their experiences of mental health and capacity issues which is reflected in their artwork.

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Ministerial Foreword

The Capacity and Self-Determination (Jersey) Law 2016 is an important piece of legislation. It introduces legal principles and safeguards relating to decisions made by, and on behalf of, persons who lack capacity to make decisions for themselves. This Law will make a real difference to the lives of people who may lack capacity. It empowers people to make decisions for themselves wherever possible, and protects people who lack capacity by ensuring they are at the heart of decision-making about their lives. The Law also enshrines maximising people's participation in any decisions made on their behalf, with such decisions made in their best interests. For many people, it allows them to make future plans for a time when they may lack capacity to make decisions for themselves.

The Law is supported by practical guidance and this Code of Practice is an essential part of this. It explains how to use the Law on a day-to-day basis for professionals and public alike. In writing the Code, Jersey has reviewed many lessons from the implementation of the Mental Capacity Act 2005 in England and Wales. Jersey's Code of Practice is very much up-to-date in terms of current best practice and legal thinking around capacity.

All citizens of Jersey have equal human rights, irrespective of capacity. Sometimes when we provide treatment or care, there are circumstances where restrictions are necessary to keep someone safe. A person who lacks capacity cannot consent to such restrictions. The Law introduces a process to legally authorise the interference with the liberty and freedom of persons who lack capacity. This will only be authorised where such significant restriction on liberty is assessed as being proportionate, necessary and in the person's best interests.

The Law provides safeguards and a legally defined process in any decision to significantly restrict the liberty of a person who lacks capacity to agree to such treatment or care. A deprivation of a person's liberty is in conflict with their human rights and a matter I take very seriously. I firmly believe, and I am supported by law in my view, that this should not happen unless it is absolutely necessary, hence the importance of this part of the Law.

There is a broad range of people who will use the Code. Therefore it has been written to make it as user-friendly as possible. We are grateful to all those who have commented during the consultation on the Code to achieve that goal. I was particularly warmed by the response from members of the public, who had many useful suggestions that were incorporated into the Code.

The Code is important in shaping the way the Law is put into practice and I encourage you to take the time to review it and consider how it will help you promote self-determination and support those in our society who need assistance with decision-making due to capacity matters.

Deputy Richard Renouf

Minister for Health and Community Services

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Introduction

The Capacity and Self-Determination (Jersey) Law 2016 Code of Practice, hereto referred to as the Code will come into force on 1 October 2018. The Code is issued under Article 68 of the Capacity and Self-Determination (Jersey) Law 2016 (“the Law”).

The legal framework provided by the Law is supported by the Code, which provides guidance and information about how the Law works in practice. The Law requires the Minister for Health and Community Services (“the Minister”) to produce a Code of Practice for the guidance of a range of people with different duties and functions under the Law.

The Code has been prepared through consultation by and on behalf of the Minister with various agencies and other persons.

The Code is not law but it exists to support and guide the implementation of the Law. As such, any departure from the Code must be clearly justified and recorded. It is acknowledged that any such departure might be referred to in legal proceedings.

Employed individuals using the Code are accountable to their employing organisation and any relevant professional body for any decisions they make regarding the treatment and care provided to people under the Law. Consequently, where staff make decisions under the Law, they are both personally and professionally accountable.

Executive summary

The Capacity and Self-Determination (Jersey) Law 2016 Code of Practice (the Code) is a document intended for active use by professionals, patients, carers and the public. It provides guidance in using the Law, both personally and professionally. The Code has statutory force, which means that people working under the Law have a legal duty to have due regard to it when working with or caring for people who may lack capacity to make decisions for themselves.

The Capacity and Self-Determination (Jersey) Law 2016 (the Law), provides a statutory framework for people who lack capacity to make decisions for themselves, or who have capacity and want to make preparations for a time when they may lack capacity in the future. It sets out who can take decisions, in which situations, and how they should go about this. The Law received Royal Assent on 23 December 2016 and will come into force on 1 October 2018.

The fundamental premise of the Law is that individuals, aged 16 and over, are assumed to have the ability to make decisions (capacity) for themselves about their lives (self-determination) unless it can be shown that they are unable to make a decision for themselves (lack of capacity) at the time the decision needs to be made. This is known as the assumption of capacity. The Law's also confirms safeguards to an individual's human rights in statute. It is also designed to ensure that people are enabled, so far and for as long as possible, to self-determine how decisions are made for them when they can no longer make those decisions for themselves in accordance with their own values, beliefs and wishes, through future decision-making options.

Whenever the term 'lack of capacity' is used, it should be regarding a specific decision at a specific time. Whilst an individual may have capacity to make decisions for everyday issues such as what to wear or what to eat, they may also concurrently lack capacity to make decisions in other areas, such as care needs, finance or accommodation.

The Law reflects the fact that a person who lacks capacity to make a decision for themselves at a certain time may be able to make that decision at a later date. This may be because they have an illness or condition that means their capacity changes.

The Code is a document intended for active use by professionals, patients, carers and the public. It provides guidance in using the Law, both personally and professionally. The Code has statutory force, which means that people working under the Law have a legal duty to have due regard to it when working with or caring for people who may lack capacity to make decisions for themselves.

The chapters have been grouped into 5 sections. These are summarised below.

Using the Law: chapters 1-7

These chapters introduce the Law and set out the five core principles that underpin it and the way they affect how the Law is understood and used in practice. They also include the test for capacity and how we make decisions on behalf of a person who lacks capacity. The chapters also deal with some common practicalities that may arise when caring for, or providing treatment to, a person who lacks capacity.

Future decision-making: chapters 8-10

These chapters detail future decision-making options that people can use, if they are able and wish to do so. They also explain how future decisions can be made when someone has not used these options, but require ongoing support with decision-making or need a significant decision to be made.

Capacity and liberty: chapter 11

This chapter details the requirements under the Law to uphold the human rights of a person who lacks capacity in situations where there is significant interference of their rights through the care and treatment provided to them. The primary focus is addressing significant restriction on liberty, but encompasses any restrictions on a person's human rights.

Safeguards under the Law: chapters 12-14

These chapters introduce statutory safeguards for people who lack capacity in addition to those already present elsewhere in the Law. The safeguards offer extra checks and balances to those most in need of them. The statutory nature of the safeguards gives their application both weight and consequence in upholding the human rights of a person who lacks capacity.

Other matters: chapters 15-16

These chapters address other areas where guidance may be required in relation to a person who lacks capacity.

Acronyms

ADRT	advance decision to refuse treatment
AO	Authorised Officer
AP	Approved Practitioner
CLA	Capacity and Liberty Assessor
CoP	Code of Practice
CSDL	Capacity and Self-Determination (Jersey) Law 2016
ECHR	European Convention on Human Rights
ICA	Independent Capacity Advocate
IMHA	Independent Mental Health Advocate
LPA	lasting power of attorney
MHL	Mental Health (Jersey) Law 2016
SRoL	significant restriction on liberty

Abbreviations

the Administrator	Mental Health and Capacity Law Administrator
the Code	Capacity and Self-Determination (Jersey) Law 2016 Code of Practice
the Convention	European Convention on Human Rights
the MHL Code	Mental Health (Jersey) Law 2016 Code of Practice
the Court	Royal Court
the Department	States of Jersey Health and Community Services
the Law	Capacity and Self-Determination (Jersey) Law 2016
the Minister	Minister for Health and Community Services
the Tribunal	Mental Health Review Tribunal

Glossary

advance decision to refuse treatment (ADRT)	A recorded decision to refuse specific medical treatments that you do not want to be given in the future. This will be used only when you lack capacity to make or communicate the decision. An ADRT can be used to refuse life sustaining treatment but rules apply.
Approved Establishments	These are places approved by the Minister (for Health and Community Services) for the purpose of providing care and treatment to patients under the MHL.
Approved Practitioner (AP)	A doctor with specialist training in relation to both mental health practice and capacity who is approved by the Minister to carry out specific functions under the Law. The AP carries out elements of a significant restriction on liberty assessment in conjunction with a CLA.
attorney	Someone appointed under an LPA who has the legal right to make decisions within the scope of their authority on behalf of the person who made the LPA.
Authorised Officer	This is a health professional with specific training in the application of the MHL. They are responsible for making applications for admission to Approved Establishments.
best interests	Any decisions made, or anything done for a person who lacks capacity to make specific decisions, must be in the person's best interests. There are standard minimum steps to follow when working out someone's best interests. These are set out in Article 7 of the Law.
Bournemouth judgment	The commonly used term for the October 2004 judgment by the European Court of Human Rights in the case of HL v the United Kingdom that led to the introduction of the deprivation of liberty safeguards.
capacity	The ability to make a decision about a particular matter at the time the decision needs to be made. A legal definition is contained in Article 4 of the Law.
Capacity and Liberty Assessor (CLA)	A person who carries out a and is responsible for a significant restriction on liberty assessment in conjunction with an AP.
Care Commission	The regulator for health and social care operating under the Regulation of Care (Jersey) Law 2014.
carer	Someone who provides care to a person who needs support because of sickness, age or disability. In this Code, the term carer does not mean a paid care worker.
child	A person under 16 years old.
conditions	Requirements that the Minister may impose when giving an authorisation for SRoL, after taking account of any recommendations made by the CLA.

consent	Agreeing to a course of action. For consent to be legally valid, the person giving it must have the capacity to take the decision, have been given sufficient information to make the decision, and not have been under any duress or inappropriate pressure.
core principles	The five principles are set out in Article 3 of the Law. They are designed to emphasise the fundamental concepts and core values of the Law and to provide a benchmark to guide decision-makers, professionals and careers acting under the Law's provisions. The principles apply to all actions and decisions taken under the Law.
Court	In the chapters throughout this Code 'Court' refers to the Royal Court sitting on capacity and liberty matters.
Data Protection (Jersey) Law 2018	A law controlling the handling of, and access to, personal information, such as medical records, files held by public bodies and other organisations.
decision-maker	Under the Law, many different people may be required to make decisions or act on behalf of someone who lacks capacity to make decisions for themselves. The person making the decision is referred to throughout the Code, as the 'decision-maker', and it is the decision-maker's responsibility to work out what would be in the best interests of the person who lacks capacity.
delegate	Someone appointed by the Court with ongoing legal authority, as prescribed by the Court, to make decisions on behalf of a person who lacks capacity to make particular decisions.
deprivation of liberty	Deprivation of liberty is a term used in the ECHR about circumstances when a person's freedom is taken away. Its meaning in practice is being defined through case law.
donor	A person who makes a lasting power of attorney.
European Convention on Human Rights (ECHR)	A convention drawn up within the Council of Europe setting out a number of civil and political rights and freedoms, and setting up a mechanism for the enforcement of the obligations entered into by contracting states. Jersey has enacted ECHR in local law.
European Court of Human Rights (ECtHR)	The court to which any contracting state or individual can apply when they believe that there has been a violation of the ECHR.
fiduciary duty	In essence, this means that any decision taken or act done as an agent (such as an attorney or delegate) must not benefit themselves, but must benefit the person for whom they are acting.
guardianship	The appointment of a guardian to help and supervise patients in the community for their own welfare or to protect other people. The guardian may be either the Minister or a private individual approved by the Minister.
health and welfare	This can cover any decisions about person's healthcare, where they live, what clothes they wear, what they eat and anything needed for their general care and well-being. Attorneys and delegates can be appointed to make decisions about health and welfare on behalf of a person who lacks capacity.

Human Rights (Jersey) Law 2000	A law largely incorporating the ECHR into Jersey law.
ill-treatment	Article 67 of the Law introduces a new offence of ill-treatment of a person who lacks capacity by someone who is caring for them, or acting as a delegate or attorney for them. That person can be guilty of ill treatment if they have deliberately ill-treated a person who lacks capacity, or been reckless as to whether they were ill-treating the person or not. It does not matter whether the behaviour was likely to cause, or actually caused, harm or damage to the victim's health.
Independent Capacity Advocate (ICA)	Someone who provides support and representation for a person who lacks capacity to make specific decisions, where the person has no-one else to support them. The ICA role is established under Part 6 of the Law. The ICA role is not the same as an ordinary advocacy service.
Information Commissioner's Office	An independent authority set up to promote access to official information and to protect personal information. It has powers to ensure that the laws about information, such as the Data Protection (Jersey) Law 2018, are followed.
lasting power of attorney (LPA)	A legal document created under the Law by a person (donor) appointing an attorney (or attorneys) to make decisions about their personal welfare (including healthcare) and/or deal with their property and affairs.
Law	In the chapters throughout this Code 'Law' refers to the Capacity and Self-Determination (Jersey) Law 2016.
life-sustaining treatment	Treatment that, in the view of the person providing health care, is necessary to keep a person alive.
maximum authorisation period	The maximum period for which the Minister may give an authorisation for SRoL. This must not exceed the period recommended by the CLA and cannot be for more than 12 months.
mental disorder	Any disorder or disability of the mind, apart from dependence on alcohol or drugs.
Mental Health (Jersey) Law 2016 (MHL)	Legislation mainly about the compulsory care and treatment of patients with mental health problems. It covers detention in hospital for mental health treatment, leave of absence and guardianship.
Mental Health Review Tribunal (the Tribunal)	An independent judicial body with powers to deal with review matters for the Law and the MHL.
property and affairs	Any possessions owned by a person (such as a house or flat, jewellery or other possessions), the money they have in income, savings or investments and any expenditure. Attorneys and delegates can be appointed to make decisions about property and affairs on behalf of a person who lacks capacity.
protection from liability	Legal protection, granted to anyone who has acted or made decisions in line with the Law's principles.
qualifying requirement	Any one of the six qualifying requirements (age, mental health, mental capacity, best interests, eligibility and no refusals) that need to be assessed and met in order for an authorisation for SRoL to be given.

relevant place	The hospital or approved care home in which the person is, or may become, subject to an SRoL. This can also be other establishments regulated under the Regulation of Care (Jersey) Law 2014 or any place designated by the Minister, for the purpose of providing health or social care.
restraint	The use, or threat of force, to help carry out an act that the person resists. Restraint may only be used where it is necessary to protect the person from harm and is a proportionate response to the serious and likelihood of harm.
restriction	An act imposed on a person that is not of such a degree or intensity as to amount to a significant restriction on liberty.
review	A formal, fresh look at a person's situation when there has been, or may have been, a change of circumstances that may require an amendment to an authorisation for SRoL.
significant restriction on liberty (SRoL)	The framework of safeguards under the CSDL for people who need to be deprived of their liberty in a relevant place in their best interests for care or treatment and who lack the capacity to consent to the arrangements made for their care or treatment.
significant restriction on liberty assessment	An assessment made up of six elements that need to be undertaken as part of the authorisation process for SRoL.
test of capacity	Articles 4 and 5 of the Law are combined to assess whether or not a person has a capacity to make a decision for themselves at that time. This is a single test of capacity with three elements.
urgent authorisation	An authorisation for SRoL given by the Minister which lasts a maximum of 28 days. The urgent authorisation is cancelled by a standard authorisation being granted or where the assessment of the person does not support using SRoL process.
wilful neglect	An intentional or deliberate omission or failure to carry out an act of care by someone who has care of a person who lacks (or whom the person reasonably believes lacks) capacity to care for themselves. Article 67 introduces a new offence of wilful neglect of a person who lacks capacity.
written statements of wishes and feelings	Written statements the person might have made before losing capacity about their wishes and feelings on any matter. These might include issues such as the type of medical treatment they would want in the case of future illness, where they would prefer to live, or how they wish to be cared for. They should be used to help find out what someone's wishes and feelings might be, as part of working out their best interests. They are not the same as advance decision to refuse treatment as they are not legally binding.

Capital letters are used and shown in this glossary as a guidance for replication.

A word or expression used in this Law and defined in the Mental Health (Jersey) Law 2016 shall, unless otherwise indicated or required by the context, be taken to have the same meaning for the purposes of this Law as that word or expression is given in the Mental Health (Jersey) Law 2016.

Section 1: Using the Law

Why read this section?

These chapters introduce the Law and set out the five core principles that underpin it and the way they affect how the Law is understood and used in practice. They also include the test for capacity and how we make decisions on behalf of a person who lacks capacity. The chapters also deal with some common practicalities that may arise when caring for, or providing treatment to, a person who lacks capacity.



Chapter 1: Principles of the Capacity and Self-Determination Law

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Chapter 1: Principles of the Capacity and Self-Determination Law

- 1.1** The Capacity and Self-Determination (Jersey) Law 2016 (the Law) provides the legal framework to ensure people can make as many decisions for themselves as possible. It introduces legal measures to allow people with capacity to make decisions about their future, for times when they lack the capacity to make the decisions for themselves.
- 1.2** There are a number of factors that might affect a person's decision-making. The understanding of these can be subjective and can be value-based. The Law addresses this through five core principles that must always be considered when working with people to make decisions.
- 1.3** The Law highlights that any assessed lack of capacity cannot be viewed as universal. This means that decision-making using the Law is linked to the specific decision at the time it needs to be made. Everyone working with and/or caring for an adult who may lack capacity must follow the Law when making decisions or acting for that person. The same rules apply whether the decisions are life-changing events or everyday matters.
- 1.4** The Law's starting point is the assumption that all people, aged 16 and over, have legal capacity to make decisions for themselves (the right to self-determination) unless shown that they lack capacity to make a decision for themselves at the time the decision needs to be made. This is called the '*assumption of capacity*'.
- 1.5** The Law also states that every reasonable step and support is taken to enable a person to make their own decisions and to maximise their participation in any decision-making process. This must be done before any consideration can be given to whether they may lack capacity to make the decision themselves.

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- 1.6 The Law allows for people to make unwise decisions, even when others do not agree with the decision, or the decision may be viewed by others as harmful.
- 1.7 The Law aims to balance an individual's right to make decisions for themselves against their right to protection from harm when they cannot make decisions for themselves. The Law sets out how to assist and support people who lack capacity to make a decision and to discourage anyone involved in caring for someone who lacks capacity from being too restrictive or controlling.
- 1.8 The underlying philosophy of the Law is to ensure that when people cannot make decisions for themselves, any decision made, or action taken on their behalf is in their best interests and least restrictive of their rights and freedoms. People will always know their own best interests and can make a document to record these about treatments they would never like to receive. This is called an Advance Decisions to Refuse Treatment (ADRT). There are more details about this in chapter 9.
- 1.9 This Code of Practice (the Code) explains the legal framework of how to make decisions on behalf of people who lack capacity to make the specific decision for themselves at the time it needs to be made. The Code will cover the core principles and methods for making decisions in relation to personal welfare, healthcare and financial matters for people who lack capacity to do so.

Principles of the law

- 1.10 The intent of the Law is to enable and support people who lack capacity, not to restrict or control their lives. It aims to protect people who lack capacity to make particular decisions, but also to maximise their ability to make decisions and to take part in decision-making, as far as they are able to do so. Article 3 of the Law sets out the five core principles – the values that underpin the legal requirements in the Law.
- 1.11 The five core principles are:

1. a person must be assumed to have capacity unless it is established that they lack capacity
2. a person is not to be treated as unable to make a decision unless all practicable steps to support them to do so have been taken without success

3. a person is not to be treated as unable to make a decision merely because they make an unwise decision
4. an act done, or decision made, under the Law for or on behalf of a person who lacks capacity must be done, or made, in their best interests
5. before an act is done, or a decision made which is restrictive of a person's rights and freedom of action, regard must be had to whether the purpose for which it is needed can be achieved as effectively in a less restrictive way.

Applying the principles of the law

Principle 1: 'A person must be assumed to have capacity unless it is shown that the person lacks capacity'.

1.12 This principle states that every person has the right to make their own decisions – unless there is clear evidence that they lack the capacity to make a particular decision at the time it needs to be made.

1.13 Some people may need support to be able to make a decision or to communicate their decision. This does not mean that they cannot make that decision. Anyone who believes that a person lacks capacity should be able to provide evidence to support this assertion.

Principle 2: 'A person is 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'.

1.14 Practicable is something that can be reasonably done. This means that what is reasonable will vary depending on the decision to be made and the circumstances. What is viewed as practicable in an emergency situation will be very different from other situations, such as a planned move, where more time can be taken to support the person make their own decision. However, this principle must be undertaken for all decisions. The Law states that you cannot claim that someone is unable to make their own decision unless this principle has been carried out without success.

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- 1.15** In all circumstances, it is important to ensure every reasonable effort is taken to support and enable a person to make a decision for themselves before concluding that they lack capacity to do so. People with an illness or disability which could affect their ability to make decisions should receive support to assist them to make as many decisions as possible.
- 1.16** This principle stops the presumption that some people lack capacity to make decisions based upon their age, appearance or behaviours. It requires individuals to be as fully involved in decision-making as they are able. It is also intended to reduce unnecessary interventions in people's lives by putting them at the centre of decision-making.
- 1.17** It is reasonable for practicable steps to take time. If a decision does not need to be made now, it can be delayed as we 'build' someone's decision-making skills and ability. It is good practice to offer a person education and specific support around a decision to try and increase the likelihood of them making their own decision at a future time, rather making the decision for them.
- 1.18** Where a person use services and receives professional support, effective care planning should always anticipate future decisions to ensure practicable steps begin in advance to promote their autonomy and decision-making.
- 1.19** The types of intervention and input which people might need to support them make a decision varies. It depends on personal circumstances, the decision to be made and the time available to make the decision. It might include:

- using a different form of communication (for example, non-verbal communication)
- providing information in a more accessible form
- treating a medical condition which may be affecting the person's capacity or
- having a structured programme to improve a person's ability to make particular decisions (for example, supporting a person with learning disabilities to learn new skills).

1.20 It is important to provide the person with appropriate advice and information. However, anyone supporting a person who may lack capacity should not use excessive persuasion or undue pressure. This might include behaving in a manner which is overbearing or dominating, or seeking to influence the person to make a decision they might not otherwise have made.

1.21 There are several ways in which people can be supported to make a decision for themselves. These will vary depending on the decision to be made, the time-scale for making the decision and the individual circumstances of the person making it. It may be useful to consider these points:

Making the person feel at ease

- identify particular times of day when the person's understanding is better
- identify particular locations where they may feel more at ease
- consider delaying the decision to see whether the person can make the decision at a later time

Supporting the person

- find the most effective way of communicating with the person
- identify anyone else who can support the person to make choices or express a view

1.22 The Law applies to a wide range of people with different conditions that may affect their capacity to make decisions. Therefore the appropriate steps to take will depend on:

- a person's individual circumstances (for example, somebody with learning difficulties may need a different approach to somebody with dementia)
- the decision the person has to make; and
- the length of time they have to make it.

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- 1.23 Significant, one-off decisions, such as moving house, will need different considerations from day-to-day decisions about a person's care and welfare. However, the same processes should apply to each decision.
- 1.24 In some situations treatment cannot be delayed. This can happen in emergency situations or when it is an urgent decision, such as a medical emergency.

Principle 3: 'A person is not to be treated as unable to make a decision merely because the person makes an unwise decision'.

- 1.25 Everybody has their own values, beliefs, preferences and attitudes. It cannot be an assumption that a person lacks the capacity to make a decision because other people believe their decision is unwise. This applies even if family members, friends, or professionals are unhappy with a decision.
- 1.26 There may be instances where a person makes many unwise decisions that put them at significant risk of harm or exploitation. A person may also make an unwise decision that is irrational or out of character. In such circumstances, there may be a need for further exploration, taking into account the person's past decisions and choices.
- 1.27 Such decisions do not in themselves show that a person lacks capacity. If concerns are present, it may be necessary to review whether the person has developed a medical condition or disorder that is affecting their capacity to make decisions. There may be a need to provide clearer or more information to enable the person to better understand the consequences of their decisions.
- 1.28 This principle upholds a person's human rights by acknowledging they can self-determine through their own choices. This can be difficult when a person appears to disregard 'sensible' advice. However, there is a temptation to base a judgement of a person's capacity upon whether they seem to have made a good or bad decision, and in particular on whether they have accepted or rejected such advice. This temptation must be avoided. The Law states that you cannot claim that someone is unable to make a decision simply because they make one which is unwise.

Principle 4: ‘Any action done, or decision made, on behalf of a person who lacks capacity must be done, or made, in their best interests’.

1.29 A person’s best interests must be the basis for all decisions made on their behalf in situations where they lack capacity to make those particular decisions for themselves. A person may have recorded in advance what is in their best interests in an ADRT.

1.30 It is impossible to give a single definition of best interests, because this will depend on individual circumstances. There is further information about best interests later in the Code.

Principle 5: ‘Before an act is done or a decision is made which is restrictive of the person’s rights or freedom of action, regard must be had to whether the purpose for which the act or decision is needed can be as achieved as effectively in a less restrictive way’.

1.31 Before somebody makes a decision on behalf of a person who lacks capacity, they must always question if they can do something else which is effective and would interfere less with the person’s human rights. This is the *‘least restrictive principle’*. It includes considering whether there is a need to act or make a decision at all.

1.32 Where there is more than one option, it is important to explore ways that would be least restrictive and allow the most freedom for the person lacking capacity affected by the decision. However, the final decision must still enable the original outcome of the decision or act to be achieved.

1.33 In practice, the process of choosing the least restrictive option and deciding what is in the person’s best interests will be combined. Both principles apply each time a decision or action is taken on behalf of a person who lacks capacity to make the relevant decision.



Chapter 2: Capacity

Chapter 2

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Chapter 2: Capacity

2.1 Capacity can be described as a person's decision-making ability when a decision needs to be made.

- This includes the ability to make a decision that affects daily life. Examples include deciding when to get up, what to wear or whether to go to the doctor when feeling ill, as well as more serious or significant decisions.
- It also refers to a person's ability to make a decision that may have legal consequences for them or others. Examples include buying expensive items, making a will, as part of valid consent to medical treatment or refusing medical treatment.

Lack of capacity

2.2 Article 4 (1) of the Law states:

'For the purposes of this Law, a person lacks capacity in relation to a matter if at the material time the person is unable to make his or her own decision in relation to the matter because he or she suffers from an impairment or a disturbance in the functioning of his or her mind or brain.'

This means that a person lacks capacity if:

- they are unable to make a specific decision in relation to a matter; **because**
- they have an impairment or disturbance that affects the way their mind or brain works.

2.3 An assessment of a person's capacity must be based on their inability to make a specific decision at the time it needs to be made. Such assessments are decision specific and cannot be used to infer a lack of capacity to make decisions in general.

2.4 Article 4 (2) states that the impairment or disturbance does not have to be permanent. A person can lack capacity to make a decision at the time it needs to be made even if:

- the loss of capacity is partial
- the loss of capacity is temporary
- their capacity changes over time.

A person may lack capacity to make a decision about one issue but not about another.

Safeguards in assessing capacity

2.5 Those assessing capacity must never base this on reference to, or unjustified presumptions about the following:

- the person's age
- the person's appearance
- any aspects about the person's condition or their behaviour.

2.6 Appearance refers to all aspects of the way people look. This includes, but is not limited to, the physical characteristics of certain conditions (for example, scars, features linked to Down's syndrome or muscle spasms caused by cerebral palsy) as well as aspects of appearance like skin colour, tattoos and body piercings, or the way people dress.

2.7 Condition refers to physical disabilities, cognitive impairment, learning difficulties and disabilities, illness related to age, and temporary conditions (for example, intoxication or unconsciousness). Aspects of behaviour might include extrovert (for example, shouting or gesticulating) or withdrawn behaviour (for example, talking to yourself or avoiding eye contact).

Evidence required by the Law in relation to capacity

- 2.8** The Law works on the assumption of capacity. There is no expectation that a person would have to prove they have capacity. The burden of proving a person's lack of capacity always lies with those who believe that they should be making the decision on behalf of the person.
- 2.9** Where there is a legal challenge to a claim that an individual lacks capacity, the evidence provided to substantiate this will be decided on the balance of probabilities. This would examine whether the individual lacked capacity to make a particular decision, at the time it needed made. In practice, this means it must be shown that it is more likely than not that the person lacked capacity to make the decision in question.

Assessment of capacity

- 2.10** Responsibility for assessing capacity normally rests with the individuals who are involved in the decision that is being made. In many day-to-day decisions such as what to wear, what to eat or drink, the assessor and decision-maker is often the person's carer.
- 2.11** Individuals are not expected to be professionally qualified to assess capacity. For those supporting family at home it is sufficient to use what you know, see and experience to demonstrate your assessment. However, it is important to be able to explain how you came to decisions. If the decision in question has long term consequences, it may be advisable to seek support with a formal assessment or diagnosis before making the decision. Examples of these decisions are the person needing an operation, selling their home/moving home or giving up their tenancy.
- 2.12** If a doctor or healthcare professional proposes treatment or an examination, they must assess the person's capacity to make the decision about treatment. Where they assess the person lacks capacity to make the decision, they must then follow the best interests process. In settings such as a hospital, this can involve the multi-disciplinary team (a team of people from different professional backgrounds who share responsibility for a patient). Nonetheless, it remains the responsibility of the registered professional undertaking the person's treatment to assess capacity.

- 2.13** For a legal transaction (for example, making a will), a solicitor or legal practitioner should assess the client's capacity to make the decision to instruct them. If they are unsure whether there is an impairment or disturbance in the mind or brain, they should seek an opinion from a registered professional.
- 2.14** Professional opinion on the person's capacity can be sought. This could be, for example, from a psychiatrist, psychologist, a speech and language therapist, occupational therapist or social worker. However, whilst such professional opinion may contribute to the outcome, the final decision about a person's capacity must be made by the person intending to make the decision or carry out the action on behalf of the person who lacks capacity.
- 2.15** To determine if a person has capacity to make particular decisions, the Law uses Article 4 as a single 'test' of capacity. This requires asking whether a person is unable to make a decision for themselves (functional) 'because' they suffer from an impairment of, or a disturbance of the functioning of their mind or the brain (diagnostic).
- 2.16** It is important to understand that there are actually three elements when assessing capacity. After carrying out the functional and diagnostic elements, the next question to consider is whether the person's inability to make the decision is 'because of' the impairment or disturbance. Case law refers to this as the 'causative nexus'. In all cases, all three elements must be satisfied for a person to be viewed as lacking capacity to make the decision under the Law.
- 2.17** The terms functional, diagnostic and causative nexus do not appear in the Law, although they are sometimes used in professional communication. However, the use of the term 'diagnostic' does not mean that only health professionals are capable of conducting capacity assessments. Capacity assessments can be undertaken by anyone in relation to a person's decision-making ability.
- 2.18** The Law prescribes the order in which a capacity test should be constructed. The assumption of capacity is the first core principle and any assessment should begin with looking at the inability to make a decision, the functional element, before considering any disorder or impairment. Assessing in this order is anti-discriminatory and in line with the Disability Strategy for Jersey (endorsing the principles of the United Nations Convention on the Rights of Persons with Disabilities).

- 2.19** If a person is able to demonstrate decision-making ability about the decision to be made when using the functional element, considerations regarding capacity must stop. The person must be unable to make the decision prior to consideration of the diagnostic and causative nexus elements.
- 2.20** Assessments of capacity must not make assumptions about the ability or inability of the person to make their own decisions until the core principles have been applied and the three elements in assessing capacity satisfied. Principles 2 and 3 state that you cannot demonstrate 'unable' until you have fully satisfied these principles. For example, more practicable steps may be required prior to being able to claim that a person is unable to make the decision.
- 2.21** In some circumstances more focus may be placed upon either the diagnostic or functional test. For example, if a person is in a psychiatric ward with a clear diagnosis of a mental disorder, then it may be that more attention is required considering whether that disorder means that they are unable to make the specific decision.
- 2.22** The test, if used as described in the Code, guides individuals and professionals and gives legal protection in deciding about a person's capacity for the purposes of the Law.

Functional element

- 2.23** Is the person unable to make their own decision in relation to the matter in question?

The Law states a person is unable to make a decision if they cannot satisfy one or more of the below:

1. understand the information relevant to the decision to be made
2. retain that information in their mind, even for a short period, sufficient to make the decision
3. use or weigh the information as part of the decision-making process
4. communicate their decision by any means.

Understanding information about the decision

2.24 It is important not to assess someone's understanding before they have been given relevant information about a decision. Every effort must be made to provide information in a way that is most appropriate to support the person to understand.

Relevant information includes:

- the nature of the decision
- the reason why the decision is needed, and
- the likely effects of deciding one way or another, or making no decision at all.

2.25 It is important to present information in a way that is appropriate to meet the individual's needs and circumstances.

For example:

- a person with a learning disability may need somebody to read information to them. They might also need illustrations to support them to understand what is happening. Or they might stop the reader to ask what things mean. It might also be helpful for them to discuss information with someone who can support them
- a person with anxiety or depression may find it difficult to reach a decision about treatment in a group meeting with professionals. They may prefer to read the relevant documents in private. This way they can come to a conclusion alone, and ask for support if necessary
- someone who has a brain injury might need to be given information several times. It will be necessary to check that the person understands the information. If they have difficulty understanding, it might be useful to present information in a different way (for example, different forms of words, pictures or diagrams). Written information, audiotapes, videos and posters can support people to remember important facts.

2.26 In some cases, it may be enough to give a broad explanation using simple language. If a decision could have serious or grave consequences, a person might need more detailed information or access to advice. In such circumstances, it is even more important that a person understands the information relevant to that decision.

Retaining information

- 2.27** The person must be able to hold the information in their mind only for long enough to use it to make the decision. People who can only retain information for a short period cannot automatically be assumed to lack the capacity to decide. Items such as notebooks, photographs, posters, videos and voice recorders can support people record and retain information.

Using information in decision-making

- 2.28** For someone to be deemed to have capacity, they must have the ability to weigh up information or use it to make a decision. Sometimes people can understand information but an impairment or disturbance stops them using it. In other cases, the impairment or disturbance leads to a person making a specific decision without weighing up the information they have been given.
- 2.29** For example, a person with the eating disorder anorexia nervosa may understand information about the consequences of not eating. But their compulsion not to eat might be too strong for them to ignore. Some people who have serious brain damage might make impulsive decisions regardless of information they have been given or their understanding of it. Therefore to be able to use information refers to the ability to apply it in practice.
- 2.30** However, a person can dismiss information they do not believe is correct when making decisions, even if this is contrary to the views of others. Unless the basis for ignoring the information is based on symptoms of any impairment or condition, this may be an unwise decision.
- 2.31** It is necessary to be clear what information is given to the person and how it is said to be relevant to the decision. It is not necessary for a person to use or weigh every detail of options available to them in order to demonstrate capacity, only the salient points. Therefore, a person may be unable to use or weigh some information relevant to the decision in question but they may still be able to use or weigh other parts of the information sufficiently to be able to make a capacitous decision.
- 2.32** If a person makes an irrational decision this is not to be confused with the inability to make one. Whilst a person may not agree with given advice, it does not mean that they lack capacity to make the decision.

- 2.33** If a person is able to use the relevant information, the weight they attach to information in the decision-making process is for the person to decide. This requires care when assessing a person's capacity to ensure that you do not confuse the way the person applies their own values and outlook with the inability to use or weigh information.

Inability to communicate a decision in any way

- 2.34** Occasionally it may be not be possible for a person to communicate at all. This will apply to very few people, but it does include:

- people who are unconscious or in a coma, or
- those with the very rare condition sometimes known as 'locked-in syndrome', who are conscious but cannot speak or move at all.

- 2.35** If a person cannot communicate their decision in any way at all, the Law says they should be treated as if they are unable to make that decision.

- 2.36** Before deciding that someone falls into this category, it is important to make all practical and appropriate efforts to support them to communicate. This might call for the involvement of speech and language therapists, specialists in non-verbal communication or other professionals.

- 2.37** Communication by simple muscle movements can show that somebody can communicate and may have capacity to make a decision. For example, a person might blink an eye or squeeze a hand to say 'yes' or 'no'.

- 2.38** Consideration of the diagnostic element should only be undertaken if the person meets one or more of these four criteria.

Diagnostic element

2.39 Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain?

This stage requires demonstrative evidence that the person has an impairment of the mind or brain, or some sort of disturbance that affects the way their mind or brain works. If a person does not have an impairment of, or a disturbance in the functioning of their mind or brain, they will not lack capacity under the Law.

2.40 Examples of an impairment of, or a disturbance in the functioning of their mind or brain may include the following:

- conditions associated with some forms of mental illness
- dementia
- significant learning disabilities
- the long-term effects of brain damage
- physical or medical conditions that cause confusion, drowsiness or loss of consciousness
- delirium
- being deprived of powers of communication by trauma or a stroke
- mental disorder as defined by the Mental Health Law (Jersey) 2016
- concussion following a head injury
- the symptoms of alcohol or drug use.

2.41 If there is no disturbance or impairment in the functioning of the mind or brain present then the person will not lack capacity under the Law.

2.42 The disturbance or impairment in the functioning of the mind or brain must render the person unable to make the decision. A person does not lack capacity under the Law if their decision-making is merely impaired. Demonstrating that the disturbance or impairment is the reason the person unable to make the decision must be undertaken by linking the functional and diagnostic elements through analysis of the causative nexus.

Causative Nexus

- 2**
- 2.43** The use of the word ‘because’ in Article 4 of the Law is deliberate and carries legal significance. When completing capacity assessments, the assessor must consider ‘is the person’s inability to make their own decision in relation to the matter *because* of the identified impairment or a disturbance?’
- 2.44** Capacity assessments must record why and how the inability to make a decision is ‘because of’ the impairment or disturbance in the functioning of the mind or brain. It is not enough to rely on the fact that there is a diagnosis or condition or that it ‘may be’ related to the inability to make the decision. The Law uses ‘because of’ to ensure there is a link between the inability to make the decision and the impairment or disturbance in the functioning of the mind or brain. This must be established when formally determining whether someone lacks capacity. It is not enough for an impairment or disturbance simply to be present.

People with fluctuating or a temporary lack of capacity

- 2.45** Some people have fluctuating capacity – they have an illness or condition that gets worse occasionally and affects their ability to make decisions. Temporary factors may also affect someone’s ability to make decisions. Examples include acute illness, severe pain, the effect of medication, intoxication, and distress after a death or shock.
- 2.46** As in any other situation, an assessment must only examine a person’s capacity to make a particular decision when it needs to be made. It may be possible to put off the decision until the person has the capacity to make it. However, it may not always be possible or appropriate to delay decision making. In such instances, a decision may need to be made on that person’s behalf on the balance of probabilities that they lack capacity to make the decision at that time.

Capacity assessments

- 2.47** Assessing capacity correctly is important to everyone affected by the Law. Someone who is assessed as lacking capacity may be denied their right to make a specific decision, particularly if others think that the decision would not be in the individual's best interests or could cause them harm. Also, if a person lacks capacity to make specific decisions, that person might make decisions they do not really understand. Again, this could cause harm to the person or put them at risk. Therefore it is important to carry out an assessment when a person's capacity is in doubt. It is also important that the person who undertakes an assessment can justify their conclusions.
- 2.48** Capacity assessments must be related to a specific decision. There may be people with an ongoing condition that affects their ability to make certain decisions. One decision on its own may make sense, but may give cause for concern when considered alongside others.
- 2.49** Information about previous decisions the person has made based on a lack of understanding of risk or inability to weigh up the information can form part of a capacity assessment particularly if someone repeatedly makes decisions that puts them at risk or results in significant harm to themselves.
- 2.50** Capacity should be regularly reviewed as it is decision and time specific. People can improve their decision-making capabilities. In particular, someone with an ongoing condition may become able to make some, if not all, decisions.
- 2.51** The person has nothing to prove in relation to their capacity. The first core principle is the assumption of capacity. It is the individual who is claiming that the person lacks capacity who must provide evidence to prove their assertion on the balance of probabilities i.e. it is more likely than not.

'Reasonable belief' of lack of capacity

- 2.52** The Law does not specify who should assess capacity. This is deliberate as anyone can undertake a capacity assessment. The person carrying out the act or treatment is the decision-maker and should undertake the capacity assessment. They must be satisfied that the person cannot make the decision because of an impairment or disturbance in the functioning of the mind or brain.

- 2.53** Carers (whether family carers or other carers) and care workers are not expected to be ‘experts’ in assessing capacity. However, to have protection from liability when providing care or treatment, they must have a ‘reasonable belief’ that the person they care for lacks capacity to make relevant decisions about their own care or treatment.
- 2.54** To have reasonable belief of a lack of capacity, any person must have taken ‘reasonable’ steps to establish that the person lacks capacity to make a decision or consent to an act at the time the decision or consent is needed. This would require them to be satisfied there is an inability to make the decision by checking this out against the four criteria of the functional element described earlier in this chapter.
- 2.55** Carers would not usually need to follow formal processes, such as involving a professional to make an assessment. However, if somebody challenges their assessment, they should be able to describe the steps they have taken. They must also have clear reasons for believing the person lacks capacity before making the decision in question. Paid carers may wish to make note of such decisions in agency recordings.
- 2.56** The steps that are accepted as ‘reasonable’ will depend on individual circumstances and the urgency of the decision. Professionals, who are qualified in their particular field, are normally expected to undertake a fuller assessment, reflecting their higher degree of knowledge and experience, than other carers who have no formal qualifications or family members.

Considerations of factors that might impact capacity assessment

- 2.57** It is important to assess people when they are at their best to make a decision. For example, this may be a particular time of day or a specific setting that would help to achieve this aim. This may not be possible, in some circumstances, depending on the nature and urgency of the decision to be made.
- 2.58** Anyone assessing capacity must not assume that a person lacks capacity simply because they have a particular diagnosis or condition. There must be evidence that the impairment or disturbance in the functioning of the mind or brain directly affects the ability to make a decision at the time it needs to be made.

Involving professionals

2.59 When decisions are of a complex or significant nature, it may be necessary for a person assessing someone's capacity to seek professional support and guidance. If the person has a particular condition or disorder, it may be appropriate to contact a specialist or other professional with experience of caring for patients with that condition.

2.60 Professional involvement might be needed if:

- the decision that needs to be made is complicated or has serious consequences
- an assessor concludes a person lacks capacity, and the person challenges the finding
- family members, carers and/or professionals disagree about a person's capacity
- there is a conflict of interest between the assessor and the person being assessed
- the person being assessed is expressing different views to different people – they may be trying to please everyone or telling people what they think they want to hear
- somebody might challenge the person's capacity to make the decision – either at the time of the decision or later
- somebody has been accused of abusing a vulnerable adult who may lack capacity to make decisions that protect them
- a person repeatedly makes decisions that put them at risk or could result in them suffering significant harm.

2.61 In some cases, a multi-disciplinary approach is best. This means combining the skills and expertise of different professionals. Specialists or professionals should never express an opinion on capacity without their own assessment of the person's ability to make the decision. Everyone must apply the core principles of the Law.

2.62 The person carrying out the act or providing the care or treatment always remains the decision-maker. When other professionals are used, this is to support the decision-maker with decisions, not to make them on the decision-maker's behalf. Where consent to medical treatment is required, the health professional proposing the treatment has the responsibility of ensuring that they are satisfied with the assessment of capacity.

Refusal of assessment

2.63 There may be circumstances in which a person whose capacity is in doubt refuses to undergo an assessment of capacity or refuses to be examined by a doctor or other professional. In these circumstances, it is important to explain to someone refusing an assessment why it is needed and what the consequences of refusal are. The use of threats or attempts to force the person to agree to an assessment are not acceptable.

2.64 If the person lacks capacity to agree or refuse, the assessment can go ahead, as long as the person does not object to the assessment, and it is in their best interests for the assessment to take place.

2.65 Nobody can be forced to undergo an assessment of capacity. If someone refuses to open the door to their home, it cannot be forced. If there are serious worries about the person's mental health, it may be more appropriate to consider the Mental Health Law. That a person refuses to be assessed does not in itself justify the undertaking of a Mental Health Law assessment.

Recording of assessments

2.66 Assessments of capacity to make day-to-day decisions or consent to care require no formal assessment procedures or recorded documentation. But, it is good practice for paid care workers to keep a record of the steps they take when caring for the person concerned.

2.67 An assessment of a person's capacity to decide to accept the provision of services will be part of the care planning processes for health and social care needs and should be recorded in the relevant documentation.

2.68 It is good practice for any concerned professional to carry out an assessment of a person's capacity to take particular decisions and to record the findings in their relevant professional records. The records must demonstrate that the professional has followed the core principles of the Law, in addition to establishing the inability to make a decision because of a disturbance in the functioning of the mind or brain. In practice the professional will also have to demonstrate the person's ability or inability to understand, retain, use or weigh and communicate the decision.

Challenging a finding of lack of capacity

2.69 There are likely to be occasions when someone may wish to challenge the results of an assessment of capacity. The first step is to raise the matter with the person who carried out the assessment. If the challenge comes from the individual who is said to lack capacity, they might need support from family, friends or an Independent Capacity Advocate (ICA). The person or supporter should ask the assessor to:

- give reasons why they believe the person lacks capacity to make the decision, and
- provide objective evidence to support that belief.

There is further information about the ICA in chapter 13.

2.70 The assessor must show they have applied the principles of the Law. All people making decisions for a person who lacks capacity will need to show that they have also followed guidance in this chapter. This includes attorneys, delegates, family as well as all professionals.

2.71 It might be possible to get a second opinion from an independent professional or another expert in assessing capacity. If a disagreement cannot be resolved, the person who is challenging the assessment may refer the matter to the Royal Court (the Court). The Court can rule on whether a person has capacity to make the decision covered by the disputed assessment.



Chapter 3: Best interests

Chapter 3

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Chapter 3: Best interests

- 3.1** The best interests principle is one of the five core principles under the Law:
- ‘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’.
- 3.2** This principle covers all aspects of financial, personal welfare and healthcare decision-making and actions. It applies universally to everyone making decisions under the Law.
- 3.3** The Law’s first key principle is that people must be assumed to have capacity to make a decision for themselves unless it is established that they lack capacity. That means that working out a person’s best interests is only relevant when that person has been assessed as lacking, or is reasonably believed to lack, capacity to make the decision about the act being done. The best interests process can only be used where a lack of capacity is established.

Exceptions to the best interests principle

- 3.4** There are two circumstances when the best interests principle will not apply. The first is where someone has previously made a valid Advance Decision to Refuse Treatment (ADRT) while they had the capacity to do so. Their ADRT should be respected when they lack capacity, even if others think that the decision to refuse treatment is not in their best interests.
- 3.5** The second concerns the involvement in research, in certain circumstances, of someone lacking capacity to consent. There are more details about this in chapter 16.
- 3.6** There are also decisions that cannot be made on behalf of a person who lacks capacity as these are excluded by the Law. There are more details about this in chapter 4.

Best interests definition

- 3.7** The term ‘best interests’ is not defined in the Law. This is because there are many different types of decisions that can be undertaken using the Law on behalf of those people who lack capacity to make such decisions for themselves.

Workings out best interests

- 3.8** Every decision is different. The Law cannot set out all factors that will need to be taken into account in working out someone’s best interests. There are some common factors that must be considered when trying to work out someone’s best interests. These factors are detailed elsewhere in the Code, but for practicality, are summarised below.

A determination as to what is in a person’s best interests cannot be established merely by reference to:

- someone’s age or appearance; or
- aspects of their condition or behaviour that lead to unjustified presumptions about their capacity.

In addition, the following factors often referred to as the ‘best interest checklist’, where reasonably ascertainable, must also be considered:

- every effort should be made to encourage and support the person who lacks capacity to take part in making the decision
- decide if it is possible to delay the decision if the person may regain the capacity to make it
- past and present wishes and feelings in relation to the matter in question, including any ADRT or other written statement
- the beliefs and values which would likely have had an influence on the decision if the person did not lack capacity
- any other factors which that person would likely consider if they did not lack capacity
- the views of other people who are close to the person who lacks capacity should be sought.

- 3.9** ‘Reasonably ascertainable’ means considering all possible information in the time available. What is available in an emergency will be different to what is available in a non-emergency. However, even in an emergency, there may still be an opportunity to try to communicate with the person’s friends, family or carers.
- 3.10** What is in a person’s best interests may change over time. This means that even where similar actions need to be taken repeatedly in connection with the person’s care or treatment, the person’s best interests should be regularly reviewed. Some reviews may be a conversation with the person, whereas others may be part of a care planning review and be more thorough.
- 3.11** In setting out the requirements for working out a person’s ‘best interests’, the Law puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be given due consideration, whether expressed in the past or now.
- 3.12** Any staff involved in the care of a person who lacks capacity should make sure they are familiar with the care plan which will detail the process of working out the best interests of that person for each relevant decision, setting out:

- how the decision about the person’s best interests was reached
- what the reasons for reaching the decision were
- who was consulted to support working out best interests; and
- what particular factors were taken into account.

This record should remain on the person’s file. Capacity can fluctuate and therefore interactions are a useful opportunity to review a person’s capacity. Any significant changes may require a further capacity assessment or care review. For major decisions based on the best interests of a person who lacks capacity, it may also be useful for family carers and other carers to keep a similar kind of record.

Decision-makers

- 3**
- 3.13** Under the Law, many different people are able to make decisions on behalf of someone who lacks capacity to make decisions for themselves. The person making the decision is referred to throughout the Code as the ‘decision-maker’. It is the decision-maker’s responsibility to work out what would be in the best interests of the person who lacks capacity.
- 3.14** If there is an attorney or delegate, they would be the decision-maker for all decisions within the scope of their authority. The scope of decision-making will be set out in the lasting power of attorney (LPA) for attorney’s and set by the Court for delegates.
- 3.15** Often, the same person may make different types of decision for someone who lacks capacity to make decisions for themselves. This may be an attorney under an LPA. However, the scope of an attorney’s authority under an LPA’s may have been limited by the person who made it. Checking out if someone can make a decision would be viewed as upholding a person’s best interests.
- 3.16** In the absence of an attorney or delegate, a range of different decision-makers may be involved with a person who lacks capacity. The decision-maker varies depending on the decision to be made. For example:
- for day-to-day actions or decisions, the decision-maker will be the family member or carer most directly involved with the person at the time
 - for medical treatment, the doctor or another member of healthcare staff responsible for carrying out the particular treatment or procedure is the decision-maker
 - where nursing or paid care is provided, the nurse or paid carer will be the decision-maker around care needs.
- This list is not exhaustive.
- 3.17** No matter who is making the decision, the most important thing is that the decision-maker tries to work out what would be in the best interests of the person who lacks capacity.

Past and present wishes and feelings

- 3.18** People who cannot express their current wishes and feelings in words may express themselves through their behaviour. Expressions of pleasure or distress and emotional responses will also be relevant in working out what is in their best interests. It is also important to be sure that other people have not influenced a person's views.
- 3.19** The person may have held strong views in the past which could have a bearing on the decision now to be made. All reasonable efforts must be made to find out whether the person has expressed views in the past that will shape the decision to be made. This could have been through verbal communication, writing, behaviour or habits, or recorded in any other way (for example, video or audio recordings).
- 3.20** When a decision is to be made for a person lacking capacity and the wishes of that person can be reasonably ascertained, the best interests decision-maker should look to make a decision that is in line with known wishes. Examples of sources of known wishes include ADRT, knowledge of friends and family or a written statement made when the person had capacity. However, there may be circumstances where to follow known wishes could create adverse effects for the person. Decision-makers may make best interest decisions contrary to the known wishes. In such circumstances, the justification for departing from the known wishes of the person should be clearly recorded.

Beliefs and values

- 3.21** Everyone's beliefs and values influence the decisions they make. They may become especially important for someone who lacks capacity to make a decision because of a progressive illness such as dementia. Evidence of a person's beliefs and values can be found in things like their:

- cultural background
- religious beliefs
- political convictions, and
- past behaviours or habits.

Some people set out their values and beliefs in a written statement while they still have capacity. These should be respected and considered in best interest decision-making.

Other factors a decision-maker should consider

- 3.22** The Law requires decision-makers to consider any other factors the person who lacks capacity would consider if they were able to do so. This might include the effect of the decision on other people, obligations to dependants or the duties of being a responsible citizen.
- 3.23** The Law allows actions that benefit other people, as long as they are in the best interests of the person who lacks capacity to make the decision. For example, having considered all the circumstances of the particular case, a decision might be made to take a blood sample from a person who lacks capacity to consent, to check for a genetic link to cancer within the family, because this might benefit someone else in the family. The decision would be based on the understanding of what the person would likely decide if they had capacity. 'Best interests' therefore extends beyond the person's immediate interests.

Who to consult when working out someone's best interests

- 3.24** The Law places a duty on the decision-maker to consult other people close to a person who lacks capacity, where practical and appropriate, on decisions affecting the person and about what might be in the person's best interests. This also applies to those involved in caring for the person and interested in the person's welfare. The Law states the decision-maker must take into account the views of the following people, where it is practical and appropriate to do so:

- anyone named by the person lacking capacity as someone to be consulted on the matter in question or matters of that kind
- anyone engaged in caring for that person or interested in that person's welfare
- any attorney or delegate, if they are not the decision-maker.

- 3.25** If there is no-one to speak to about the person's best interests, in specific circumstances the person may qualify for an ICA. There are more details about this in chapter 13.

3.26 The decision-maker should try to find out:

- what the people consulted think is in the person's best interests in the matter, and
- if they can give information on the person's wishes and feelings, beliefs and values.

3.27 Decision-makers must demonstrate that they have thought carefully about who to consult. If it is practical and appropriate to speak to the above people, they must do so and must take their views into account. They must also be able to explain why they may not have spoken to any particular person. It is good practice to have clear recording on this matter.

3.28 Information may be available from somebody the person named before they lost capacity as someone they wish to be consulted. People who are close to the person who lacks capacity are likely to know them best. They may also be able to support with communication or interpret signs that show the person's present wishes and feelings. Everybody's views are equally important even if they do not agree with each other. They must be considered alongside the views of the person who lacks capacity and other factors.

3.29 Where an attorney has been appointed under an LPA or a delegate has been appointed by the Court, they must make the decisions on any matters they have been appointed to deal with. Where attorneys and delegates are not the decision-maker they can be consulted, if practical and appropriate, on other issues affecting the person who lacks capacity.

Best interests relating to life-sustaining treatment

3.30 Where there is no ADRT, the Law states that decision-making about whether life-sustaining treatment is in the best interests of someone who lacks capacity to consent to or refuse such treatment must not be motivated by a desire to bring about the person's death.

- 3.31** This should not be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person. Futile treatments are not in a person's best interests. Doctors must apply the best interests principle and use their professional skills to decide whether life-sustaining treatment is in the person's best interests.
- 3.32** If a doctor's assessment is disputed, and there is no other way of resolving the dispute, the Court may be asked to decide what is in the person's best interests.

Confidentiality

- 3.33** Decision-makers must balance the duty to consult other people with the right to confidentiality of the person who lacks capacity. Therefore, if confidential information is to be discussed, they should only seek the views of people who it is appropriate to consult, where their views are relevant to the decision to be made and the particular circumstances.
- 3.34** There may be occasions where it is in the person's best interests for personal information (for example, about their medical condition, if the decision concerns the provision of medical treatment) to be revealed to the people consulted as part of the process of working out their best interests. Health and social care staff who are trying to determine a person's best interests must follow their professional guidance, as well as other relevant guidance, about confidentiality.
- 3.35** The best interests process cannot be used to access the records of a person who lacks capacity. This can only be undertaken by an attorney through a valid LPA, or in some circumstances by a delegate appointed by the Court. This would not limit anyone sharing relevant information as part of any best interest process.

Reasonable belief about a person's best interests

- 3.36** Decision-makers must have reasonable belief that they are acting in a person's best interests. This prevents decision-makers imposing their own views as they must have objective reasons for their decisions and be able to demonstrate this. They must be able to show they have considered all relevant circumstances and applied the core principles of the Law including the best interest process.

- 3.37** Article 6 confirms that if someone makes a decision in the reasonable belief that what they are doing is in the best interests of the person who lacks capacity, provided they have followed the principles and factors detailed in this chapter, will have complied with the Law.
- 3.38** Coming to an incorrect conclusion about a person's capacity or best interests does not necessarily mean that the decision-maker would not get protection from liability. They may be able to show that it was reasonable for them to think that the person lacked capacity and that they were acting in the person's best interests at the time they made their decision.
- 3.39** Where there is a need for the Court to decide, it is likely to require formal evidence of what might be in the person's best interests. This will include evidence from relevant professionals. In most day-to-day situations, there is no need for such formality. In emergency situations, it may not be practical or possible to gather formal evidence.

Managing disagreement

- 3.40** A decision-maker may be faced with people who have differing perspectives about a person's best interests. Family members, partners and carers may disagree between themselves or they might have different memories about the views which the person expressed in the past. Carers and family might also not agree with a professional's view about the person's care or treatment needs.
- 3.41** The decision-maker must find a way of balancing these different points of view or deciding between them. The first approach should be to review all elements of the best interests process with everyone involved. They should also include the person who lacks capacity (as much as they are able to take part), and anyone who has been involved in earlier discussions. It may be possible to reach an agreement. However such an agreement in itself might not be in the person's best interests. Ultimate responsibility for working out best interests lies with the decision-maker.
- 3.42** If disagreement continues, the decision-maker will need to weigh up the views of different parties. This will depend entirely upon the circumstances of each case, the people involved and their relationship with the person who lacks capacity.

3.43 People with conflicting interests should not be excluded from the process. Nonetheless decision-makers must always ensure that the interests of those consulted do not overly influence the process of working out a person's best interests.

3

Settling disputes about best interests

3.44 If significant others involved in a best interest decision wish to challenge a decision-maker's conclusions, they must be able to demonstrate that the decision-maker has not followed the best interest process or has not known about pertinent information. Decision-makers are able to use and weigh information as they understand P and their best interests. There are several options to review decisions:

- informal feedback to the individual about the decision
- hold a formal 'best interests' case conference
- hold a review of the process e.g. by a Capacity & Liberty Assessor
- pursue a complaint through the organisation's formal procedures.

If these steps are exhausted and fail to resolve the dispute, the Court might need to decide what is in the person's best interests.



Chapter 4: Excluded decisions

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Chapter 4: Excluded decisions

4.1 There are certain decisions which can never be made on behalf of a person who lacks capacity. This is because they are either so personal to the individual concerned, or governed by other legislation. Article 7 of the Law sets out the specific decisions which can never be made under the Law, whether by family members, carers, professionals, attorneys or the Court. These are summarised below.

Decisions concerning family relationships

4.2 Nothing in the Law permits a decision to be made on someone else's behalf on any of the following matters:

- marriage or a civil partnership
- sexual relationships
- decree of divorce
- dissolution of a civil partnership
- a child being placed for adoption
- the making of an adoption order
- organ donation
- fertility treatment
- the discharge of parental responsibilities in matters other than those relating to a child's property.

Mental Health Law matters

4.3 Where a person who lacks capacity is currently being treated under Part 6 of the Mental Health (Jersey) Law 2016 (MHL), nothing in this Law authorises anyone to:

- give the person treatment for mental disorder, or
- decide to such treatment.

4

Voting rights

4.4 Nothing in the Law permits a decision on voting, at an election for any public office or in a referendum, to be made on behalf of a person who lacks capacity to vote.



Chapter 5: Care and treatment

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Chapter 5: Care and treatment

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- 5.1** Article 8 of the Law enables carers, health and social care staff to make decisions to carry out certain actions without fear of liability. This protection only applies to actions which are linked to the care and treatment of the person who lacks capacity.

Protection for people caring for those who lack capacity to consent

- 5.2** By necessity, acts need to be done to and for people who lack capacity to make decisions about their own care or treatment. The Law provides protection from liability only if the criteria under Article 8 have been followed. Article 8 states:

- before undertaking an act, reasonable steps have been taken to establish that the person lacks capacity in relation to the act or treatment
- when undertaking the act, there is reasonable belief that the person lacks capacity in relation to the act or treatment and it will be in their best interests for the act to be done.

The person carrying out the act or treatment will not incur liability if these steps are followed.

- 5.3** Article 8 protects people who carry out these actions. It stops them being prosecuted for acts that could otherwise be classed as civil wrongs or crimes. By protecting family and other carers from liability, the Law allows necessary caring acts or treatment to take place as if a person who lacks capacity had consented to them. These are referred to as 'permitted acts' in the Law. People providing care of this sort do not therefore need to get formal authority to act.

- 5.4 Importantly, Article 8 does not give people caring for or treating someone the power to take any other decisions on behalf of those who lack capacity to take their own decisions.

Protection from liability

- 5.5 Every day lots of decisions are undertaken about what acts are done to and for people who lack capacity to make their own decisions about their care or treatment. Such acts range from everyday tasks of caring (for example, helping someone to wash) to life-changing events (for example, serious medical treatment or arranging for someone to go into a care home). In theory, many of these actions could be against the law. Legally, people have the right to stop others from interfering with their body or property unless they give permission.

- 5.6 In order to benefit from Article 8 protection for decisions carried out in connection with acts of care or treatment, the action should be carried out on behalf of a person who is believed to lack capacity to agree to it, so long as it is in that person's best interests.

- 5.7 Prior to undertaking any action, the individual carrying out the act must have taken reasonable steps to establish that the person lacks capacity to consent to the action and the action is in the person's best interests as detailed under the Law. If these steps are not undertaken, there is no protection from liability.

- 5.8 Actions that might be covered by Article 8 include:

Personal care

- supporting with washing, dressing or personal hygiene
- supporting with eating and drinking
- supporting with communication
- supporting with mobility (moving around)
- supporting someone to take part in education, social or leisure activities
- going into a person's home to drop off shopping or to see if they are alright
- doing the shopping or buying necessary goods with the person's money

- arranging household services (for example, arranging repairs or maintenance for gas and electricity supplies)
- providing services that help around the home (such as homecare)
- undertaking actions related to community care provision
- supporting someone to move home (including moving property and clearing the former home).

Healthcare and treatment

- carrying out diagnostic examinations and tests (to identify an illness, condition or other problem)
- providing professional medical, dental and similar treatment
- giving medication
- taking someone to hospital for assessment or treatment
- providing nursing care (whether in hospital or in the community)
- carrying out any other necessary medical procedures (for example, taking a blood sample) or therapies (for example, physiotherapy or chiropody)
- providing care in an emergency.

5

5.9 These actions only receive protection from liability if the person is reasonably believed to lack capacity to give permission for the action. The action must also be in the person's best interests and follow the Law's other core principles.

5.10 There is no protection under Article 8 for actions that conflict with a decision of an attorney or delegate.

5.11 Some decisions in connection with care or treatment may cause major life changes with significant consequences for the person concerned. Those requiring particularly careful consideration include a change of residence, perhaps into a care home or nursing home, or major decisions about healthcare and medical treatment. These are described in the following paragraphs.

Change of residence

- 5.12** If the person lacks capacity to make the decision about a change of residence, the decision-maker must consider whether the move is in the person's best interests as detailed in this Code. The decision-maker must also consider whether there is another less restrictive option.
- 5.13** Sometimes the final outcome may not be what the person who lacks capacity wanted. For example, they might want to stay at home, but those caring for them might decide a move is in their best interests.
- 5.14** In situations where a change of residence is proposed and there is no-one willing and appropriate to support the person and their best interests, an Independent Capacity Advocate (ICA) will be instructed to represent the person. There is more information about the role of an ICA in Chapter 13.
- 5.15** If there is a serious disagreement about the need to move the person that cannot be settled in any other way, the Court can be asked to decide what the person's best interests are and where they should live. For example, this could happen if members of a family disagree over what is best for a relative who lacks capacity to make their own decision about the move.
- 5.16** In some circumstances, being placed in a hospital or care home may impose a significant restriction on the person's liberty. This means that the individual is not free to leave and that they are under continuous supervision and control. If this is the case, in order for there to be protection from liability, a formal process must be followed. In the first instance it is the responsibility of the decision-maker to first look at the range of alternative and consider less restrictive options to see if there is any way of avoiding significantly restricting the person's liberty.
- 5.17** If there is no alternative way of meeting the person's needs, authorisation will be required in order to keep the person in a situation which significantly restricts their liberty (if this is in the person's best interests). This might require a Ministerial decision authorising a significant restriction on liberty. Alternatives which could be considered might include requesting an order of the Court or using the powers in the Mental Health Law. Significant restrictions on liberty are explained further in chapter 11.

Healthcare and treatment decisions

- 5.18** The Law also allows actions to be taken to ensure a person who lacks capacity receives necessary medical treatment. This could involve taking the person to hospital for out-patient treatment or arranging for an admission to hospital. Even if a person who lacks capacity objects to the proposed treatment or admission to hospital, the action might still be allowed under Article 8. But there are limits about force or restraint being used to impose treatment.
- 5.19** Major healthcare and treatment decisions will also need special consideration. Unless there is a valid and applicable ADRT, a delegate or an attorney, healthcare staff must carefully work out what would be in the person's best interests under the Law.
- 5.20** In situations where a serious medical treatment is proposed and there is no-one willing and appropriate to support the person and their best interests, an ICA will be instructed to represent the person.
- 5.21** Healthcare staff must also consider whether there are alternative treatment options that might be less intrusive or restrictive. When deciding about the provision or withdrawal of life-sustaining treatment, anyone working out what is in the best interests of a person who lacks capacity must not be motivated by a desire to bring about the person's death.
- 5.22** Multi-disciplinary meetings are often a good way to decide on a person's best interests. However final responsibility for deciding what is in a person's best interest lies with the member of healthcare staff responsible for the person's treatment. They should record their decision, how they reached it and the reasons for it in the person's clinical notes. As long as they have recorded objective reasons to show that the decision is in the person's best interests, and the other requirements of the Law are met, all healthcare staff taking actions in connection with the particular treatment will be protected from liability.
- 5.23** Some treatment decisions are so serious that the Court has to make them, unless the person has appointed an attorney to make such healthcare decisions for them or they have made an ADRT regarding the proposed treatment. Where there is conflict or doubt, it is advisable for parties to seek legal advice.

- 5**
- 5.24** Where there is a delegate or attorney with authority to make the decision, the Law does not authorise or protect against any act that would conflict with their decision. Where there has been disagreement about a decision for treatment that has been referred to the Court, acting contrary to a delegate or attorney's decision may be viewed as a permitted act if it is in relation to sustaining life, whilst awaiting a decision of the Court on the treatment.
- 5.25** Carers who provide personal care services must not carry out specialist procedures that are normally done by trained healthcare staff. If the action involves medical treatment, the doctor or other member of healthcare staff with responsibility for the patient will be the decision-maker who has to decide whether the proposed treatment is in the person's best interests. A doctor can delegate responsibility for giving the treatment to other people in the clinical team who have the appropriate skills or expertise. People who do more than their experience or qualifications permit may not be protected from liability.

Administering medication covertly

- 5.26** Covert administration of medication is a complex issue. It involves the disguising of a medicine, sometimes in food or drink, to a patient lacking capacity to make a decision about treatment. When covert administration of medication is used, this must be necessary and in accordance with the principles of the Law.
- 5.27** If a person lacks the capacity to understand the risks to their health if they do not take their prescribed medication and they refuse to take the medication, then it should only be administered covertly in exceptional circumstances.
- 5.28** Before any medication is administered covertly there must be a best interests meeting which include relevant health professionals and those who are involved in the person's care such as family and significant others. If it is an emergency, medication may be administered with a best interest meeting following as soon as possible.

- 5.29** Prescribers should never physically alter medication, such as crushing tablets, or give this as advice as doing so may increase their professional liability. Altering medication may affect efficacy and absorption, resulting in a person receiving the wrong dosage. Where possible, a pharmacist should be part of a best interest meeting. If this is not possible, the prescriber should seek advice on any pharmaceutical issues. Medications are available locally in alternative forms, such as liquid or capsules to allow administration safely, without any alteration.
- 5.30** If it is agreed that the administration of medication covertly is in the person's best interests then this must be recorded in the person's records. This recording must also include an agreed medication management and review plan.
- 5.31** If there is disagreement with significant others and professionals then legal advice should be sought regarding whether the matter should be referred to the Court. Attorneys and delegates can refuse to agree to medication being administered covertly, if this is in the scope of their authority. If the prescriber does not agree that the decision-maker is acting in the person's best interests or strongly disagrees with the decision-maker they can refer the matter to Court for a best interests determination.
- 5.32** The prescriber should carry out regular reviews of all medications as a person who lacks capacity may not be able to communicate how the medication is affecting them or explain any side effects.

Emergency situations

- 5.33** Sometimes people who lack capacity to consent will require emergency medical treatment to save their life or to protect them from serious harm. In these situations, what steps are 'reasonable' will differ to those in non-urgent cases. In emergencies, it will almost always be in the person's best interests to give urgent treatment without delay. One exception to this is when the healthcare staff giving treatment are satisfied that an ADRT exists that would provide them with the person's decision on the proposed treatment.

Negligence

- 5.34** Article 8 of the Law does not provide a defence in cases of negligence, whether carrying out a particular act or by failing to act where necessary.
- 5.35** The Law imposes some important limitations on acts which can be undertaken with protection from liability. The key areas where acts might not be protected from liability are where there is inappropriate use of restraint or where a person who lacks capacity is subjected to significant restrictions on their liberty.



Chapter 6: Restraint

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Chapter 6: Restraint

6.1 Article 9 of the Law states that someone is using restraint if they:

- use or threaten to use, force to secure the doing of an act which a person resists, or
- restricts a person's liberty of movement, whether or not the person resists or objects to the restriction.

6.2 Any action intended to restrain a person who lacks capacity will not attract protection from liability unless the following two conditions are met:

- the person reasonably believes that it is necessary to do the act in order to prevent harm to the person, and
- the action is a proportionate response to the likelihood of the person's suffering harm, and the seriousness of that harm.

6.3 There is no protection under Article 9 for actions that conflict with a valid decision of a delegate or attorney.

6.4 However, health and social care staff have a duty of care in respect of all people to whom they provide services. The Law does not seek to interfere with this duty of care. This means if any staff member needs to take appropriate action to restrain or remove any person, in order to prevent harm to the person concerned or to anyone else, they should continue to do so.

6.5 In addition to any professional and departmental guidance, health and social care staff should also refer to Departmental training and techniques to manage conflict situations.

Necessary restraint

- 6.6** Anybody considering using restraint must have sufficient reason to justify that restraint is necessary. They must be able to show that the person being cared for is likely to suffer harm unless proportionate restraint is used. A carer or professional must not use restraint just so that they can do something more easily. If restraint is necessary to prevent harm to the person who lacks capacity, it must be the minimum amount of force for the shortest time possible.

Harm

- 6.7** The Law does not define ‘harm’, because it will vary depending on the situation. Simple measures can often be put in place to reduce the risk of harm, for example, by locking away poisonous chemicals or removing obstacles. Care planning should include risk assessments and set out appropriate actions to try to minimise possible risks. It is impossible to remove all risk, and a proportionate response is needed when the risk of harm does arise.

6

Responding proportionately

- 6.8** A ‘proportionate response’ means using the least intrusive type and minimum amount of restraint to achieve an outcome in the best interests of the person who lacks capacity. On occasions when the use of force may be necessary, carers, healthcare and social care staff should use the minimum amount of force for the shortest possible time.
- 6.9** Carers, healthcare and social care staff must always consider least restrictive options before using restraint. Considering the least restrictive option is one of the core principles of the Law. Where possible, they should ask other people involved in the person’s care what action they think is necessary to protect the person from harm.

Restraint and administering medication covertly

- 6.10** Covert administration of medication is a complex issue. It involves the disguising of a medicine, sometimes in food or drink, to a patient lacking capacity to make the decision about treatment. When covert administration of medication is used, this must be necessary and in accordance with the principles of the Law. This is covered in more detail in chapter 5.
- 6.11** Medications that have a sedative effect should be considered a form of restraint. Information in relation to covert medication must be easily accessible on any viewing of a person's records where they receive care. It is important that medications and their purpose are clear in the person's records for consideration in relation to whether it contributes to significant restriction on liberty.
- 6.12** Prescribers must review medication on a regular basis, with consideration being given to its necessity and in light of the least restrictive principle.

Significant restrictions on liberty

- 6.13** Although Article 9 of the Law permits the limited use of restraint, where necessary, there is no protection under the Law for actions that result in someone being deprived of their liberty (as defined by Article 5(1) of the European Convention on Human Rights). This applies not only to public authorities covered by the Human Rights (Jersey) Law 2000 but to everyone who might otherwise get protection for decisions about permitted acts under Article 8 of the Law.
- 6.14** It is recognised that, sometimes, there is no alternative way to provide care or treatment other than through imposing a significant restriction on a person's liberty. Actions that amount to a significant restriction will not be lawful unless formal authorisation is obtained. Such authority can only be granted through either the authority of the Court or the Minister through Part 5 of the Law. Significant restrictions on liberty are explained further in chapter 11.



Chapter 7: Using a person's money

Chapter 7

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Chapter 7: Using a person's money

Who can pay for goods or services?

- 7.1** Carers may have to spend money on behalf of someone who lacks capacity to decide to purchase necessary goods or services. Carers are protected from liability if their actions are in the best interests of the person who lacks capacity.
- 7.2** Article 10 of the Law states that where the contract is for necessary goods or services for a person who lacks capacity to make the arrangements for themselves, that person must pay a reasonable price for them. Arrangement and payments of goods must follow best interest principles in order to be lawful.

Necessary goods and services

- 7.3** 'Necessary' means something that is suitable to the person's requirements, at the time they are supplied, to maintain their 'condition in life'. Condition in life is taken to mean their place in society, rather than any mental or physical condition. The aim is to make sure that people can enjoy a similar standard of living and way of life to those they had before lacking capacity.
- 7.4** Goods are not necessary if the person already has a sufficient supply of them.

Arranging payments

- 7.5** A carer must take reasonable steps to check whether a person can arrange for payment themselves, or has the capacity to decide that the carer can do it for them. If the person lacks capacity, the carer must decide what goods or services are necessary for the person and in their best interests. The carer can then lawfully deal with payment for those goods and services in one of three ways:

- If neither the carer nor the person who lacks capacity can produce the necessary funds, the carer may promise that the person who lacks capacity will pay
- If the person who lacks capacity has cash, the carer may use that money to pay for goods or services
- The carer may choose to pay for the goods or services with their own money. The person who lacks capacity must pay them back. This may involve using cash in the person's possession or running up an IOU. This may not be appropriate for paid care workers, whose contracts might stop them handling their clients' money.

7.6 Carers should keep bills, receipts and other proof of payment when paying for goods and services. They will need these documents when asking to get money back.

7

Access to a person's assets

7.7 The Law does not give a carer or care worker access to a person's income or assets. Nor does it allow them to sell the person's property.

7.8 Anyone wanting access to money in a person's bank account will need formal legal authority. They will also need legal authority to sell a person's property. Such authority could be given in an LPA appointing an attorney to deal with property and affairs, or in an order of the Court (either a single decision of the Court or an order appointing a delegate to make financial decisions for the person who lacks capacity to make such decisions).

7.9 The Law is clear that a family carer or other carer cannot make arrangements for goods or services to be supplied to a person who lacks capacity if this conflicts with a decision made by someone who has formal powers over the person's property and affairs, such as an attorney or delegate acting within the scope of their authority. Where there is no conflict and the carer has paid for necessary goods and services the carer may ask for money back from an attorney or delegate.

Section 2: Future decision-making

Why read this section?

These chapters detail future decision-making options that people can use, if they are able and wish to do so. They also explain how future decisions can be made when someone has not used these options, but require ongoing support with decision-making or need a significant decision to be made.



Chapter 8: Lasting Powers of Attorney

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Chapter 8: Lasting Powers of Attorney

Lasting Power of Attorney

- 8.1** A Lasting Power of Attorney (LPA) is a legal document that enables a person to give another person authority to make a decision on their behalf. Through a valid LPA the chosen person can make decisions that are as valid as ones made by the person.
- 8.2** An appointed decision maker is called an attorney. The person can choose one person or several to make different kinds of decisions. A person may appoint different people for different decisions or ask that some decisions are made by more than one person.
- 8.3** As well as property and affairs (including financial matters), LPAs can also cover health and welfare (including healthcare and medical treatment) to authorise decision-making for a time when a person lacks capacity to make such decisions for themselves.
- 8.4** The authority of an LPA will change in line with the person's capacity. Attorney's must also follow the core principles including best interest guidelines and supporting the person's decision-making before deciding how best to proceed.

Making a valid LPA

- 8.5** There is a formal procedure for creating and registering an LPA. Otherwise the LPA will not be valid. It is not necessary to get legal advice. This would be a personal choice and dependent upon a person's circumstances.

8.6 Only people aged 18 or over can make an LPA and they can only make an LPA if they have the capacity to do so. For an LPA to be valid it must be registered with the Judicial Greffe. The Judicial Greffe will only register LPA's that meet the following conditions:

- the LPA must be set out in the statutory form online, if a person has difficulty using a computer someone else can type it for them
- the person must declare that they have read and understood information about the effects of the LPA, that they intend to confer the authority to those named in the LPA to make decisions on their behalf in circumstances where they no longer have capacity to do so (or choose immediate effect for affairs and property)
- the attorney(s) must declare that they have read the information and that they understand their duties, in particular the duty to act in the person's best interests
- it must be witnessed by an independent third party who will confirm that:
 - in their opinion, the person understands the LPA's purpose and the scope of the authority it confers
 - nobody has used fraud or undue pressure to trick or force the person into making the LPA; and
 - to the best of their knowledge, there is nothing else to stop the LPA being registered.

8.7 While they still have capacity, persons should let the Judicial Greffe know of permanent changes of address for the person or the attorney or any other changes in circumstances. If the person no longer has capacity to do this, attorneys should report any such changes to the Judicial Greffe.

8.8 Once someone becomes an attorney, they cannot give up that role without notifying the person and the Judicial Greffe. If they decide to give up their role, they must follow the relevant guidance available from the Judicial Greffe.

Attorneys

8.9 A person should think carefully before choosing someone to be their attorney. An attorney should be someone who is trustworthy, competent and reliable.

8.10 Attorneys must be at least 18 years of age. For property and affairs LPAs, the attorney could be either:

- an individual (as long as they are not bankrupt at the time the LPA is made), or
- a trust corporation (often parts of banks or other financial institutions).

If an attorney nominated under a property and affairs LPA becomes bankrupt at any point, they will no longer be allowed to act as an attorney for property and affairs. People who are bankrupt can still act as an attorney for health and welfare LPAs.

8.11 The person should name an individual rather than a job title in a company or organisation, for example, 'The Director of Adult Services' or 'my solicitor' would not be sufficient. A paid care worker, such as a care home manager, should not agree to act as an attorney.

8.12 Article 12(2) of the Law allows the person to appoint two or more attorneys and to specify whether they should act 'solely', 'jointly', 'jointly and severally', or 'jointly in respect of some matters and jointly and severally in respect of others'. For clarity:

- sole decisions can only be made by the named attorney
- joint attorneys must always act together. All attorneys must agree decisions and sign any relevant documents
- joint and several attorneys can act together but may also act independently if they wish. Any action taken by any attorney alone is as valid as if they were the only attorney.

- 8.13** The person may want to appoint attorneys to act jointly in some matters but jointly and severally in others. For example, a person could choose to appoint two or more financial attorneys jointly and severally. But they might stipulate that when selling the person's house, the attorneys must act jointly. The person may appoint health and welfare attorneys to act jointly and severally but specify that they must act jointly in relation to giving consent to surgery. If a person who has appointed two or more attorneys does not specify how they should act, the law states they must always act jointly.
- 8.14** A person may choose to name replacement attorneys to take over the duties in certain circumstances (for example, in the event of an attorney's death). The person may name a specific attorney to be replaced, or the replacements can take over from any attorney, if necessary. Whilst a person can name a number of replacement attorneys, the Law does not allow attorneys the right to appoint a substitute or successor.

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Guidance for an attorney

- 8.15** Article 12 states that attorneys must meet the requirements set out in the Law. Attorneys also have to follow the principles of the Law and make decisions in the best interests of the person who lacks capacity. They must also respect any conditions or restrictions that the LPA document contains.
- 8.16** Attorneys should refer to the guidance in this Code when assessing the person's capacity to make particular decisions, and in particular, should follow the steps suggested for establishing a 'reasonable belief' that the person lacks capacity.
- 8.17** Attorneys should refer to the guidance in this Code regarding best interests. This includes consideration of the person's past and present wishes and feelings, beliefs and values. Where practical and appropriate, they should also consult with others.
- 8.18** Attorneys cannot delegate their authority to someone else unless stipulated in the LPA. They must carry out their duties personally. The attorney may seek professional or expert advice, for example, investment advice from a financial adviser or advice on medical treatment from a doctor. They cannot allow someone else to make a decision that they have been appointed to make unless this has been specifically authorised by the person in the LPA.

Decisions an LPA attorney can make

Health and welfare LPA

- 8.19** A health and welfare LPA can only be used at a time when the person lacks capacity to make a specific health and welfare decision.
- 8.20** A health and welfare LPA allows attorneys to make all decisions about anything that relates to the person's health and welfare unless the person adds restrictions or conditions to areas where they would not wish the attorney to have the power to act.
- 8.21** This means that health and welfare attorneys have the authority to make decisions to accept or refuse healthcare or treatment unless the person has stated clearly in the LPA that they do not want their attorney to make these decisions.
- 8.22** Attorneys do not have the right to consent to or refuse treatment in situations where the person has made an ADRT in relation to the proposed treatment. However, if the LPA has been made after the ADRT and the person has given the attorney the right to consent to or refuse the treatment, the attorney can choose not to follow the ADRT.
- 8.23** The following circumstances also affect decision-making:
- an attorney has no authority to consent to or refuse life sustaining treatment, unless the LPA document expressly authorises this
 - an attorney has no authority to refuse treatment for mental disorder when the person is detained under the Mental Health Law.

However, in both circumstances they retain decision making power for all other medical decisions that they are authorised to make.

8.24 Before making a decision under a health and welfare LPA, the attorney must be sure that:

- the LPA has been registered with the Judicial Greffe
- the person lacks the capacity to make the particular decision or the attorney reasonably believes that the person lacks capacity to take the decisions covered by the LPA;
- there is no valid ADRT; and
- they are making the decision in the person's best interests.

8.25 LPAs cannot give attorneys the power to demand specific forms of medical treatment that healthcare staff do not believe are necessary or appropriate for the person's particular condition.

8.26 When health or social care staff are involved in writing a care plan for someone who has appointed a health and welfare attorney, they must first assess whether the person has capacity to agree to the care plan or to parts of it. If the person lacks capacity, professionals must then consult the attorney and get their agreement to the care plan. They will also need to consult the attorney when considering what action is in the person's best interests. Professionals should satisfy themselves that any attorney has the scope and authority to make the decision under a valid LPA.

8.27 If healthcare staff disagree with the attorney's assessment of best interests, they should discuss the matter further with the attorney. If there is still no agreement, they can discuss the case with other medical experts and/or get a formal second opinion. If they cannot settle the disagreement, they can apply to the Court to make the decision. While the Court is coming to a decision, healthcare staff can give life-sustaining treatment to prolong the person's life or stop their condition getting worse.

Property and affairs LPAs

8.28 A person can make an LPA giving an attorney the right to make decisions about property and affairs (including financial matters). Unless the person states otherwise, once the LPA is registered, the attorney is allowed to make all decisions about the person's property and affairs even if the person still has capacity to make the decisions for themselves. In this situation, the LPA will continue to apply when the person no longer has capacity.

- 8.29** Alternatively a person can state in the LPA document that the LPA should only apply when they lack capacity to make a relevant decision. Financial institutions may wish to see the written confirmation before recognising the attorney's authority to act under the LPA.
- 8.30** The fact that someone has made a property and affairs LPA does not mean that they cannot continue to carry out financial transactions for themselves. The person may have capacity, but perhaps anticipates that they may lack capacity at some future time or they may have fluctuating capacity and therefore be able to make some decisions at some times, but need an attorney to make others at other times. The attorney should allow and encourage the person to do as much as possible, and should only act when the person asks them to or to make those decisions the person lacks capacity to make. However, in other cases, the person may wish to hand over responsibility for all decisions to the attorney even though they may still have capacity.
- 8.31** Property and affairs LPAs allow attorneys to make all decisions about anything that relates to the person's finances, property and affairs unless the person adds restrictions or conditions to areas where they would not wish the attorney to have the power to act. If the person holds any assets as trustee, they should get legal advice about how the LPA may affect this.
- 8.32** The attorney must make these decisions and cannot generally give someone else authority to carry out their duties. However, a person may give authority to an attorney in order that they can utilise a specialist to make specific decisions, for example, appointing an investment manager to make particular investment decisions. This needs to be clearly stated in the LPA document. If there is a change in circumstances, such as an inheritance for a person, the attorney can seek approval from Court to undertake a course of action, not detailed in the LPA, if it is in their best interests.
- 8.33** People will have different financial circumstances. A person may wish to appoint someone to go through their accounts with the attorney from time to time. The person should ensure that the individual or organisation is willing to carry out this role and is prepared to ask for the accounts if the attorney does not provide them. They should include this arrangement in the signed LPA document. The LPA should also say whether a fee can be charged for this service.

Gifts an attorney can make under a property and affairs LPA

8.34 An attorney can make gifts of the person's money or belongings to people who are related to or connected with the person (including the attorney) on specific occasions, including:

- births or birthdays
- weddings or wedding anniversaries
- civil partnership ceremonies or anniversaries, or
- any other occasion when families, friends or associates usually give presents.

8.35 A person can impose conditions or restrictions on the attorney's powers to make gifts. They should state these restrictions clearly in the LPA document when they are creating it. When deciding on appropriate gifts, the attorney should consider the person's wishes and feelings to work out what would be in the person's best interests. The attorney can apply to the Court for permission to make gifts that are not included in the LPA (for example, for tax planning purposes).

8.36 If the person previously made donations to any charity regularly or from time to time, the attorney can make donations from the person's funds. This also applies if the person could have been expected to make such payments. The value of any gift or donation must be reasonable and take into account the size of the person's estate.

Powers of the Royal Court

8.37 The Court has a range of powers to:

- determine whether an LPA is valid
- give directions about using the LPA where matters are unclear
- request reports or accounts in some circumstances such as suspected wrong doing
- make specific decisions, and
- to remove an attorney (for example, if the attorney does not act in the best interests of the person).

8.38 The Court can also stop somebody registering an LPA or rule that an LPA is invalid if:

- the person made the LPA as a result of undue pressure or fraud, or
- the attorney behaves, has behaved or is planning to behave in a way that goes against their duties or is not in the person's best interests.

8.39 The Court can also clarify an LPA's meaning, if it is not clear, and it can tell attorneys how they should use an LPA. If an attorney thinks that an LPA does not give them enough powers, they can ask the Court to extend their powers if the person no longer has capacity to authorise this. The Court can also authorise an attorney to give a gift that the Law does not normally allow, if it is in the person's best interests.

8.40 If somebody has concerns about an attorney's payment or expenses, the Court can resolve the matter by ordering an attorney to produce records (for example, financial accounts) and to provide specific reports, information or documentation.

8.41 Attorneys must comply with any decision or order that the Court makes.

Attorneys duties and responsibilities

8.42 Attorneys acting under an LPA have a duty to:

- follow the Law's core principles
- make decisions in the person's best interests
- have regard to the guidance in this Code
- only make those decisions the LPA gives them authority to make.

8.43 A person cannot insist on somebody agreeing to become an attorney. It is down to the proposed attorney to decide whether to take on this responsibility. When an attorney accepts the role by signing up to the LPA, this is confirmation that they are willing to act under the LPA once it is registered. An attorney can withdraw from the appointment if they ever become unable or unwilling to act.

- 8.44** Once the attorney starts to act under an LPA, they must meet the standards outlined in this Code. If they don't carry out the duties responsibly, they could be removed from the role. In some circumstances they could be sanctioned by the Court.
- 8.45** 'Duty of care' means applying a certain standard of care and skill. The level to which this is applied will depend on whether the attorney is paid for their services or holds relevant professional qualifications.

- attorneys who are not being paid must apply the same care, skill and diligence they would use to make decisions about their own life. An attorney who claims to have particular skills or qualifications must show greater skill in those particular areas than someone who does not make such claims
- attorneys who undertake their duties in the course of their professional work, such as solicitors or corporate trustees, must display professional competence and follow their profession's rules and standards

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- 8.46** Fiduciary duty means attorneys must not take advantage of their position. Attorneys should never put themselves in a position where their personal interests conflict with their duties. They also must not allow any other influences to affect the way in which they act as an attorney. Decisions should always benefit the person, and not the attorney. Attorneys must not profit or get any personal benefit from their position, apart from receiving gifts where the Law allows it, whether or not it is at the person's expense.
- 8.47** An attorney for property and affairs should keep some records of transactions carried out on the person's behalf. If the attorney is not a financial expert and the person's affairs are relatively straightforward, a record of the person's income and expenditure (for example, through bank statements) may be enough. The more complicated the person's affairs, the more detailed the accounts may need to be.
- 8.48** Property and affairs attorneys should usually keep the person's money and property separate from their own or anyone else's. There may be occasions where persons and attorneys have agreed in the past to keep their money in a joint bank account, for example, if a wife is acting as her husband's attorney. It will be possible to continue this under an LPA, but it can be helpful in some circumstances to keep finances separate to avoid any possibility of mistakes or confusion.

Confidentiality

8.49 Attorneys should keep the person's affairs confidential, unless:

- before they lost capacity to do so, the person agreed that some personal or financial information may be revealed for a particular purpose; or
- there is some other good reason to release it. In these circumstances, it may be advisable to get legal advice.

8.50 Article 7 of the Data Protection (Jersey) Law 2018 gives everyone the right to see personal information that an organisation holds about them. They may also authorise someone else to access their information on their behalf. The person holding the information has a legal duty to release it.

8.51 A person may have the capacity to agree to someone seeing their personal information, even if they do not have the capacity to make other decisions. In some situations, a person may have previously given consent, while they still had capacity, for someone to see their personal information in the future.

8.52 An attorney acting under a valid LPA can ask to see information concerning the person they are representing, as long as the information applies to decisions the attorney has the legal right to make.

8.53 In practice, an attorney may only require limited information and may not need to make a formal request. In such circumstances, they can approach the information holder informally. Once satisfied that the request comes from an attorney, the person holding information should release it. The attorney can still make a formal Subject Access Request for information in the future.

8.54 An information holder should not release information if doing so would cause serious physical or mental harm to anyone – including the person the information is about. This applies to information on health, social care and education records.

8.55 The Information Commissioner's Office can give further details on:

- how to request personal information
- restrictions on accessing information, and
- how to appeal against a decision not to release information.

8.56 The attorney must treat the information confidentially. They should be extremely careful to protect it. If they fail to do so, the Court can cancel the LPA.

Action to be taken when someone believes an attorney is abusing their position

8.57 Attorneys are in a position of trust, so there is always a risk of them abusing their position. Persons can minimise the risk of abuse by carefully choosing a suitable and trustworthy attorney. But others have a role to play in looking out for possible signs of abuse or exploitation.

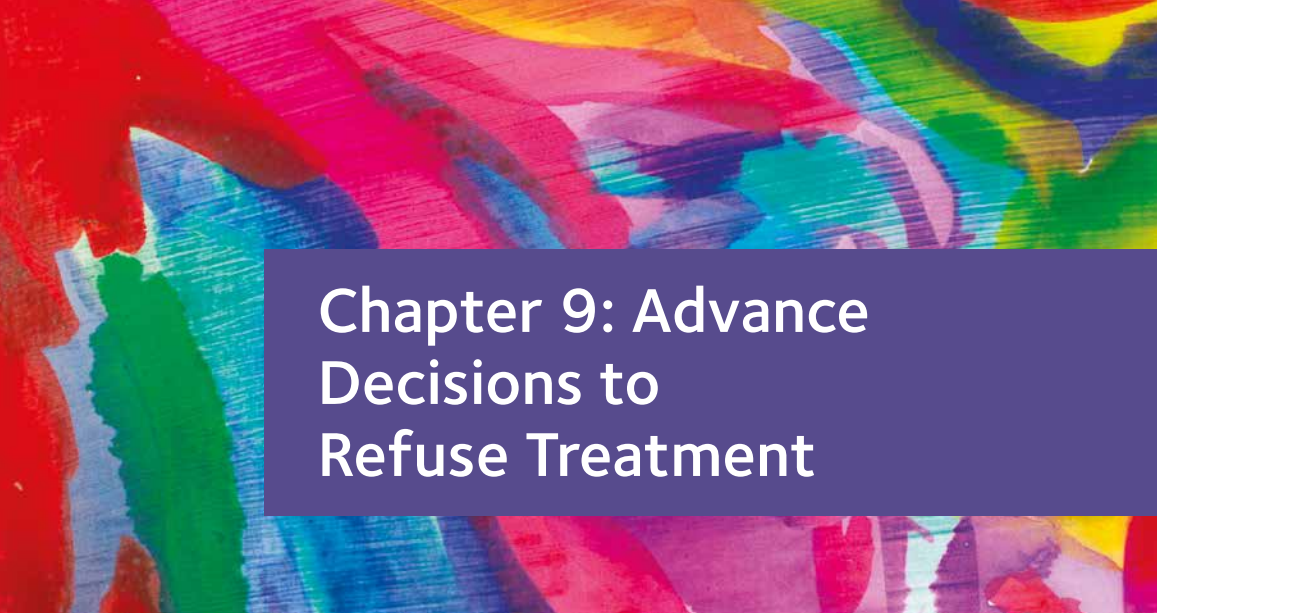
8.58 Somebody who suspects abuse should contact the Viscount or Judicial Greffe immediately. In cases of suspected physical or sexual abuse, theft or serious fraud, the person should contact the police. They might also be able to refer the matter to the Department's adult safeguarding service.

8.59 In these circumstances, the Court may request records, reports or accounts in order to examine the attorney's conduct and decision-making with regards to the person's health or financial affairs.

8.60 In serious cases, the Court might then consider:

- ending the LPA
- legal sanctions against the attorney
- appointing a delegate.

8.61 The Court may also end an attorney's appointment and then reappoint them as a delegate, if they feel that the attorney's actions, whilst not criminal, require ongoing supervision and scrutiny. This would be used as an option to maximise the wishes and feelings of the person, whilst safeguarding them, following the least restrictive principle.



Chapter 9: Advance Decisions to Refuse Treatment

Chapter 9

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Chapter 9: Advance Decisions to Refuse Treatment

- 9.1** It is a general principle of law and medical practice that people have a right to consent to or refuse treatment. The Law recognises that adults have the right to say in advance that they want to refuse treatment if they lose capacity in the future, even if this results in their death. It is up to individuals to decide whether they want to refuse treatment in advance. They are entitled to do so if they want, but there is no obligation to do so.
- 9.2** A valid and applicable Advance Decision to Refuse Treatment (ADRT) has the same effect as if the decision was made at the time the treatment is proposed. An ADRT can be made by anyone who is aged 16 or older and has the capacity to do so.
- 9.3** Healthcare professionals must follow an ADRT where it applies to the particular circumstances. If they do not, they could face criminal prosecution or civil liability.
- 9.4** People can only make ADRT to refuse treatment. Nobody has the legal right to demand specific treatment, either at the time or in advance. However, people can make a request or state their wishes and preferences in advance in relation to the type of treatment they would prefer to receive. Nobody can ask for and receive procedures that are against the law.
- 9.5** An ADRT can have serious consequences for the people who make them. They can also have an impact on family, friends and professionals involved in the person's care. Before healthcare professionals apply the ADRT they must satisfy themselves that it exists, is valid and is applicable in the current circumstances.
- 9.6** An ADRT never applies to any decision or treatment whilst a person has capacity to consent or refuse treatment.

Capacity and ADRT

- 9.7** For most people, there will be no doubt about their capacity to make an ADRT. Even those who lack capacity to make some decisions may have the capacity to make an ADRT. In some cases it may be helpful to obtain evidence of a person's capacity to make an ADRT, for example, if there is a possibility that the ADRT may be challenged in the future. It is also important to remember that capacity can change over time, and a person who lacks capacity to make a decision now might be able to make it in the future.
- 9.8** Healthcare professionals should always start from the assumption that a person who has made an ADRT had capacity to make it, unless they are aware of reasonable grounds to doubt the person had the capacity to make the ADRT at the time it was made. If a healthcare professional is not satisfied that the person had capacity at the time they made the ADRT they may wish to seek legal advice as the Court can make declarations on whether an ADRT is valid and applicable to a treatment.

Contents of ADRT

9.9 There are no particular formalities about the format of an ADRT. It can be written or verbal, unless it deals with life-sustaining treatment, in which case it must be written and specific rules apply.

9.10 An ADRT:

- should state what treatments are to be refused
- may set out the circumstances when the refusal should apply – it is helpful to include as much detail as possible
- only applies at a time when the person lacks capacity to consent to or refuse the specific treatment
- does not need to be expressed in medical terms.

9.11 People can use medical language or everyday language in their ADRT. Whichever they choose, they must make it clear what their wishes are and what treatment they would like to refuse.

- 9.12** An ADRT refusing all treatment in any situation, for example, where a person explains that their decision is based on their religion or personal beliefs would be valid and applicable. It may be helpful for people who are thinking about making an ADRT to get advice from healthcare professionals or an organisation that can provide advice on specific conditions or situations. However, it is up to the person whether they want to do this or not. Healthcare professionals should record details of any discussion about ADRT on healthcare records and ensure it is representative of the patient's wishes.
- 9.13** Some people may also want to obtain legal advice. This will support them in making sure that they express their decision clearly and accurately. It will also support in making sure that people understand their ADRT in the future.
- 9.14** If an ADRT is recorded on a patient's healthcare records, it is confidential. Some patients will tell others about their ADRT, others will not. People who do not ask for their ADRT to be recorded on their healthcare record will need to think about where it should be kept and how they are going to let people know about their decision.

Life-sustaining treatment

- 9.15** A written ADRT is necessary to make decisions regarding life-sustaining treatment. A written ADRT will not be applicable to life-sustaining treatment unless:

- it contains a statement by the person that confirms the decisions in the ADRT are to apply to refusal of treatment, even if their life is at risk
- is signed by the person, or by another in the person's presence, on their instruction; and
- the signing is witnessed and the witness signs the ADRT in the person's presence.

- 9.16** It is helpful to discuss an ADRT to refuse life-sustaining treatment with a healthcare professional. However, it is not compulsory. A healthcare professional will be able to explain:

- what types of treatment may be life-sustaining treatment, and in what circumstances
- the implications and consequences of refusing such treatment.

Written ADRTs

9.17 A written document can provide clear evidence of an ADRT. It is helpful to tell others that the document exists and where it is. A person may want to carry it with them in case of emergency, or carry a card, bracelet or other indication that they have made an ADRT and explaining where it is kept if it is not in their medical records.

9.18 A form is available to help with making an ADRT. The form is a suggested format and does not need to be used for a written ADRT. This is because contents will vary depending on a person's wishes and situation. But it is helpful to include the following information:

- full details of the person making the ADRT, including date of birth, home address and any distinguishing features (in case healthcare professionals need to identify an unconscious person, for example)
- the name and address of the person's GP and whether they have a copy of the document
- a statement that the document should be used if the person ever lacks capacity to make treatment decisions
- a clear statement of the decisions, the treatments to be refused and the circumstances in which the decision will apply
- if linked to life-sustaining treatment, a statement that confirms the decisions in the ADRT are to apply to refusal of treatment, even if life is at risk
- the date the document was written (or reviewed)
- the person's signature (or the signature of someone the person has asked to sign on their behalf and in their presence)
- the signature of the person witnessing the signature, if there is one (this is necessary for an ADRT in relation to life-sustaining treatment).

9.19 It is possible that a professional acting as a witness will also be the person who assesses the person's ability to make an ADRT. If so, the professional should also make a record of the assessment, because acting as a witness does not prove that there has been an assessment.

Verbal ADRT's

- 9.20** There is no set format for a verbal ADRT. This is because they will vary depending on a person's wishes and situation. Healthcare professionals will need to consider whether a verbal ADRT exists and whether it is valid and applicable.
- 9.21** Where possible, healthcare professionals should record a verbal ADRT to refuse treatment in a person's healthcare record. This will produce a written record that could prevent confusion about the decision in the future. The record should include:

- a note that the decision should apply if the person lacks capacity to make treatment decisions in the future
- a clear note of the decision, the treatment to be refused and the circumstances in which the decision will apply
- details of someone who was present when the oral ADRT was recorded and the role in which they were present (for example, healthcare professional or family member); and
- whether they heard the decision, took part in it or are just aware that it exists.

Updating an ADRT

- 9.22** Anyone who has made an ADRT is advised to regularly review and update it as necessary. Decisions made a long time in advance are not automatically invalid or inapplicable, but they may raise doubts when deciding whether they are valid and applicable.
- 9.23** A written decision that is regularly reviewed is more likely to be viewed as valid and applicable to current circumstances, particularly for progressive illnesses. This is because it is more likely to have taken on board any changes that have occurred in a person's life since they made their decision.
- 9.24** Views and circumstances may change over time. A new stage in a person's illness, the development of new treatments or a major change in personal circumstances may be appropriate times to review and update an ADRT.

Changing an ADRT

- 9.25** People can cancel or alter an ADRT at any time while they still have capacity to do so. There are no formal processes to follow. People can cancel their decision verbally or in writing, and they can destroy any original written document. Where possible, the person who made the ADRT should tell anybody who knew about their ADRT that it has been cancelled or, if relevant, updated with new information. They can do this at any time.
- 9.26** People can make changes to an ADRT verbally or in writing whether or not the ADRT was made in writing. It is good practice for healthcare professionals to record any change of decision in the person's healthcare notes. If the person wants to change an ADRT to include a refusal of life-sustaining treatment, they must follow the appropriate procedure.
- 9.27** Healthcare professionals should record a verbal cancellation in healthcare records. This then forms a written record for future reference.

ADRT and other decision-making

- 9.28** A valid and applicable ADRT is as effective as a refusal made when a person has capacity. Therefore, an ADRT overrules:

- the decision of any health and welfare attorney appointed before the ADRT was made. So an attorney cannot give consent to treatment that has been refused in an ADRT made after the time LPA was registered
- the decision of any Court appointed delegate
- the provisions of Article 6 of the Law, which would otherwise allow healthcare professionals to give treatment that they believe is in a person's best interests.

- 9.29** An LPA for health and welfare made after an ADRT will make the ADRT invalid, if the LPA gives the attorney the authority to make decisions about the same treatment. However, the attorney would have to justify why they deviated from a written statement of wishes, the ADRT, in their best interests decision-making.

- 9.30** The Court may make declarations as to the existence, validity and applicability of an ADRT, but it has no power to overrule a valid and applicable ADRT.
- 9.31** Where an ADRT is being followed, the best interests principle does not apply. This is because an ADRT reflects the decision of an adult with capacity who has made the decision for themselves. Healthcare professionals must follow a valid and applicable ADRT, even if they think it goes against a person's best interests.

ADRT regarding treatment for mental disorder

- 9.32** An ADRT can refuse any kind of treatment. However, an ADRT for an impairment or disturbance in the functioning of their mind or brain can be overruled if the person is detained in hospital under the Mental Health Law (MHL) for compulsory treatment. ADRT's for other illnesses or conditions are not affected by the fact that the person is detained in hospital under the MHL.
- 9.33** The MHL Codes of Practice highlight the use of Advanced Statements (AS) for recording a person's wishes and preferred treatment for their mental disorder. To be valid and applicable, an AS must be signed by the patient and witnessed by a professional who is involved in the patient's care and treatment for mental health. The witness must sign to confirm the patient's statement was made at a time when they had capacity to determine what is detailed within the statement.
- 9.34** The AS is not legally binding but aims to empower patients, giving a mechanism where their views regarding treatment and care are given due regard, whilst acknowledging that their choices may not be adhered to. It upholds the ethos that people with mental health conditions are equally entitled to control their physical and mental health care.

Determining the existence, validity and applicability of an ADRT

- 9.35** It is the responsibility of the person making the ADRT to make sure their decision will be drawn to the attention of healthcare professionals when it is needed. Some people will want their decision to be recorded on their healthcare records. Those who do not, will need to find other ways of alerting people that they have made an ADRT and where somebody will find any written document and supporting evidence. It is also useful to advise family and friends about an ADRT, as they can tell healthcare professionals.

Deciding whether an advance decision is valid

9.36 An existing ADRT must still be valid at the time it needs to be put into effect. Healthcare professionals must consider the factors in Article 22 of the Law before concluding that an ADRT is valid. Events that would make an ADRT invalid include those where:

- the person withdrew the decision while they still had capacity to do so
- after making the ADRT, the person made an LPA giving an attorney authority to make treatment decisions that are the same as those covered by the ADRT
- the person has done something that clearly goes against the ADRT which suggests that they have changed their mind.

Deciding whether an ADRT is applicable

9.37 To be applicable, an ADRT must apply to the treatment in question and the current circumstances. Healthcare professionals must first determine if the person still has capacity to accept or refuse treatment at the relevant time as an ADRT is only valid when a person lacks capacity to make the treatment decision.

9.38 The ADRT must also apply to the proposed treatment. It is not applicable to the treatment in question if:

- the proposed treatment is not the treatment specified in the ADRT
- the circumstances set out in the ADRT are absent, or
- there are reasonable grounds for believing that there have been changes in circumstance and these would have affected the person's decision if they had known about them at the time they made the ADRT.

Situations where an ADRT is not valid or applicable

9.39 If an ADRT is not valid or applicable to current circumstances healthcare professionals should still consider the ADRT as part of their assessment of the person's best interests if they have reasonable grounds to think it is a true expression of the person's wishes. Written statements would provide reasonable grounds.

ADRT made prior to the Law

9.40 ADRTs made before the Law came into force may still be valid and applicable if they are set out as described in this Code. Healthcare professionals should apply the rules in the Law to ADRTs made before the Law came into force.

Implications of ADRT

9.41 Where appropriate, when discussing treatment options with people who have capacity, healthcare professionals should ask if there are any specific types of treatment they do not wish to receive if they ever lack capacity to consent in the future.

9.42 If somebody tells a healthcare professional that an ADRT exists for a patient who now lacks capacity to consent, the healthcare professional must make reasonable efforts to find out what the decision is.

9.43 If healthcare professionals are satisfied that an ADRT to refuse treatment exists, is valid and is applicable, they must follow it and not provide the treatment refused in the ADRT.

9.44 If healthcare professionals are not satisfied that an ADRT exists that is both valid and applicable, they can treat the person without fear of liability. But treatment must be in the person's best interests. They must make clear notes explaining why they have not followed the ADRT and why they consider it to be invalid or not applicable.

9.45 Professionals can give or continue treatment while they resolve doubts over an ADRT. It may be useful to get information from someone who can provide information about the person's capacity when they made the ADRT. The Court can settle disagreements about the existence, validity or applicability of an ADRT.

ADRT in emergencies

9.46 Healthcare professionals should not delay emergency treatment to look for an ADRT if there is no clear indication that one exists. If it is clear that a person has made an ADRT that is likely to be relevant, healthcare professionals should assess its validity and applicability as soon as possible. Sometimes the urgency of treatment decisions will make this difficult or impossible.

Healthcare professional liability

- 9.47** Healthcare professionals must follow an ADRT if they are satisfied that it exists, is valid and is applicable to their circumstances. Failure to follow an ADRT in this situation could lead to a claim for damages.
- 9.48** Healthcare professionals will be protected from liability for failing to provide treatment if they 'reasonably believe' that a valid and applicable ADRT to refuse that treatment exists.

Disagreement about an ADRT

- 9.49** It is ultimately the responsibility of the healthcare professional who is in charge of the person's care when the treatment is required to decide whether there is an ADRT which is valid and applicable in the circumstances. In the event of disagreement about an ADRT between healthcare professionals, or between healthcare professionals and family members or others close to the person, the decision-maker must consider all the available evidence and make a decision in the person's best interests.

Powers of the Court

- 9.50** The Court can make a decision where there is genuine doubt or disagreement about an ADRT's existence, validity or applicability. The Court does not have the power to overturn a valid and applicable ADRT.
- 9.51** The Law allows healthcare professionals to give necessary treatment, including life-sustaining treatment, to stop a person's condition getting seriously worse while the Court makes a decision.



Chapter 10: Delegates and the role of the Royal Court

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Chapter 10: Delegates and the role of the Royal Court

- 10.1** The Court has overall responsibility for the appointment of delegates where a person does not have capacity in relation to a specific decision and they have not made provision for an attorney of their choice and/or there is no relevant ADRT.

Powers of the Court

- 10.2** The Court can:

- make decisions and orders on financial and welfare matters affecting people who lack, or are alleged to lack, capacity (the lack of capacity must relate to the particular issue being presented to the Court)
- appoint delegates to make decisions for people who lack capacity to make those decisions
- remove delegates or attorneys who act inappropriately.

The Court's powers concerning delegates are set out in Part 4 of the Law.

- 10.3** The Court will also follow the core principles set out in Article 3 of the Law and make the decision in the best interests of the person concerned.

Appointing delegates

- 10.4** However, if there is a need for ongoing decision-making powers and there is no current delegate or LPA, the Court may appoint a delegate to make future decisions. The Court will define and limit the scope of decisions the delegate has the authority to make on the person's behalf, as capacity is decision and time specific. Where possible, the Court should take the decision itself in preference to appointing a delegate.

- 10.5** It is for the Court to decide who to appoint as a delegate. Different skills may be required depending on whether the delegate's decisions will be about a person's health and welfare, their finances or both. The Court will decide whether the proposed delegate is reliable and trustworthy and has an appropriate level of skill and competence to carry out the necessary tasks.
- 10.6** In many circumstances, the delegate is likely to be a family member or someone who knows the person well. In some cases the Court may decide to appoint a delegate who is independent of the family.
- 10.7** Whether a person who lacks capacity to make specific decisions needs a delegate will depend on a number of factors. These may include the specific circumstances relating to the person concerned; whether future or ongoing decisions are likely to be necessary and the nature of the decision or decisions that need to be made.

Property and affairs

- 10.8** The Court may appoint a delegate to manage a person's property and financial affairs. If a person who lacks capacity to make decisions about property and affairs has not made an LPA, applications to the Court will be necessary.
- 10.9** The Court must be satisfied that anybody considered for appointment as a property and affairs delegate is able to manage the person's financial affairs. The delegate must understand the tasks and duties they are appointed to undertake on behalf of the person. The delegate must assure the Court that they have the skills, knowledge and commitment to carry them out.

Health and welfare

- 10.10** Delegates for health and welfare decisions will only be required where:

- important and necessary actions cannot be carried out without the Court's authority, or
- there is no other way of settling the matter in the best interests of the person who lacks capacity to make particular welfare decisions; or
- an individual or individuals seek some scope of decision-making authority for a person's ongoing care and treatment.

Requirements of a delegate

- 10.11** Delegates must be at least 18 years of age. Delegates with responsibility for property and affairs can be either an individual or an organisation. No-one can be appointed as a delegate without their consent.
- 10.12** Paid care workers should not agree to act as a delegate because of the possible conflict of interest. However, the Court can appoint someone who has a professional role within the Department. In this situation, the Court will need to be satisfied that there is no conflict of interest before making such an appointment.
- 10.13** The Court can appoint two or more delegates and state whether they should act 'jointly', 'jointly and severally' or 'jointly in respect of some matters and jointly and severally in respect of others'.
- 10.14** Joint delegates must always act together. They must all agree decisions or actions, and all must sign any relevant documents.
- 10.15** Joint and several delegates can act together, but they may also act independently if they wish. Any action taken by any delegate alone is as valid as if that person were the only delegate.
- 10.16** Delegates may be appointed jointly for some issues and jointly and severally for others. For example, two delegates could be appointed jointly and severally for most decisions, but the Court might rule that they act jointly when selling property.

10

Arrangements when a delegate can no longer carry out their duties

- 10.17** When appointing a delegate, the Court can also appoint someone to be a successor delegate (someone who can take over the delegate's duties in certain situations). The Court will state the circumstances under which this could occur. In some cases it will also state a period of time in which the successor delegate can act. Appointment of a successor delegate might be useful if the person appointed as delegate is already elderly and wants to be sure that somebody will take over their duties in the future.

Protections from financial loss for people lacking capacity

10.18 Under Article 34 (8) of the Law the Court can ask a property and affairs delegate to provide some form of security (for example, a guarantee bond) to cover any loss as a result of the delegate's behaviour in carrying out their role.

Restrictions on a delegate's powers

10.19 Article 35 sets out some specific restrictions on a delegate's powers. In particular, a delegate has no authority to make decisions or take action:

- if they think that the person concerned has capacity to make the particular decision for themselves
- if their decision goes against a decision made by an attorney acting under an LPA granted by the person before they lost capacity
- if their decision goes against a decision made within a valid ADRT made by the person before they lost capacity.

10.20 If a delegate thinks their powers are not enough for them to carry out their duties effectively, they can apply to the Court to change their powers.

10

Responsibilities of delegates

10.21 Once a delegate has been appointed by the Court, they will be directed regarding their specific powers and the scope of their authority. On taking up the appointment, the delegate will assume a number of duties and responsibilities and will be required to act in accordance with certain standards. Failure to comply with the duties set out below could result in the Court revoking the order appointing the delegate and, in some circumstances, the delegate could be personally liable to claims for negligence or criminal charges of fraud or wilful neglect.

10.22 Delegates should always inform any third party they are dealing with that the Court has appointed them as delegate. The Court will give the delegate official documents to prove their appointment.

10.23 A delegate must act whenever a decision or action is needed and it falls within their duties as directed by the Court. A delegate who fails to act at all in such situations could be in breach of duty.

10.24 A delegate appointed to manage property and affairs is expected to keep accounts of all their dealings and transactions on the person's behalf. The Judicial Greffe will set out the reporting standards needed for delegates and when the reports must be submitted.

Duties imposed by the Law

10.25 Delegates must:

- follow the Law's core principles
- make decisions or act in the best interests of the person who lacks capacity without undue delay
- have regard to the guidance in this Code
- only make decisions the Court has given them authority to make.

Other duties of delegates

10.26 Delegates must carry out their duties carefully and responsibly. They have a duty to:

- act with due care and skill
- not take advantage of their situation
- indemnify the person against liability to third parties caused by the delegate's negligence
- not delegate duties
- respect the person's confidentiality, and
- comply with the directions of the Court.

10

Duty of care

10.27 Delegates whose duties form part of their professional work (for example, solicitors or accountants) must display normal professional competence and follow their profession's rules and standards.

10.28 Delegates who are not being paid must use the same care, skill and diligence they would use when making decisions for themselves or managing their own affairs. If they do not, they could be held liable for acting negligently. A delegate who claims to have particular skills or qualifications must show greater skill in those particular areas than a person who does not make such claims.

Finances

10.29 A fiduciary duty means delegates must not take advantage of their position. Nor should they put themselves in a position where their personal interests conflict with their duties. For example, delegates should not buy property that they are selling for the person they have been appointed to represent. They should also not accept a third party commission in any transactions. Delegates must not allow anything else to influence their duties. They cannot use their position for any personal benefit, whether or not it is at the person's expense.

10.30 In many cases, the delegate will be a family member. In rare situations, this could lead to potential conflicts of interests. When making decisions, delegates should follow the Law's core principles and apply the best interests principles and not allow their own personal interests to influence the decision.

10.31 Property and affairs delegates should usually keep the person's money and property separate from their own or anyone else's. This is to avoid any possibility of mistakes or confusion in handling the person's affairs. Sometimes there may be good reason not to do so (for example, where a couple have had a joint account for many years).

No further delegation

10.32 A delegate may seek professional or expert advice (for example, investment advice from a financial adviser or a second medical opinion from a doctor). However, they cannot give their decision-making responsibilities to someone else. The Court can authorise the delegation of specific tasks (for example, appointing a discretionary investment manager for the conduct of investment business).

Confidentiality

10.33 Delegates have a duty to keep the person's affairs confidential, unless:

- before they lost capacity to do so, the person agreed that information could be revealed where necessary
- there is some other good reason to release information (for example, it is in the public interest or in the best interests of the person who lacks capacity, or where there is a risk of harm to the person concerned or to other people).

In the latter circumstances, it is advisable for the delegate to contact Viscount for guidance or get independent legal advice.

10.34 A person may have the capacity to agree to someone seeing their personal information, even if they do not have the capacity to make other decisions. If someone lacks the capacity to decide, someone with appropriate authority might still be able to see their personal information such as an attorney.

10.35 Delegate's powers are limited by the Court and any delegate seeking information about a person must ensure that they have appropriate authority to access records. If they have any doubt and need to access records to carry out their duties, they should ask the Court for this authority.

10.36 An information holder should not release information if doing so would cause serious physical or mental harm to anyone – including the person the information is about. This applies to information on health, social care and education records.

10.37 The Information Commissioner's Office can give further details on:

- how to request personal information
- restrictions on accessing information, and
- how to appeal against a decision not to release information.

10.38 A delegate must treat the information confidentially. They should be extremely careful to protect it. If they fail to do so, the Court can end the role of the delegate.

Changes of contact details

10.39 A delegate should inform the Judicial Greffe of any changes of contact details or circumstances (for the delegate or the person they are acting for). This will make sure the Judicial Greffe has up-to-date records.

Supervision

10.40 Delegates are accountable to the Court. The Court can cancel a delegate's appointment at any time if it decides the appointment is no longer in the best interests of the person who lacks capacity.

10.41 The Viscount is responsible for supervising and supporting delegates. However, it must also protect people lacking capacity from possible abuse or exploitation. Anybody who suspects that a delegate is abusing their position should contact the Viscount immediately.

10.42 The Viscount will consider carefully any concerns or complaints against delegates. If somebody suspects physical or sexual abuse or serious fraud, they should contact the police and/or social services immediately, as well as informing the Viscount.

10

Other roles of the Court

10.43 In most cases concerning health and welfare matters, the core principles of the Law and best interest processes will be sufficient in order to:

- support people to take action or make decisions in the best interests of someone who lacks capacity to make decisions about their own care or treatment, or
- find ways of settling disagreements about such actions or decisions.

10.44 An application to the Court may be necessary for:

- particularly difficult decisions
- disagreements that cannot be resolved in any other way, or
- situations where ongoing decisions may need to be made about the personal welfare of a person who lacks capacity to make decisions for themselves.

10.45 There will be a process for curators appointed by the Court before the Law commenced to become delegates. They will keep equivalent powers and duties. However, they will have an additional responsibility to consider the person's capacity. They must meet the requirements set out in the Law and, in particular, follow the core principles in relation to the best interests of the person for whom they have been appointed. They must also have regard to guidance in this chapter and other parts of the Code.

Making the application

10.46 The person making the application will vary, depending on the person's circumstances. Article 25 of the Law provides further details in respect of who may be eligible to make an application to the Court for a decision or to be appointed as a delegate.

10.47 The applicant will usually be the individual who needs specific authority from the Court to make decisions on behalf of the person. This will normally be immediate family or someone in an existing relationship with the person.

10.48 An ICA can make an application to the Court regarding decisions around significant restriction on liberty. This may be in relation the authorisation or with a view to appointing a delegate for the person.

10.49 For cases about serious or major decisions concerning medical treatment, where there is no attorney, the hospital or other organisation responsible for the patient's care will be required to seek permission of the Court to make an application or make representations to the Attorney General to do so on their behalf.

10.50 The Law also allows others to make applications. However, where the link to the person is less clear, they must seek the permission of the Court to make the application. The following determinations will be used to consider whether to admit the application:

- the applicant's connection to the person the application is about
- the reasons for the application
- whether a proposed order or direction of the Court will benefit the person the application is about, and
- whether it is possible to obtain that benefit another way.

Significant restrictions on liberty

10.51 In some circumstances the Court will hear cases involving significant restriction on liberty. This may be to determine whether a significant restriction on liberty is in effect or to review and authorise a significant restriction on liberty in circumstances where the Minister cannot.

Significant restrictions on liberty of children aged under 16

10.52 In some circumstances the Court will hear cases involving children under 16 years old. The Law does not cover significant restrictions on liberty for people under 16 years old and it may be necessary to use the inherent jurisdiction of the Court to review and authorise their care and or treatment. This is an additional safeguard for children. There are more details on children and inherent jurisdiction in chapter 11.

Decisions of the Court

10.53 Article 24 of the Law provides the Court with powers to make decisions on specific issues. The Court will require evidence of any assessment of the person's capacity and may wish to see relevant written documentation. If the Court decides the person has capacity to make that decision, they will not take the case further. The person can now make the decision for themselves.

10.54 Applications concerning a person's capacity are likely to be rare. However, an application may be relevant if:

- a person wants to challenge a decision that they lack capacity
- there is unresolvable disagreement about a person's capacity to make a specific (usually serious) decision.

10.55 The Court can also make a decision as to whether a specific act relating to a person's care or treatment is lawful. This can include an omission or failure to provide care or treatment that the person needs. Healthcare staff can still give life-sustaining treatment, or treatment which stops a person's condition deteriorating while the Court is coming to a decision.

Serious healthcare and treatment decisions

10.56 Cases involving serious healthcare and treatment decisions can be brought before the Court where there is a doubt or dispute about whether a particular treatment will be in a person's best interests.

10.57 Cases involving medical procedures being performed on a person who lacks capacity and cannot consent, but which would benefit a third party, may also be referred to the Court. Sometimes such procedures may be in the person's overall best interests.

10.58 Non-therapeutic sterilisation is the sterilisation for contraceptive purposes of a person who cannot consent. Such cases will require a careful assessment of whether such sterilisation would be in the best interests of the person who lacks capacity and such cases should be referred to the Court.

10.59 Other cases likely to be referred to the Court include those involving ethical dilemmas in untested areas, or where there are otherwise irresolvable conflicts between healthcare staff, or between staff and family members.

Other decisions the Court can make

10.60 In cases of serious dispute, where there is no other way of finding a solution or when the authority of the Court is needed in order to make a particular decision or take a particular action, the Court can be asked to make a decision to settle the matter using its powers under Article 24.

10.61 The Court can determine any questions as to the meaning or effect of a person's LPA, where there is any doubt.

10.62 In some cases, the Court will make a decision, because someone needs specific authority to act and there is no other route for getting it. These include cases where:

- there is no delegate or property and affairs LPA in place and someone needs to make a financial decision for a person who lacks capacity to make that decision, or
- it is necessary to make a will, or to amend an existing will, on behalf of a person who lacks capacity to do so.

10.63 Anyone carrying out actions under a decision of the Court must still also follow the Law's principles.

Section 3: Capacity and liberty

Why read this section?

This chapter details the requirements under the Law to uphold the human rights of a person who lacks capacity in situations where there is significant interference of their rights through the care and treatment provided to them. The primary focus is addressing significant restriction on liberty, but encompasses any restrictions on a person's human rights.



Chapter 11: Significant Restrictions on Liberty

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Chapter 11: Significant Restrictions on Liberty

Significant restriction on liberty

- 11.1** Part 5 of the Law deals with restrictions on liberty for people who lack capacity. It defines restrictions on liberty and provides safeguards when these become significant. Article 5 of the European Convention on Human Rights (ECHR) talks of 'deprivation' of liberty and in Jersey significant restriction on liberty should be taken to have the same meaning.
- 11.2** Every effort should be made, in both commissioning and providing care and treatment, to prevent significant restriction on liberty. If significant restriction on liberty cannot be avoided, it should be for no longer than is necessary and authorised.

11

Some definitions

- 11.3** The safeguards allow significant restrictions on liberty to be made lawful through 'standard' or 'urgent' authorisation processes. Authorisations are designed to prevent arbitrary decisions that deprive a person of their liberty. The safeguards also provide a right to review of authorisations.
- 11.4** The term 'authorisation' for a significant restriction on liberty means that the manager of a relevant place, such as a care home or hospital, must seek authorisation from the Minister in order to be able lawfully to restrict a person's liberty. Before giving an authorisation, the Minister must be satisfied that the person is unable to make a decision about residence or treatment in the setting because they suffer from an impairment or disturbance in the functioning of the mind or brain, which prevents them making the decision.

- 11.5** A decision as to whether or not significant restriction on liberty arises will depend on all the circumstances. It is neither necessary nor appropriate to apply for authorisation for everyone who is in hospital or a care home simply because the person concerned lacks capacity to decide whether or not they should be there. In deciding whether or not an application is necessary, the manager should carefully consider whether any restrictions that are, or will be, needed to provide ongoing care or treatment amount to a significant restriction on liberty when looked at altogether.
- 11.6** People receive care and treatment in a variety of settings. Where the Department provides or commissions services there is a responsibility to ensure that any known significant restrictions on liberty are authorised.

Safeguards

- 11.7** Authorisations apply to people in Jersey who lack capacity to consent to the arrangements made for their care or treatment because they have an impairment or disturbance in the functioning of the mind or brain. An application is likely to be required when such arrangements amount to a significant restriction on liberty. Such restrictions must be necessary to protect the person from harm, be in their best interests and the least restrictive approach.
- 11.8** There will be occasions when people who lack capacity to consent to admission are taken to hospital for treatment of physical illnesses or injuries and then need to be cared for in circumstances that amount to a significant restriction on liberty. In these circumstances, a significant restriction on liberty authorisation must be applied for.
- 11.9** An authorisation of a significant restriction on liberty cannot be used to enable treatment for a medical condition. A person may be treated with their agreement if they have capacity to consent to treatment. If they lack such capacity, treatment can only be given through the use of a best interest decision, a legal decision-maker (such as an attorney or delegate), or an order issued by the Court.
- 11.10** An authorisation cannot apply to people while they are detained in hospital under the Mental Health Law (MHL) for either a period of assessment or treatment. In such cases the authority provided by the MHL is likely to be sufficient to treat them unless treatment is also required for a physical condition. The MHL cannot be used to treat any non-mental health conditions, such as physical health conditions.

11.11 Authorisations can only be made in relation to people aged 16 and over. If the issue of restricting the liberty of a person under the age of 16 arises, other safeguards must be considered. This would be under the inherent jurisdiction of the Court.

The Law and children

11.12 There are lawful processes that can authorise significant restrictions on liberty for a child, such as a secure accommodation order or criminal court proceedings. This Law can only be used for people aged 16 and over, and cannot be used for authorisation of restrictions on a child's liberty and freedom. However, best practice and human rights case law highlight the need for oversight and legal authorisation for significant restrictions on liberty for children for whom the Department is directly involved in funding or meeting treatment and care needs.

11.13 Significant restrictions on liberty are likely to be in place when a person is under continuous supervision and control and not free to leave a place. The application of this is more complex with those under 16 years old as they require supervision and control, with additional restrictions placed on their freedom of movement for both safety and boundary setting. When considering significant restrictions on liberty for children under 16 years old, it is important to focus on whether the child is confined in a particular place.

11.14 The following suggestions are a 'rule of thumb' when considering whether confinement is a factor in a child's care:

- a child aged 10 or under, even if under almost continuous supervision, is unlikely to be viewed as confined
- a child aged 11, if under continuous supervision may be considered as confined
- a child aged 12 or over, who is under continuous supervision should be considered confined.

11.15 It is also important to consider the confinement of a child in a developmental context. The restrictions should be compared against a child of the same age, station, familial background and relative maturity who is free from disability. The comparison is not with other children on care orders but children in the wider community.

- 11.16** The presence of confinement may mean that the child's care amounts to a significant restriction on liberty and an assessment must be undertaken. If the care amounts to a significant restriction on liberty, this must be authorised with valid consent from someone with parental responsibility, if appropriate, or by the Court.
- 11.17** It is understood that those with parental responsibility supervise children and exercise a degree of control on a child's choices and actions. This supervision and control normally lessens as a child develops and matures. Therefore, there are circumstances in which the valid consent of someone with parental responsibility will allow the confinement of a child under 16 years old. Circumstances where this may be appropriate are not unlimited.
- 11.18** When a child is subject to an interim or final care order, neither the Minister nor a parent can exercise parental responsibility to provide valid consent for the confinement of the child. Where the placement of a child who is subject to an interim or final care order involves confinement, the Court must authorise this using inherent jurisdiction.

Restricting liberty

- 11.19** Restricting a person's liberty is a serious matter and the decision to do so should not be taken lightly. Part 5 of the Law makes it clear that such an authorisation should only be granted if:

- it is in a person's best interests to protect them from harm
- it is a proportionate response to the likelihood and seriousness of the harm, and
- there is no less restrictive alternative.

11

Identifying significant restriction on liberty

- 11.20** A restriction on liberty becomes significant at the point where the degree or intensity of the restriction conflicts with a person's right to liberty as described under ECHR Article 5(1). The ECHR states that everyone is entitled to liberty and security of person. The ECHR also states that no-one should be deprived of their liberty unless this has been lawfully sanctioned. In Jersey, for people aged 16 and over, a significant restriction on liberty can only be lawful when it is authorised by the Minister or the Court.

11.21 A straightforward way of deciding whether a significant restriction exists is to ask whether their care or treatment plan means:

- the person is under continuous supervision and control; and
- the person is unable to leave where they live.

When considering whether a person is unable to leave, this is not related to their requests or actions to leave, but whether someone caring for them would stop them from doing so.

11.22 For quick reference the following factors should be considered:

- What measures are being taken in relation to the individual? When are they required? For what period do they endure? What are the effects of any restraints or restrictions on the individual? Why are they necessary? What aim do they seek to meet?
- What are the views of the person, their family and/or carers? Do any of them object to the measures?
- How are any restrictions implemented?
- Are there any less restrictive options for delivering care or treatment that avoid significant restriction on liberty altogether?
- Does the cumulative effect of restrictions imposed on the person amount to a significant restriction on liberty, even if individually they would not?

11.23 Under no circumstances must significant restrictions on liberty authorisations be used as a form of punishment or for the convenience of professionals, carers or anyone else. Significant restriction on liberty should not be extended due to delays in moving people between care or treatment settings, for example when somebody awaits discharge after completing a period of hospital treatment.

Examples of significant restriction on liberty

11.24 The difference between significant restriction on liberty and restriction upon liberty is one of degree or intensity.

11.25 Although there is no single definition of a significant restriction, the Law defines some areas which may amount to a significant restriction on liberty if applied to a person on a regular basis. These are as follows:

- the person is not permitted to leave the relevant place unaccompanied
- the person is unable to leave the relevant place unassisted and such assistance as may be reasonably provided to assist the person is not provided
- the person's freedom of movement in the relevant place is controlled so as to limit their access to only part of that place
- the person's actions are so controlled (whether or not in the relevant place) through the use of physical force and/or restraint
- the person is subject (whether or not in the relevant place) to continuous supervision
- the person's social contact (whether or not in the relevant place) with people other than those employed to work in the relevant place, is restricted.

11.26 Blanket restrictions such as a key pad on the main entrance of the relevant place which is for the benefit of the safety of all people residing in the relevant place should not be regarded as a significant restriction provided that it does not unduly impact upon a specific individual.

11.27 A person who has a physical impairment which makes it impossible for them to leave a relevant place without support, should not be viewed as being significantly restricted provided that any limit to the time or duration of assistance for them to do so is not excessive or unreasonable.

11

Cultural considerations

11.28 The significant restriction on liberty authorisations should not impact in any different way on minority ethnic groups and care should be taken to ensure that the provisions are not operated in a manner that is discriminatory. It is the responsibility of the manager of the relevant place to ensure that their staff are aware of their responsibilities in relation to anti-discriminatory service delivery.

- 11.29** Assessors who undertake Capacity and Liberty Assessments to decide whether a person is experiencing a significant restriction on liberty should have the necessary skills and experience to take account of people's diverse backgrounds. Accordingly, they will need to have an understanding of, and respect for, the background of the person.
- 11.30** If needed, interpreters must be available to help assessors to communicate not only with the person, but also with those people who have an interest in the person's care and treatment. An interpreter should be suitably qualified and experienced to enable them to provide effective language and communication support in the particular circumstances and to offer appropriate assistance to the assessors involved. Information should be made available in other languages and formats, where relevant.

Significant restrictions on liberty in other settings

- 11.31** The Human Rights (Jersey) Law 2000, places a duty on public authorities to act in accordance with human rights, detailed in the ECHR. However, everyone is subject to this Law and should be guided by this Code.
- 11.32** There are two relevant ways in which public authorities have responsibility to protect people from unlawful significant restrictions on liberty. The first is to prevent direct significant restrictions experienced through the public authorities care or treatment. This is called the public authorities 'negative' obligation. The second is its 'positive' obligation to intervene to protect people from significant restrictions on liberty by private persons or organisations. These include private providers of care as well as family and friends.
- 11.33** This means where a public authority becomes aware that the care and treatment of a person who lacks capacity is significantly restricting liberty, they have a duty to carry out enquiries, even if in a private residence, and look to uphold the person's human rights. This would normally be achieved by assessing and seeking authorisation for any necessary and proportionate significant restrictions on liberty.

The importance of a process to significantly restrict a person's liberty

- 11.34** It is acknowledged that usually when restrictions are put in place, it is to protect and safely meet the needs of people who access services. A person who has the capacity to consent to any restrictions may do so with an understanding of the need for such restrictions and also have the opportunity to challenge any restrictions when they feel they are unjust, disproportionate or service led.
- 11.35** A person without capacity to consent to such care or treatment may not have the same understanding of restrictions imposed in relation to care or treatment. Part 5 of the Law is designed to guide carers, professionals and service providers who support or deliver services for people without capacity, to ensure that their actions remain lawful in upholding the rights of the person receiving care, as if that person were able to do so for themselves.

Positive risk taking

- 11.36** Positive risk taking is weighing up the potential benefits and risks of a choice or decision. Whilst this can be more easily undertaken by people for themselves, it can prove daunting to do so for another. Whilst risk can never be entirely eliminated, considered risk taking can have many positive outcomes for an individual. Part 5 of the Law is not intended to discourage positive risk taking that would be beneficial and in the best interests of a person who lacks capacity.

Practical steps to reduce SRoL

- 11.37** The European Court on Human Rights and UK courts have determined a number of cases about significant restriction on liberty. Their judgments indicate that the following factors can be relevant to identifying whether steps taken are greater than restriction, instead amounting to a significant restriction on liberty. It is important to remember that the following list is not exhaustive, other factors may arise in future in particular cases:

- Restraint is used, including sedation, to admit a person to an institution where that person is resisting admission

- Staff exercise complete and effective control over the care and movement of a person for a significant period
- Staff exercise control over assessments, treatment, contacts and residence
- A decision has been taken by the institution that the person will not be released into the care of others, or permitted to live elsewhere, unless the staff in the institution consider it appropriate
- A request by carers for a person to be discharged to their care is refused
- The person is unable to maintain social contacts because of restrictions placed on their access to other people
- The person loses autonomy because they are under continuous supervision and control.

11.38 There are many ways in which providers and commissioners of care can take steps to reduce the likelihood of a significant restriction on liberty occurring, by minimising the restrictions imposed and ensuring that decisions are taken with the involvement of the person and their family, friends and carers. The processes for staff to follow are:

- make an assessment of whether the person lacks capacity to decide whether or not to accept the care or treatment proposed, in line with the principles of the Law
- make sure that all decisions are taken (and reviewed) in a structured way, and reasons for decisions recorded
- follow established good practice for care planning
- before admitting a person to hospital or residential care in circumstances that may amount to a significant restriction on liberty, consider whether the person's needs could be met in a less restrictive way
- take proper steps to help the person retain contact with family, friends and carers
- review the care plan on an ongoing basis. It may well be helpful to include an independent element, possibly via an advocacy service, in the review.

Considering SRoL

- 11.39** The manager in a relevant place has responsibility for applying for authorisation for any person who lacks capacity and who is experiencing a significant restriction of their liberty through their care planning and/or service delivery.
- 11.40** If a healthcare or social care professional thinks that an authorisation is needed, they should inform the manager of the relevant place or a family member if the care is provided at home. This might be as a result of a care review or needs assessment but could happen at any other time too.
- 11.41** The Minister is responsible for considering requests for authorisations, requesting assessment and where the assessments indicate, authorising the significant restriction on liberty.
- 11.42** There are two types of authorisation: standard and urgent. A manager must request a standard authorisation when it appears likely that, at some time during the next 28 days, someone will be accommodated in the relevant place in circumstances that amount to a significant restriction on liberty.
- 11.43** Whenever possible, authorisation should be obtained in advance. Where this is not possible, and the manager believes it is necessary to significantly restrict a person's liberty in their best interests before the standard authorisation process can be completed, the manager must immediately request an urgent authorisation.

Applying for authorisation

- 11.44** Relevant places must have a procedure in place that identifies:

- whether significant restriction on liberty is or may be necessary in particular circumstances
- whether they have taken all practical and reasonable steps to avoid a significant restriction on liberty
- how they should review cases where authorisation needs to be renewed.

Application process

11.45 A manager must apply for any authorisations. The application should be made to the Minister, as prescribed.

11.46 In addition, where available, the request for a standard authorisation can also include the following information:

- any medical information relating to the person's health that the relevant place reasonably considers to be pertinent to the proposed significant restrictions on liberty
- any diagnosis of mental disorder, impairment or a disturbance in the functioning of the mind or brain
- any relevant care plans and needs assessments
- whether the person has any special communication needs
- whether the person is subject to any requirements of the Mental Health Law.

11.47 The request must be made to the Minister through the Administrator. The relevant place must keep a record of each request made for authorisation and the reasons for making the request.

11.48 The relevant place should tell the person, their significant others or any ICA already involved that an application for an authorisation has been undertaken. It is good practice to include anyone who is caring for the person or who has been named by them. This should be followed in writing.

11.49 The relevant place must notify the Minister if it believes that there is no one who could be consulted in determining the person's best interests, except those providing care and treatment for the person in a professional capacity or for remuneration. In such circumstances an ICA will be required.

11.50 When an application for authorisation is received, the Minister must consider whether the request is appropriate and should be pursued. If the Minister has any doubts about proceeding with the request, they should seek to resolve them with the relevant place.

- 11.51** A standard authorisation comes into force when it is given or at any later time specified in the authorisation. Applications can be made 28 days in advance in order that authorisations can be sought as part of care planning.
- 11.52** If the Minister considers that an application for an authorisation has been made too far in advance, the matter should be raised with the manager. The outcome may be an agreement with the manager that the application should be withdrawn and be resubmitted at a more appropriate time. Authorisation requests should not be made too far in advance as this may prevent an assessor from making an accurate assessment of what the person's circumstances will be at the time the authorisation will come into effect.

Referral to an ICA

- 11.53** When there is nobody appropriate to consult, other than people engaged in providing care or treatment for the person in a professional capacity or for remuneration, the manager must notify the Minister when they submit an application for the authorisation of a significant restriction on liberty.
- 11.54** The manager must also make a referral for an ICA to represent the person. It is particularly important that the ICA is instructed quickly if an urgent authorisation has been given, so that they can make a meaningful input at a very early stage in the process. There is a chapter in this Code regarding the role of an ICA.

11

Assessments

- 11.55** Once the Minister has confirmed that the request for an authorisation should be pursued, all relevant assessments must be undertaken.
- 11.56** The assessment process will comprise of six elements:

Age

The person must be aged 16 or older. If there is any doubt a full age assessment must be carried out.

Mental Health

This is undertaken by an Approved Practitioner to establish whether a mental disorder is present as defined in the MHL. It should also encompass a view on whether the proposed restrictions would adversely impact on the person's mental health.

Eligibility

This is to establish whether the person is being treated or should be treated instead under the MHL.

Capacity

This is to establish whether a person lacks the ability to make the decision about the treatment or care in the place that is applying for the authorisation because of an impairment or disturbance of mind or brain that is affecting decision-making.

No Refusals

This is to establish whether there are any legal decisions-makers whose views might conflict with the authorisation of significant restriction. This might be in the format of an ADRT or a person who is an attorney or delegate for health and welfare.

Best Interests

This is to ensure what is being proposed is in the person's best interests in line with Article 6 of the Law.

11

11.57 The six elements of the two assessments are always completed by a minimum of two professionals. These would normally be a Capacity and Liberty Assessor (CLA) and an Approved Practitioner (AP). However, in some circumstances the mental health elements may be completed by another mental health professional with appropriate training.

11.58 Both the CLA and AP must be independent from the person requiring assessment. Assessors cannot be viewed as independent if they:

- care for or treat the person they will be assessing
- have personal relationship to the person requiring assessment, to the manager or to other individuals directly involved in the person's care or treatment.

- 11.59** Where there has been previous professional involvement by the CLA or AP with the person or any other potential conflict of interest, this must be discussed with the Administrator or other designated person. A decision will be made on how to proceed with the assessment, with the rationale for this clearly recorded.
- 11.60** Assessments must be completed within 21 days of allocation to the assessor for a standard authorisation. Where an urgent authorisation has been given, this must be before the urgent authorisation expires in 28 days.

Authorisation

- 11.61** Where the Minister authorises the SRoL they will contact the assessor and the manager of the relevant place. This will summarise the outcome of the decision. It will detail:

- the person's name
- manager's name and the name of other professionals who are involved
- the authorisation date and duration
- the nature and extent of the restrictions which are authorised
- any conditions or directions that are to be adhered to in order to allow the authorisation.

- 11.62** The Minister cannot amend the assessment or request that any professional change their viewpoint. However, the Minister is not bound by the recommendations made by the assessor in relation to SRoL and may choose to authorise restrictions that are different to those proposed. For example, where there is a significant divergence in view between the assessor and an ICA, the Minister may decide on the conditions of the authorisation based on all available information.

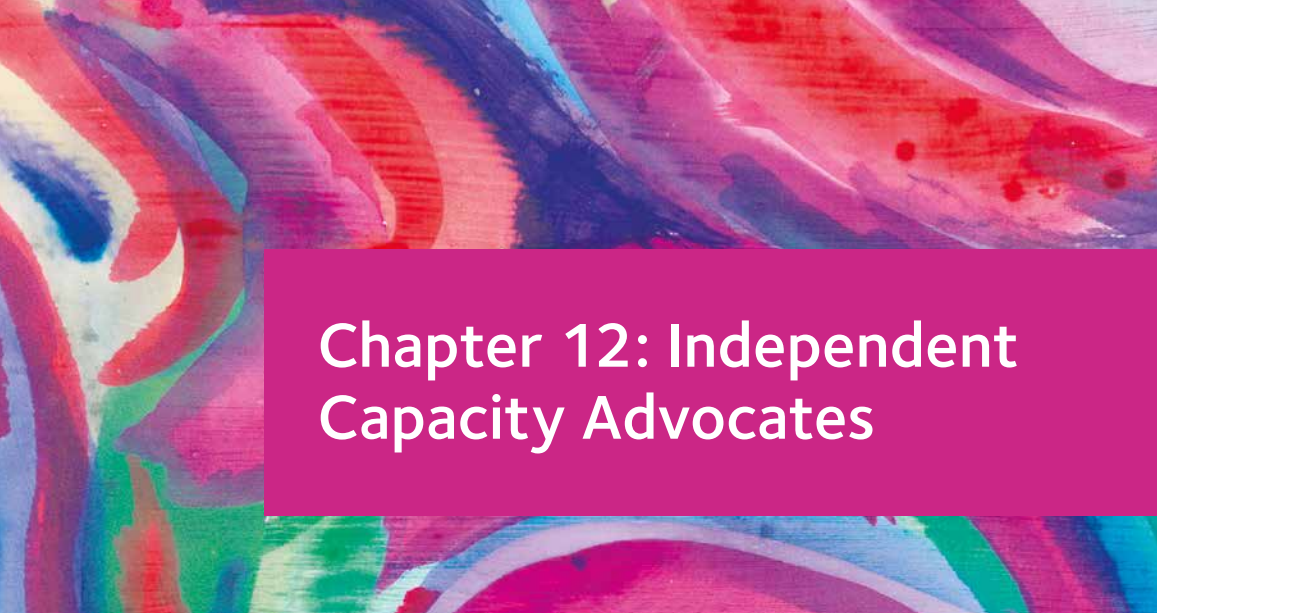
Refusals

- 11.63** There are circumstances when the authorisation needs to be referred directly to the Court by the Capacity and Liberty Assessor. This would be when the person who lacks capacity is objecting to the arrangements for their care, either verbally or by behaviour, or both. This is taken as an indication that they are objecting and would wish to apply to the Court if they had the capacity to ask.
- 11.64** Attorneys and delegates may also refuse to agree to care or treatment that amounts to a significant restrictions on liberty on behalf of the person. In these circumstances, the assessor would not proceed with Ministerial authorisation and the decision would need to be referred to the Court.
- 11.65** When a person has no other representatives an ICA is appointed. An ICA has the same rights to challenge a decision as any other person caring for the person or interested in her welfare. If the ICA is in disagreement with the proposed authorisation and this cannot be resolved, they can request that the Minister refer the decision to the Court for a determination.
- 11.66** The Court has the final decision-making authority to refuse or agree to care or treatment that amounts to significant restrictions on liberty on behalf of the person that lacks capacity. In relation to significant restrictions on liberty, the Court can override the decision of an attorney and delegate.
- 11.67** The Court cannot override a valid ADRT that refuses a specific treatment that would amount to a significant restriction on liberty.

Section 4: Safeguards under the Law

Why read this section?

These chapters introduce statutory safeguards for people who lack capacity in addition to those already present elsewhere in the Law. The safeguards offer extra checks and balances to those most in need of them. The statutory nature of the safeguards gives their application both weight and consequence in upholding the human rights of a person who lacks capacity.



Chapter 12: Independent Capacity Advocates

Chapter 12

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Chapter 12: Independent Capacity Advocates

The ICA service

12.1 The Law makes provision for an Independent Capacity Advocate (ICA) service that provides safeguards for people who lack capacity to make certain decisions at the time they need to be made if they have nobody else who is willing and appropriate to represent them in working out their best interests. These specific decisions are:

- change of long-term accommodation
- serious medical treatment, and
- requesting authorisation of a significant restriction on liberty.

12.2 Relevant professionals supporting a person in the circumstances detailed above should request an ICA at the earliest opportunity, preferably as soon as they are aware that a decision will need to be made.

12.3 The ICA will:

- be independent of the person making the decision
- provide support for the person who lacks capacity
- represent and support the person without capacity in discussions to work out whether the proposed decision is in the person's best interests
- raise questions or challenge decisions which appear not to be in the best interests of the person.

12.4 The information the ICA provides should be taken into account by decision-makers whenever they are working out what is in a person's best interests.

12.5 ICAs have a different role from other types of advocates. They:

- provide a statutory advocacy role
- are instructed to support and represent people who lack capacity to make decisions only on specific issues
- have a right to meet in private the person they are supporting
- are allowed access to records relevant to the decision (in line with information-sharing protocols and principles of confidentiality)
- provide support and representation specifically while the decision is being made, and
- act in a timely manner so their report can form part of decision-making.

12.6 The ICA is a professional role and the Law requires them to have relevant experience and to act with integrity on behalf of a person who lacks capacity to make a decision. The Law provides regulations around the recruitment and employment of ICAs. The purpose of these are to enhance safeguards for vulnerable people and allow the Minister to act to protect people if there are any valid concerns regarding an ICA.

12.7 ICAs must be independent. An ICA cannot be viewed as independent if they:

- care for or treat the person they will be representing
- have personal relationship to the person instructing them, to the decision-maker or to other individuals involved in the person's care or treatment
- have had previous professional involvement with the person, unless the involvement was in their role as an advocate.

- 12.8** Where there has been previous professional involvement by the ICA with the person or any other potential conflict of interest, this must be discussed with the ICA's manager or other designated person. A decision will be made on how to proceed, with the rationale for this clearly recorded. This must also be shared with the best interests decision-maker. If the decision-maker has concerns regarding the involvement, these should be shared with the ICA's manager in the first instance.

The Role of the ICA

- 12.9** The ICA must decide how best to represent and support the person who lacks capacity that they are supporting. They:

- must provide support to the person so they can participate as fully as possible in any decisions regarding their best interests
- should obtain and evaluate relevant information to support the best interests decision-making process
- should work out a viewpoint on what the person's likely wishes and feelings would be in relation to the decision if they had capacity
- must try to determine what the person's beliefs and values were
- should obtain the views of professionals and paid workers providing care or treatment for the person who lacks capacity
- should obtain the views of anybody else who can give information about the wishes and feelings, beliefs or values of the person who lacks capacity
- should consider whether getting another medical opinion would help in deciding about a proposed medical treatment
- must write a report on their findings for the Department, and
- must act in accordance with the principles of the Law and take account of relevant guidance in the Code.

- 12.10** Where possible, decision-makers should make decisions based on a full understanding of a person's known past and present wishes. The ICA should provide the decision-maker with as much of this information as possible and anything else they believe to be relevant. The report they provide to the decision-maker may include questions about the proposed action or may include proposed alternatives, if their analysis suggests that these would also be in the person's best interests.

Representing and supporting the person who lacks capacity

- 12.11** The ICA may wish to use specialist support in communicating with the person, this could be a translator or speech and language therapist. The ICA will have the same access to communication resources as the decision-maker.
- 12.12** The ICA may discover information to suggest a person might regain capacity in the future, either so they can make the decision themselves or be more involved in decision-making. In such a situation, the ICA can ask the decision-maker to delay the decision, if it is not urgent.
- 12.13** The ICA will need to get as much information as possible about the person's wishes, feelings, beliefs and values – both past and present. They should also consider the person's religion, cultural factors and any political and ethical positions that may influence the decision. The ICA should see the person as an individual with their own values, likes and dislikes in order to consider their best interests.
- 12.14** Sometimes an ICA might not be able to obtain a detailed understanding of what the person might want. In such instances the ICA should still try to make sure the decision-maker considers all relevant information by:
- raising relevant issues and questions
 - providing additional, relevant information to support the final decision
 - finding and evaluating information.
- 12.15** In some instances there may not be sufficient time to instruct an ICA (for example in an emergency). If this is the case, this should be recorded, with the reason an ICA has not been instructed. Where the decision concerns a move of accommodation, the Department must appoint an ICA as soon as possible afterwards.

‘Appropriate to Consult’

12.16 The ICA is a safeguard for those people who lack capacity, who have no-one close to them who ‘it would be appropriate to consult’. The safeguard is intended to apply to those people who have little or no network of support, such as close family or friends, who would take an interest in their welfare or no-one willing or able to be formally consulted in decision-making process.

12.17 There may be situations where a person who lacks capacity has family or friends, but it is not practical or appropriate to consult them. For example, an elderly person with dementia may have an adult child who now lives in Australia, or an older person may have relatives who very rarely visit. Similarly a family member may simply refuse to be consulted.

Powers of the ICA

12.18 Article 62 (3) provides ICAs with specific powers to enable them to carry out their duties. These are:

- the right to interview the person in private, and
- the right to examine, and take copies of, any records relevant to the decision (access to such documents will be in line with information-sharing protocols and principles of confidentiality).

12.19 The ICA needs to satisfy themselves that their instructions are given by an authorised person. This would normally be a care home manager or relevant healthcare or social care professional.

12.20 The ICA may also need to meet professionals or paid carers providing care or treatment for the person who lacks capacity. The ICA can also comment on possible alternative courses of action. Ultimately, it is the decision-maker’s responsibility to decide whether a proposed course of action is in the person’s best interests.

Considering alternative courses of action

12.21 The ICA will need to reflect on whether the decision-maker has considered all practicable options. They should also consider whether the proposed option is the least restrictive of the person’s rights or future choices.

12.22 The ICA may wish to discuss possible options with other professionals or paid carers directly involved in providing care or treatment for the person. However they must at all times respect the confidentiality of the person they are representing.

12.23 The ICA may consider seeking a second medical opinion from a doctor with appropriate expertise when considering decisions regarding serious medical treatment.

Decisions about serious medical treatment

12.24 Where a serious medical treatment decision is being considered for a person who lacks the capacity to consent, and who qualifies for additional safeguards, Article 64 of the Law imposes a duty on the Department to instruct an ICA. The Department must instruct an ICA whenever it is proposing to take a decision about 'serious medical treatment', or proposing that another organisation (such as a private hospital) carries out such treatment on its behalf, if:

- the person concerned does not have the capacity to make a decision about the treatment, and
- there is no-one appropriate to consult about whether the decision is in the person's best interests, other than paid care staff.

12.25 Serious medical treatment is defined as treatment which involves giving new treatment, stopping treatment that has already started or withholding treatment that could be offered in circumstances where:

- if a single treatment is proposed there is a fine balance between the likely benefits and the burdens to the patient and the risks involved
- a decision between a choice of treatments is finely balanced, or
- what is proposed is likely to have serious consequences for the patient.

12.26 'Serious consequences' are those which could have a serious impact on the patient, either from the effects of the treatment itself or its wider implications. This may include treatments which:

- cause serious and prolonged pain, distress or side effects
- have potentially major consequences for the patient (for example, stopping life-sustaining treatment or having major surgery such as heart surgery), or
- have a serious impact on the patient's future life choices (for example, interventions for ovarian cancer).

12.27 Decision-makers who are not sure whether they need to instruct an ICA should consult their line manager or seek legal advice.

12.28 The only situation in which the duty to instruct an ICA need not be followed, is when an urgent decision is needed (for example, to save the person's life). This decision must be recorded with the reason for the non-referral. The Department will however still need to instruct an ICA for any serious treatment that follows the emergency treatment.

12.29 While a decision-maker is waiting for the ICA's report, they must still act in the person's best interests (for example, to give treatment that stops the person's condition getting worse).

12.30 Some decisions about medical treatment are so serious that the Court will need to make them. The Department should still instruct an ICA in these cases.

12.31 The Department does not have to instruct an ICA for patients detained under the Mental Health Law (MHL), if:

- the treatment is for impairment or a disturbance in the functioning of a patient's mind or brain, and
- the treatment can be provided without the patient's consent under the MHL.

12.32 If serious medical treatment proposed for a detained patient is not for their impairment or a disturbance in the functioning of her mind or brain, the patient then has a right to an ICA – as long as they meet the Law's requirements. Therefore a detained patient without capacity to consent to cancer treatment, for example, would qualify for an ICA if there are no family or friends whom it would be appropriate to consult.

Decisions about accommodation or changes of residence

12.33 The Law imposes similar duties on the Department in relation to long-term accommodation decisions for a person who lacks the capacity to agree to the placement and who qualifies for the additional safeguard of an ICA. The right to an ICA applies to decisions about long-term accommodation in a hospital or care home if the placement is provided or arranged by the Department, or if the decision is in respect of a move between such types of accommodation.

12.34 The Department has a duty to instruct an ICA if:

- it proposes to place a person who lacks capacity in a hospital – or to move them to another hospital – for longer than 28 days, or
- it proposes to place a person who lacks capacity in a care home – or to move them to a different care home – for what is likely to be longer than 8 weeks.

12.35 These timescales are referred to as the applicable period. Consequently, if the accommodation is for less than the applicable period, then an ICA need not be appointed.

12.36 Sometimes a person's placement will be longer than expected. The Department should involve an ICA as soon as it becomes apparent that the stay will be longer than the applicable period.

12.37 The Department can only put aside the duty to involve an ICA if the move is urgent or an emergency. The Department must involve an ICA as soon as possible after making the emergency decision if the person is likely to stay for longer than the applicable period or there are further decisions to be made regarding treatment or accommodation.

12.38 The Department does not have to involve ICAs if the person in question is going to be required to stay in the accommodation under the MHL. However, if a person is discharged from detention, they have a right to an ICA in future accommodation decisions.

Significant Restrictions on Liberty

12.39 An ICA must be appointed to represent a person if requesting an authorisation for significant restriction on liberty. This only applies if the person does not have anyone willing, able or suitable to represent them.

Instructing an ICA

12.40 ICAs should not be instructed if:

- a person who now lacks capacity previously named a person that should be consulted about decisions that affect them, and that person is available and willing to support
- the person who lacks capacity has an attorney, under a health and welfare LPA
- the Court has appointed a delegate, in relation to health and welfare decisions, who continues to act on the person's behalf.

12.41 However, where a person has no family or friends to represent them, but does have an attorney or delegate who has been appointed solely to deal with their property and financial affairs, they should not be denied access to an ICA. In such circumstances, an ICA should always be appointed to represent the person's views when they lack the capacity to make decisions relating to serious medical treatment or long-term accommodation moves.

12.42 An ICA can still be instructed while the Court is deciding on a delegate, but none is in place when a decision needs to be made.

12.43 A person may be eligible for the services of an ICA but may refuse to accept such support or to engage with an ICA once one has been arranged. The person maintains the right to decline such engagement. However this does not negate the responsibility to request an ICA once it is apparent that the person is eligible for the services of an ICA.

ICAs in relation to people in prisons

12.44 ICAs should be available to people who are in prison and lack capacity to make decisions about serious medical treatment or long-term accommodation.

Managing Disagreements

- 12.45** The ICA's role is to support and represent their client. They may do this through asking questions, raising issues, offering information and writing a report. They will often take part in meetings involving different healthcare and social care staff to work out what is in the person's best interests. There may sometimes be cases when an ICA thinks that a decision-maker has not paid enough attention to their report and other relevant information and is particularly concerned about the decision made. They may then need to challenge the decision.
- 12.46** An ICA has the same rights to challenge a decision as any other person caring for the person or interested in her welfare. The right of challenge applies both to decisions about lack of capacity and a person's best interests.
- 12.47** Although formal routes are available to enable disagreements to be managed, it is expected that before using these formal methods, the ICA and the decision-maker should discuss any areas of discord. The ICA and decision-maker should make time to listen to each other's views and to understand the reason for the differences. Disagreements should be resolved informally wherever possible.
- 12.48** When it has not been possible to resolve the disagreement, the matter may ultimately be referred to the Court for a decision about the treatment or change of accommodation. The Court will make the final decision in the best interests of the person who lacks capacity.



Chapter 13: The Capacity Law Review Tribunal

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Chapter 13: The Capacity Law Review Tribunal

- 13.1** This chapter outlines the role of the Mental Health Law Review Tribunal (the Tribunal) in relation to the Law.
- 13.2** The Tribunal is an independent judicial body which provides an additional safeguard for people who have had their liberty significantly restricted under the Law. Its function is to review existing authorisations of significant restriction on liberty.
- 13.3** The Tribunal review is for use when a requested review to the Department has been carried out and disagreement remains.

Right to apply to Tribunal

- 13.4** The Department and managers are under a duty to ensure that a person and their representative understand their rights to apply for a Tribunal review when an authorisation for a significant restriction on liberty is in effect. Funded representation for the Tribunal is not means tested and available for all people.
- 13.5** A number of people can request a Tribunal review. These are:

- the person
- the person's guardian
- the person's health and welfare attorney or delegate
- any person nominated by the person, if they have the capacity to do so
- the person's ICA
- the Minister
- the Attorney General.

The Tribunal

13.6 The Tribunal will examine the authorisation, associated assessments and any other relevant information to help them in their decision-making. The Tribunal cannot authorise a significant restriction on liberty.

13.7 The Tribunal will decide on ‘capacity and liberty matters’. These are whether:

- the person lacks capacity to consent to the care or treatment in the relevant place
- the significant restrictions are necessary as a component of the care or treatment of the person, and
- whether it is in the person’s best interests to be provided the care or treatment in the relevant place with the significant restrictions imposed.

13.8 After deciding on the capacity and liberty matters the Tribunal can amend or revoke an authorisation for significant restrictions on liberty. They may also decide whether an authorisation should continue to have effect. In addition, they may also ask the Minister to carry out further relevant assessments.

Appeals

13.9 If there is disagreement with the decision of the Tribunal a person may appeal to the Court, if the disagreement is on a point of law. Procedural irregularity does not invalidate any Tribunal decision unless it prevented the person from presenting their case fairly.

13.10 If the appeal is heard, the Court may:

- quash the decision
- affirm the decision
- give direction in the matter limited to the scope of the Tribunal’s powers, or
- ask the Tribunal to reconsider the matter.

Complaints

- 13.11** Complaints from users about the Tribunal should be sent, via the Tribunal Administrator, to the Tribunal Chairperson, who will deal with the complaint promptly.

Further information on the Tribunal

- 13.12** Regard should be had to any practice directions or other further information and guidance issued by the Tribunal about its procedures and operations.



Chapter 14: Consent, coercion and wilful neglect

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Chapter 14: Consent, coercion and wilful neglect

Capacity and consent

14.1 The possession of functional decision-making capacity is only one of the three elements of valid consent. Valid consent must be:

- informed, with a person having appropriate information
- capacitous, with a person having decision-making capacity
- voluntary, with a person being free from coercion or undue influence.

All three elements must be present for a person to make an autonomous decision to give valid consent.

14.2 This Law only allows decisions to be made on behalf of a person who lacks capacity, to make the decision for themselves, under the best interests process by a decision-maker. Where adults retain capacity but their ability to promote their own interests is seriously compromised, such as being coerced, this Law cannot be used.

14.3 Controlling or coercive behaviour should be dealt with as part of safeguarding and public protection procedures.

Coercion and inherent jurisdiction

14.4 The Court's inherent jurisdiction is, in part, aimed at enhancing or liberating the autonomy of a vulnerable adult whose decision-making ability is compromised by a reason other than capacity. This can include being:

- under constraint
- subject to coercion or undue influence
- deprived of the ability to make the relevant decision or disabled from making a free choice for some other reason
- prevented from giving or expressing valid consent.

- 14.5** The purpose of applying inherent jurisdiction should be protective in relation to adults in vulnerable circumstances. The Court will always avoid undermining the five core principles in Article 3 of the Law. They will give considerable weight to the principle that a person can make unwise decisions.
- 14.6** There is no specific definition of what constitutes vulnerable in such cases. The inherent jurisdiction is not confined to vulnerable adults. Equally adults at risk of abuse and neglect do not automatically come under the definition of vulnerable.
- 14.7** There is a risk that professionals involved in the care and treatment of a person may feel drawn towards an outcome that is more protective and in certain circumstances fail to carry out an assessment that is detached and objective. The Court will critically review evidence for the 'protective imperative' to ensure that the application of inherent jurisdiction does not raise the spectre of judicial paternalism. Therefore, an application for the use of inherent jurisdiction is normally restricted in scope to an autonomy promoting or defending role.
- 14.8** Professionals must consider that the use of inherent jurisdiction would risk breaching Article 8 of the Convention, a person's right to respect for private and family life. Legal advice should be sought regarding the appropriateness of asking the Court to consider exercising its inherent jurisdiction on human rights grounds.
- 14.9** The purpose of the Court using inherent jurisdiction is not to overrule the wishes of an adult with capacity, but to ensure that the adult is making decisions freely.

Wilful neglect

14.10 Wilful neglect is where a person ill-treats or wilfully neglects any person they have the care of, by virtue of being paid to provide social care or health care. It should be noted that any neglect should be 'wilful' and that ill-treatment requires a deliberate act or action that is reckless. Genuine errors or accidents are not within the scope of the offence.

14.11 There is no definition of ill-treatment or neglect within the Law so everyday meanings provide definition. The meaning of ill-treatment relies upon definitions of types of abuse which include the following areas:

- Physical
- Sexual
- Discrimination
- Psychological
- Financial
- Emotional.

14.12 The offence applies to the care and treatment of people:

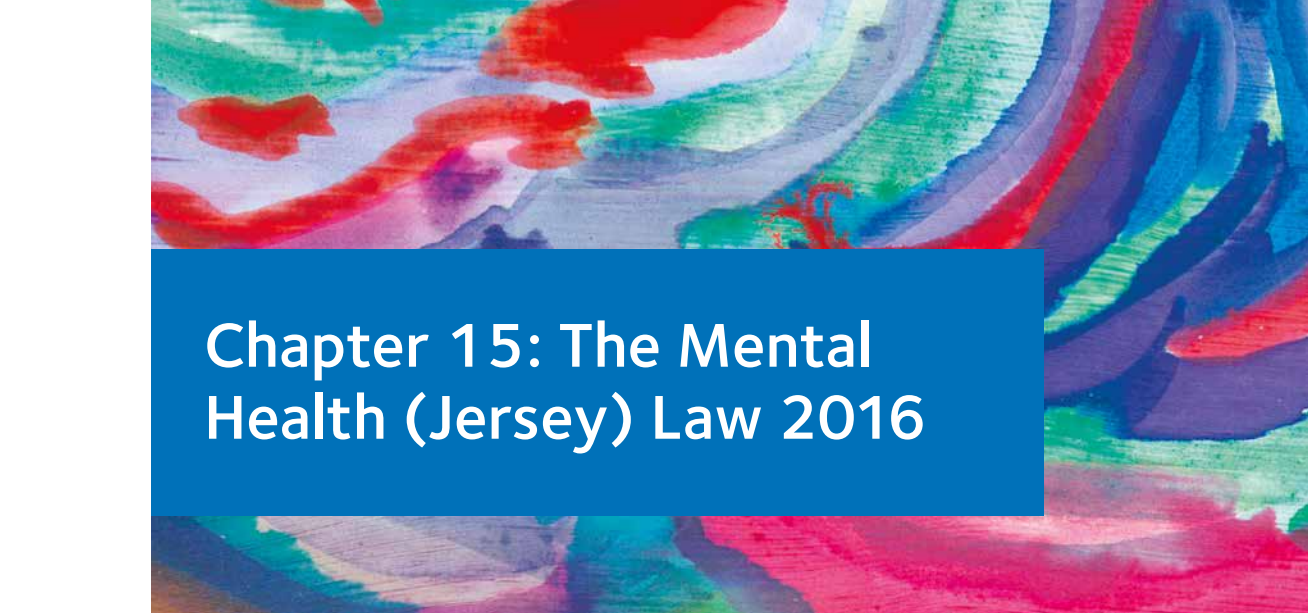
- in care homes
- provided with home care
- in supported living arrangements.

14.13 The offence of wilful neglect and ill-treatment carries the legal sanctions of both fines and imprisonment for any person found guilty of the crime.

Section 5: Other matters

Why read this section?

These chapters address other areas where guidance may be required in relation to a person who lacks capacity.



Chapter 15: The Mental Health (Jersey) Law 2016

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Chapter 15: The Mental Health (Jersey) Law 2016

For the purposes of this chapter, the Mental Health (Jersey) Law 2016 will be referred to as MHL and the Capacity and Self-Determination Law will be referred to as the Law.

Limitations of the Capacity and Self-Determination Law

- 15.1** Article 8 of the Law provides legal protection for people who care for or treat someone who lacks capacity. However, anyone acting under the Law must follow the principles of the Law and may only take action that is in a person's best interests. This applies to care or treatment for physical and mental conditions.
- 15.2** Article 9 advises that restraint of a person is not permitted unless in exceptional circumstances. For example, somebody using restraint only has protection if the restraint is:
- necessary to protect the person who lacks capacity from harm, and
 - in proportion to the likelihood and seriousness of that harm.
- 15.3** There is no protection under Article 8 or Article 9 for actions that conflict with a decision of a delegate or attorney.
- 15.4** There is no protection under Article 8 for actions that significantly restrict a person's liberty. A significant restriction on liberty can only apply once the formal process associated with this area of the Law has been followed. Similarly, the Law does not permit the giving of treatment which goes against an ADRT.

15.5 None of these restrictions apply to treatment for an impairment or a disturbance in the functioning of a person's mind or brain given under the MHL. However, other restrictions relating to use of restraint, seclusion and restricting of a person's liberty may apply. It is advisable to refer to the MHL Code of Practice.

Purpose and Scope of the Mental Health Law

15.6 The MHL provides ways of assessing, treating and caring for people who have a serious impairment or a disturbance in the functioning of their mind or brain to the extent that this puts them or other people at risk.

15.7 The MHL sets out when:

- people with an impairment or a disturbance in the functioning of their mind or brain can be detained in hospital for a period of assessment or treatment
- people who are detained can be given treatment for the impairment or disturbance without their consent (it also sets out the safeguards people must have in this situation), and
- people with an impairment or a disturbance in the functioning of their mind or brain can be made subject to Guardianship in order to protect them or other people.

15.8 The MHL does not distinguish between people who have the capacity to make decisions and those who do not. Many people subject to the provisions of the MHL have the capacity to make decisions for themselves. Most people who lack capacity to make decisions about their treatment will never be affected by the MHL, even if they need treatment for an impairment or a disturbance in the functioning of their mind or brain.

15.9 There will be situations where decision-makers will need to decide whether to use the MHL or the Law, or both, in order to meet the needs of people with mental health problems who lack capacity to make decisions about their own treatment.

Detention under the MHL

15.10 A person may be taken into hospital and detained for assessment under Article 21 of the MHL for up to 28 days if:

- the person appears to be suffering from a mental disorder that is serious enough for them to be detained in an approved establishment for assessment (or for assessment followed by treatment) for at least a limited period, and
- they need to be detained to protect their own health or safety or for the protection of other people.

15.11 A person may be admitted to hospital and detained for treatment under Article 22 of the MHL if:

- the person appears to be suffering from mental disorder of a nature or degree which warrants the detention of the patient in an approved establishment for treatment; and
- it is necessary, in the interests of their own health or safety, or for the protection of other people that the person should be so detained.

15.12 It might be necessary to consider using the MHL rather than the Law if:

- the person does not have capacity to consent to voluntary treatment
- it is not possible to give the person the care or treatment they need without carrying out an action that might deprive them of their liberty
- the person needs treatment that cannot be given under the Law (for example, because the person has made a valid and applicable ADRT to refuse all or part of that treatment)
- the person may need to be restrained in a way that is not allowed under the Law
- the person lacks capacity to decide on some elements of the treatment but has capacity to refuse a vital part of it – and they have done so, or

- there is some other reason why the person might not get the treatment they need, and they or somebody else might suffer harm as a result.

15.13 It is essential to remember that a person cannot be treated under the MHL unless they meet the relevant criteria for being detained. Unless they are conveyed to hospital under Part 9 of the MHL in connection with a criminal offence, people can only be detained where:

- the conditions for detention are met
- the relevant people agree that an application is necessary (usually this would be two doctors, including a psychiatrist and an Authorised Officer).

15.14 Compulsory treatment under the MHL is not an option if:

- the person's mental disorder does not justify detention in hospital, or
- the patient needs treatment only for a physical illness or disability.

15.15 There will be some cases where a person who lacks capacity cannot or should not be treated either under the MHL or the Law – even if the treatment is for mental disorder. This is likely to be in cases where it is not in a person's best interests to receive such treatment.

15.16 When a person is detained under the MHL, the medical practitioner must consider if the patient needs a legal decision-maker to make decisions regarding their health and welfare or property and affairs. If the patient would benefit from the appointment of a legal decision-maker due to capacity matters, this must be reported to the Minister. A report will then be required for the Attorney General to enable them to apply for a delegate to be appointed for the patient.

15.17 For the purposes of the Code, when a person is made subject to an Article under the MHL, they become a patient.

The Law and guardianship

15.18 There is no reason to assume a patient lacks capacity to make their own decisions just because they are subject, under the MHL, to guardianship.

15.19 Guardianship provides a specific individual the right to decide where a patient should reside. Somebody who knowingly supports a patient to leave the place a guardian requires them to stay may be committing a criminal offence. The guardian, in deciding living arrangements, cannot significantly restrict the patient's liberty.

15.20 The guardian can also require the patient to attend for treatment, work, training or education at specific times and places, and they can insist that a doctor, Authorised Officer (AO) or another person have access to the patient wherever they live.

15.21 Guardianship can apply whether or not the patient has the capacity to make decisions about care and treatment. It does not give anyone the right to treat the patient without their permission or to consent to treatment on their behalf. Guardianship does not prevent other people using the Law to make arrangements or to treat the patient in their best interests. People cannot use the Law in any way that conflicts with decisions which a guardian has a legal right to make under the MHL.

15.22 An application can be made for a person who has a mental disorder to be received into Guardianship under Part 4 of the MHL when:

- the situation meets the conditions set out in the MHL
- the relevant people agree an application for Guardianship should be made, and
- the proposed patient's nearest person does not object.

15.23 An application can be made in relation to any person who is 16 years or over if they appear to be suffering from a mental disorder of a nature or degree which warrants their reception into guardianship and guardianship is necessary in the interests of the welfare of the patient or to protect other people.

15.24 The AO and doctors supporting the application will need to determine whether this is the least restrictive option. For a person who lacks capacity, there may be alternative approaches, for example, a best interest decision or an authorisation for significant restriction on liberty under the Law.

15.25 However, the fact that the person lacks capacity to make relevant decision is not the only factor that applicants need to consider. They need to consider all the circumstances of the case. They may conclude that guardianship is the best option for a person with a mental disorder who lacks capacity to make those decisions if, for example:

- they conclude that it is important that one person should be in charge of making decisions about where the person should live
- they conclude that the person will probably respond well to the authority and attention of a guardian, and so be more prepared to accept treatment for the mental disorder (whether they are able to consent to it or it is being provided for them under the Law), or
- they need authority to return the person to the place they live if they were to leave without agreement.

15.26 When a person is received into guardianship, the medical practitioner must consider if the person needs a legal decision-maker to make decisions regarding their health and welfare or property and affairs. If the person would benefit from the appointment of a legal decision-maker, this must be reported to the Minister. A report will then be required for the Attorney General to enable them to apply for a delegate to be appointed for the person.

The Law and indefinite leave

15.27 The MHL allows a person's treatment to continue outside an approved establishment, normally in the community. Leave of absence can be used indefinitely. In these circumstances, the person remains under the MHL for treatment and can be recalled to an approved establishment at any time.

15.28 Conditions can be attached to indefinite leave, however, these should not amount to a significant restriction on liberty. If there are any doubts about the impact of conditions, legal advice should be sought.

15.29 However, a person may be on indefinite leave and have significant restriction on liberty authorised for other aspects of their care arrangements, not directly linked to their treatment under the MHL.

How the Law affects people covered by the MHL

15.30 There is no reason to assume a person lacks capacity to make their own decisions just because they are subject, under the MHL, to detention.

15.31 People who lack capacity to make specific decisions are still protected by the Law even if they are subject to the MHL. This includes people who are subject to the MHL as a result of court proceedings. However, there are exceptions:

- if a person can be detained under the MHL, decision-makers cannot normally rely on the Law to give mental health treatment or make decisions about that treatment on someone's behalf
- if somebody can be given mental health treatment without their consent because they are detained under the MHL, they can also be given mental health treatment that goes against an ADRT
- if a person is subject to guardianship, the guardian has the right to take certain decisions, including where the person is to live, and
- Independent Capacity Advocates do not have to be involved in decisions about medical treatments or accommodation related to their mental health, as those decisions are made under the MHL.

Implications for people who need treatment for mental disorder

15.32 The MHL enables doctors to give detained patients treatment for mental disorders without their consent, whether or not they have the capacity to give that consent. There are some exceptions to this and these are detailed in Part 3 of the MHL and guidance is provided in the MHL Code of Practice.

15.33 An attorney or delegate cannot use the Law to give consent or refuse treatment for a mental disorder under the Law. When Part 3 of the MHL is in place, this displaces all decision-making about treatment of mental disorder.

15.34 Clinicians treating people for mental disorders under the MHL cannot simply ignore a person's capacity to consent to treatment. As a matter of good practice (and in some cases in order to comply with the MHL) they will always need to assess and record:

- whether patients have capacity to consent to treatment, and
- if so, whether they have consented to or refused that treatment.

For more information, see the MHL Code of Practice

15.35 Compulsory treatment under the MHL without consent will not apply to patients whilst they are:

- temporarily detained (held in hospital) under Article 15 or 17 of the MHL while awaiting an application for detention under Article 21 or Article 22
- remanded by a court to hospital for a report on their medical condition under Article 62 of the MHL, or
- detained under Article 35 or 36 of the MHL in a place of safety.

15.36 Since the MHL does not allow treatment for these patients without their consent, the Law applies in the normal way.

15.37 Even when the MHL enables patients to be treated for mental disorder, the Law applies in the normal way to treatment for physical health. However sometimes healthcare staff may decide to focus first on treating a detained patient's mental disorder in the hope that they will regain the capacity to make a decision about treatment for their physical health.

15.38 Where people are subject to guardianship, the Law applies as normal to all treatment. Guardianship does not provide the right to treat patients without consent.

ADRT and Mental Health Law

15.39 The MHL does not affect a person's ADRT unless they are being compulsory treated under an Article in the MHL that allows treatment for mental disorder without consent. In this situation healthcare staff can treat patients for mental disorder, even if they have made an ADRT.

- 15.40** However, healthcare staff must regard a valid and applicable ADRT as they would a decision made by a person with capacity at the time they are asked to consent to treatment. For example, they should consider whether they could use a different type of treatment which the patient has not refused in advance. If healthcare staff do not follow an advance decision, they should record in the patient's records why they have chosen not to follow it.
- 15.41** Even if a patient is being treated under an Article that does not require their consent under the MHL, any ADRT regarding other forms of treatment is still valid. Being subject to Guardianship does not affect an ADRT in any way.

The impact of the MHL upon the duties of attorneys and delegates

- 15.42** Clinicians and others involved in the assessment or treatment of patients under the MHL, who lack capacity to make treatment decisions, should take reasonable steps to try to find out if the person has an attorney or delegate. In an emergency this may not be immediately practicable. However, enquires should continue after the immediate situation is resolved.
- 15.43** In general, the MHL does not affect the powers of attorneys and delegates. However, there are two exceptions:

- they will not be able to give consent on a patient's behalf for treatment for mental disorder where the patient is liable to be detained under the MHL, and
- they will not be able to take decisions:
 - about where a person subject to Guardianship should live, or
 - which conflict with decisions that a Guardian has a legal right to make.

- 15.44** Being subject to the MHL does not stop patients creating new LPA if they have the capacity to do so. Nor does it stop the Court from appointing a delegate for them.

15.45 In certain cases, people subject to the MHL may be required to meet specific conditions relating to leave of absence from hospital. Conditions vary from case to case, but could include a requirement to:

- live in a particular place
- maintain contact with health services, or
- avoid a particular area.

15.46 If an attorney or delegate takes a decision that goes against one of these conditions, this will be treated as if the patient has done so themselves. Attorneys and delegates in these circumstances should familiarise themselves with the MHL Code of Practice.

15.47 The MHL provides for a patient to have a representative called a nearest person. The role of the nearest person is detailed in the MHL and MHL Code of Practice. Attorneys and delegates may be able to exercise patients' rights under the MHL on their behalf, if they have the relevant authority.



Chapter 16: Research

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Chapter 16: Research

The Law and research

- 16.1** The Law protects people who take part in research projects but lack capacity to make decisions about their involvement. The Law states that research must be safe and produce a benefit for a person that outweighs any risk or burden.

Defining research

- 16.2** The Law does not have a specific definition for ‘research’ but for these purposes it is to be defined as ‘the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods’. Research enables services to improve the current and future health and well-being of the people they serve. However, research sometimes involves a degree of risk because researchers cannot predict the outcome with certainty. It may also involve additional burdens or intrusions exceeding those involved in normal care.

Researchers and assumptions about capacity

- 16.3** Researchers must assume that a person has capacity, unless there is evidence that they lack capacity to make a specific decision. Researchers must strictly follow the principles and best interests process in the Law and this Code.
- 16.4** The research proposal needs to state what will happen if an individual loses capacity during the project.

Research covered under the Law

16.5 It is expected that most of the researchers who ask for their proposals to be approved under the Law will be medical or social care researchers. However, the Law can cover more than just medical and social care research. Intrusive research which does not meet the requirements of the Law cannot be carried out lawfully in relation to people who lack capacity.

16.6 The Law applies to research that:

- is 'intrusive' (if a person taking part had capacity, the researcher would need to get their consent to involve them)
- involves people who have an impairment or disturbance in the functioning of the mind or brain which makes them unable to decide whether or not to agree to take part in the research (i.e. they lack capacity to consent).

16.7 There are circumstances where no consent is needed to lawfully involve a person in research. These apply to all persons, whether they have capacity or not. Situations for which permission is not required include:

- research where the samples are anonymised and the research has ethical approval
- clinical audit (comparison against a standard)
- education or training relating to human health
- performance assessment
- public health monitoring
- quality assurance.

Obtaining approval

16.8 The Department's Research Ethics Committee must review research proposals relating to areas of health and social care professional practice research. Ethical research should:

- consider the views of carers and other relevant people
- treat the person's interests as more important than those of science and society
- respect any objections a person who lacks capacity makes during research.

16.9 The research project should be linked to an impairing condition that affects the person who lacks capacity or the treatment of that condition. An impairing condition:

- is caused by (or may be caused by) an impairment of, or disturbance in the functioning of, the person's mind or brain
- causes (or may cause) an impairment or disturbance of the mind or brain, or
- contributes to (or may contribute to) an impairment or disturbance of the mind or brain.

16.10 Research should meet one of two requirements:

1. The research must be safe and have some chance of benefiting the person who lacks capacity. The benefit must be in proportion to any burden caused by taking part, or
2. The aim of the research must be to provide knowledge about the cause of, or treatment or care of, people with the same impairing condition or a similar condition.

16.11 If researchers are relying on the second requirement:

- the risk to the person who lacks capacity must be negligible
- there must be no significant interference with the physical and mental wellbeing of the individual
- there must be no significant interference with the legal rights of the individual.

Consulting carers

- 16.12** The researcher should as a matter of good practice take reasonable steps to identify someone to consult. That person (the consultee) must be involved in the person's care, interested in their welfare and must be willing to support. They must not be a professional or paid care worker. They will probably be a family member, but could be another person.
- 16.13** The researcher must take into account previous wishes and feelings that the person might have expressed about who they would, or would not, like involved in future decisions.
- 16.14** A person is not prevented from being consulted if they are an attorney authorised under an LPA or are a delegate appointed by the Court, but that person must not be acting in a professional or paid capacity.
- 16.15** The researcher must provide the consultee with information about the research project and ask them:
- for advice about whether the person who lacks capacity should take part in the project, and
 - what they think the person's feelings and wishes would be, if they had capacity to decide whether to take part.

Sometimes the consultee will say that the person would probably not take part in the project or that they would ask to be withdrawn. In this situation, the researcher must not include the person in the project, or they should withdraw them from it.

Other safeguards provided by the Law

- 16.16** Even when a consultee agrees that a person can take part in research, the researcher must still consider the person's wishes and feelings.
- 16.17** Researchers must not do anything the person who lacks capacity objects to. They must not do anything to go against any ADRT or other statement the person has previously made expressing preferences about their care or treatment. They must assume that the person's interests in this matter are more important than those of science and society.

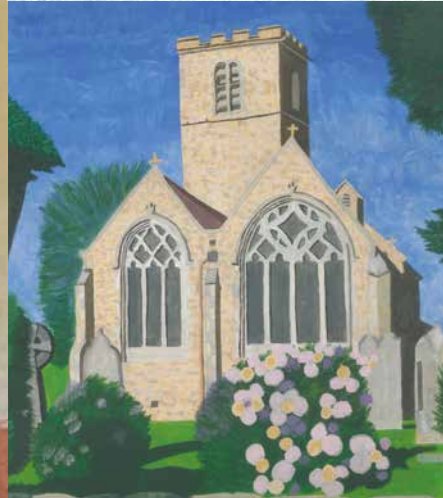
16.18 A researcher must withdraw someone from a project if they indicate in any way that they want to be withdrawn from the project, for example, if they become upset or distressed.

Research involving human tissue

16.19 A person with capacity has to give their permission for someone to remove tissue from their body (for example, taking a biopsy (a sample) for diagnosis or removal of tissue in surgery). The Law allows the removal of tissue from the body of a person who lacks capacity, if it is in their best interests.

16.20 People with capacity must also give permission for the storage or use of tissue for certain purposes, set out in the Anatomy and Human Tissue (Jersey) Law 1984, (for example, removal and use of bodies for teaching anatomy).













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