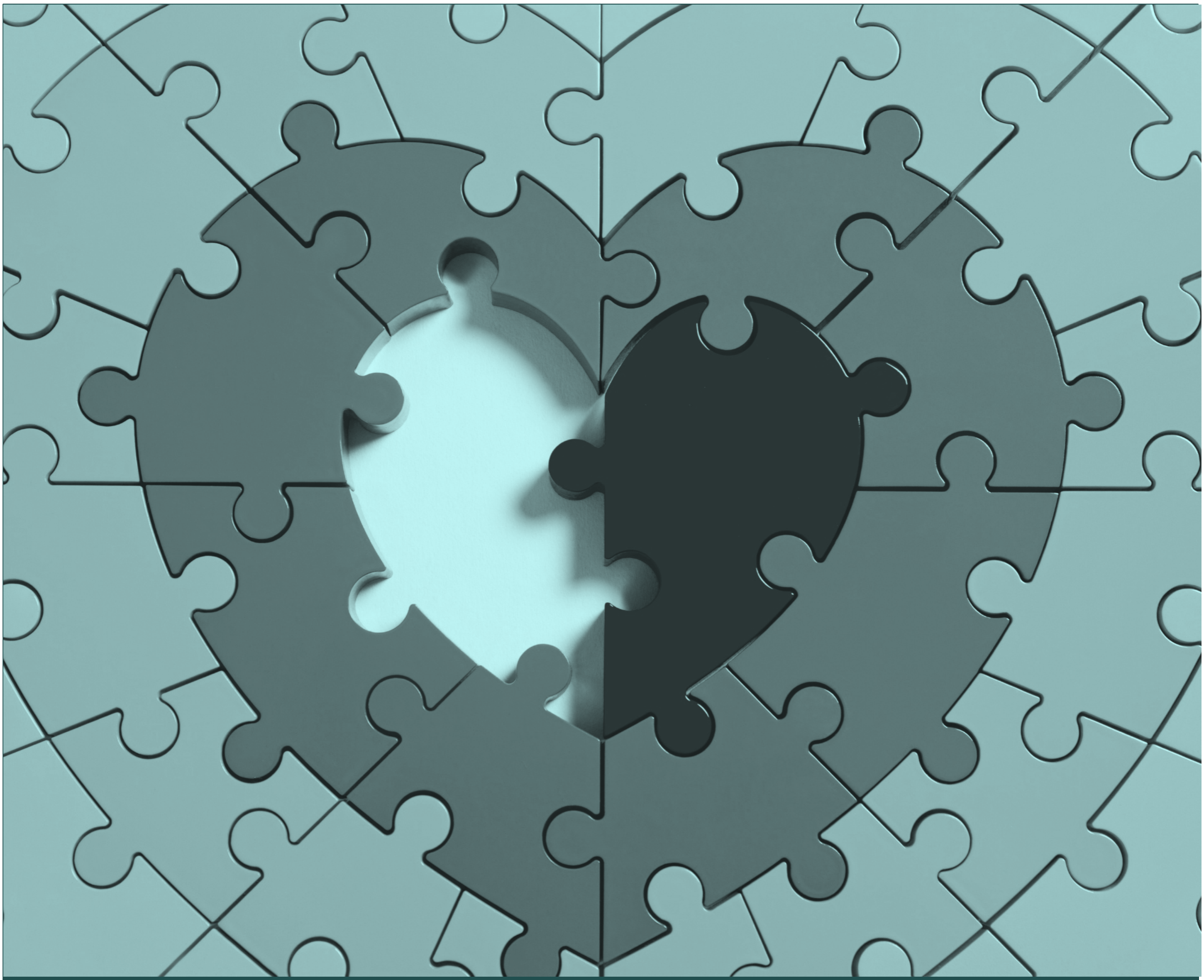

An Ethics Framework to Support Deceased Donation After Assisted Dying in Aotearoa New Zealand

Organ Donation New Zealand

ODNZ 4 May 2026 Version 2.1

This guidance document was prepared on behalf of Organ Donation New Zealand and the New Zealand Blood Service. Auckland, New Zealand; September 2025.

Organ Donation New Zealand would like to thank and acknowledge the many stakeholders and advisors who contributed to this document.

This document represents the intersection of a number of complex issues including ethics, the law and good clinical practice. It will be continuously improved and revised in accordance with these principles.

KARAKIA WHAKANOA

Whakawatea te noa i a koe,
whakawatea te hau i runga i a koe,
whakawatea te taurekareka i a koe
Ko te mumu te awha, tenei ka ngahoro
Ka ngahoro te hau otaota i runga i a koe
Ko Tiki i ahau mai i Hawaiki
Ko te mauri tena i kawea ai
Te tokomauri o te tapu, tapu nui, tapu whakahirahira,
he mauri no Rongo ki te whai-ao
Tihei mauri-ora. To koiwi ka ngaoro
Ka noa nga hau i runga i a koe.

Clear away the restrictions from you,
Clear away the spirit which is upon you,
Clear away from you any restrictions
The storm rages. This clears it
The force upon you that hinders you is cleared off
You are Tiki formed in Hawaiki
That life-force brought (to you) is the manifold life-force of the tapu,
a great tapu, a highly important tapu
It is a life-force from Rongo, leading to the dawn.
Breathe living spirit!! Your bones are cleared,
The forces over you are made unrestricted.

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Glossary of Māori Words and Terms Used in this Framework

Kaitiakitanga	guardianship, stewardship
Karakia	blessing, incantation, prayer
Kanohi ki te kanohi	face to face
Kawa	custom or ceremony; customary process
Kāwanatanga	government or governance
Mana	influence, status, authority
Noa	free from tapu, unrestricted
Ōritetanga	equity; also, equality, equal opportunity
Rangatiratanga	the right to exercise authority; also, autonomy, self-determination, sovereignty
Tangata whenua	indigenous people (referring to Māori in Aotearoa New Zealand)
Tapu	sacred, prohibited, restricted
Te Ao Māori	Māori world view, cultural framework
Te Tiriti o Waitangi	the Māori text of the constitutional document whose English version is referred to as the Treaty of Waitangi
Tikanga	correct procedure, practice or method. The customary system of practices that are embedded in Te Ao Māori
Wairuatanga	spirituality
Whakanoa	to remove tapu
Wānanga	lore, important traditional knowledge
Whānau	extended family, family group, may include people outside of kinship
Whanaungatanga	relationship, kinship, sense of family connection and belonging

Glossary / List of Abbreviations

Aotearoa New Zealand – Aotearoa New Zealand

ANZICS – Australia and New Zealand Intensive Care Society

Assisted Dying (AD) – the process of providing medical assistance for dying with the consent of an individual, as specified within the End of Life Choice Act 2019. In other jurisdictions this is named Medical Assistance in Dying (MAID); Voluntary Assisted Dying (VAD)

Assisted dying and donation (ADD) - the process of deceased donation of organs or tissues following circulatory determination of death in an individual undergoing Assisted Dying. In other jurisdictions may be termed Organ Donation after Euthanasia (ODE)

Assisted Dying Attending Medical Practitioners (AMPs) – clinicians who hold the responsibility of the oversight for the process of AD for individuals including assessment of eligibility, consent and delivery of AD and certification of death

DBD – donation after brain death. The process of deceased donation after death is confirmed by specific neurological criteria. Also known as donation after neurological determination of death (DNDD)

DCD – donation after circulatory death. The process of deceased donation after death is confirmed following permanent cessation of circulation. Also known as donation after circulatory determination of death (DCDD)

EOLCA – End of Life Choice Act

HCP – Healthcare Professionals

HTA – Human Tissue Act

NHRMZ - National Medical and Health Research Council

Organ Donation New Zealand (ODNZ) – the national agency co-ordinating the processes of deceased organ and tissue donation in Aotearoa New Zealand

PMI – pre-mortem intervention.

SCENZ Group - Support and Consultation for End of Life in New Zealand (SCENZ) Group

WLST – withdrawal of life sustaining treatment

1. Background and Purpose of the Framework

Organ and tissue donation (hereafter donation) for transplantation is recognised as an act of altruism of great potential benefit to transplant recipients and their whānau, and to the greater society. Donation should be undertaken in a respectful and dignified manner that upholds the wishes, values and needs of the donor and whānau.

There exists the potential to extend the opportunity for donation to individuals undergoing the Assisted Dying (AD) process in Aotearoa New Zealand (Aotearoa New Zealand). Organ Donation New Zealand (ODNZ) wishes to apply the same values, ethical principles and high standards to assisted dying and donation (ADD) as exists for our other current donation processes. We wish to provide appropriate safeguards for potential and actual donors and their whānau, and to ensure that the process of ADD preserves public trust in donation and transplantation.

Although many aspects of the ADD process would not differ from existing donation processes following circulatory determination of death, there are some important differences with regards to the interaction of the donation pathway with AD pathways that require specific ethical consideration.

This document seeks to provide a framework that incorporates the relevant ethical standards, and to consider how appropriate safeguards may be integral to the proposed ADD process. This document is intended to provide ethical guidance in the clinical setting for Organ Donation Specialists, Transplant Services, Assisted Dying Attending Medical Practitioners and Hospital clinical staff involved in the donation process for Assisted Dying patients.

The processes leading to deceased organ (lung, liver or kidneys) and/or tissue donation (corneas, heart valves or skin) following Assisted Dying are within the scope of this document. Living donation of organs is outside the scope of this document. The framework also does not address the ethics of eligibility for, or provision of, Assisted Dying itself.

2. Relevant Legal Documents and Guidelines

- **End-of-Life Choice Act (EOLCA) (2019)** (End of Life Choice Act, 2019) – this Act legalised the option of Assisted Dying for those persons meeting the criteria and established the statutory processes and responsibilities for Assisted Dying in Aotearoa New Zealand.

- **Human Tissue Act (HTA) (2008)** (Human Tissue Act, 2008) – this Act defines human tissue and establishes the framework for obtaining informed consent for the collection and use of human tissue after death. A hierarchy for providing consent is provided at the top of which the person who is deceased can provide their informed consent prior to their death.

- **Australia and New Zealand Intensive Care Society (ANZICS) Statement on Death and Organ Donation (2021)** (Australian and New Zealand Intensive Care Society, 2021) – this statement provides the relevant professional standards for the determination of death that apply in the context of deceased organ donation.

- **National Medical and Health Research Council (NHRMC) of Australia Ethical guidelines for cell, tissue and organ donation and transplantation (2025)** (National Health and Medical Research Council, 2025) – a detailed ethical framework for donation and transplantation including a section on donation after Voluntary Assisted Dying.

3. Development of the Framework

This framework evolved from a meeting between Organ Donation New Zealand and staff responsible for the Assisted Dying programme at the Ministry of Health in December 2023 undertaken to initiate a clinical pathway for Donation after Assisted Dying.

An initial literature review was performed to find international literature pertaining to ethical considerations for organ donation in Assisted Dying from overseas jurisdictions. Two scoping reviews (Sylva et al., 2023, Mulder et al. 2022 were found as well as individual articles reviewing this practice in Canada, the Netherlands and Australia. Additionally, grey literature was searched for national and provincial guidance and policy documents for jurisdictions that had already undertaken organ or tissue donation in this context.

The authors then worked iteratively to write a draft Framework to incorporate the key principles for a clinical pathway, as well as the ethical issues highlighted by the international literature. Extensive reference was made to the ethical values detailed in guidelines for the ethical practice of organ and tissue donation from the NHRMC of Australia (National Health and Medical Research Council, 2025) in framing ethical discussion.

Broader input was sought for the draft Framework from a number of academic and clinical bio-ethicists with interests in end-of-life care as well as from presentation to the Clinical Ethics Advisory Group at Te Toka Tumai |Auckland Hospital. This latter group includes practicing clinicians, Māori and Pacific advisors and members of the public with an interest in medical ethics. Subsequent presentation to the National Ethics Advisory Committee of the Ministry of Health occurred along with specific consultation with advisors with lived experience of disability, and specific cultural input.

4. Overview of Key Principles and Ethical Values

ODNZ identifies the following as key principles for the ADD process:

- **Principle 1.** Precedence should always be given to providing the individual a peaceful and dignified death.
- **Principle 2.** The opportunity for donation after death should be available to all potential donors. Patients undergoing Assisted Dying (AD) should have the same opportunity to donate as other individuals.
- **Principle 3.** The individual has the right to make their own decision. Donation should involve a fully informed first-person consent, free of coercion, with sufficient time for discussion and consideration.
- **Principle 4.** The decision to pursue ADD is separate to the decision to pursue AD and should only be explored once the patient's decision to pursue AD has been made AND the patient is confirmed eligible for AD.
- **Principle 5.** No one is obliged to be involved in the donation process if they do not wish to be. Consent is voluntary and can be withdrawn at any time.
- **Principle 6.** The process of ADD will work to uphold the rights and responsibilities that derive from Te Tiriti o Waitangi. It is important to note that rights and responsibilities that derive from Te Tiriti o Waitangi could be at odds with other basic ethical principles. An example of this may be the collective responsibilities and wisdom of hapu and iwi and how that intersects the individual. The complexities of this are beyond this document but require consideration when ADD is discussed.
- **Principle 7.** The process of ADD will be inclusive of, and equitable for all people. Care will be taken to identify any gaps by ethnicity, religion, gender and ability, and appropriate steps will be taken to attempt to mitigate these.
- **Principle 8.** The ADD process will be designed, delivered and monitored in a way that actively removes barriers and provides reasonable accommodations to recognise the importance of international human rights treaties and conventions such as: the Universal Declaration of Human Rights; the United Nations Declaration on the Rights of Indigenous Peoples; International Convention on the Elimination of all forms of Racial Discrimination; Convention on the Rights of Persons with Disabilities.
- Principle 9. ADD must be carried out in such a way, and with sufficient ethical safeguards, that it maintains public trust in the donation and transplantation process and does not affect public participation in other donation processes.

The ethical values that underpin the framework described in this document are:

- Respect for the dignity and autonomy of potential donors and their whānau.
- Avoidance of any conflicts of interest that may arise from the interaction of the assisted dying and donation processes (see sections **13.A** and **13.C**).
- Enabling Good Lives Principles (Enabling Good Lives Principles, 2025).
- Upholding wellbeing for potential donors and their families through balancing the benefits of ADD with potential harms (see section **13.D**).
- Promoting equity and justice in access to donation and transplantation of organs and tissues (see section **13.E**).
- Promoting solidarity and reciprocity for the process of organ and tissue donation (see section **13.F**).
- Respect for the right of healthcare providers' conscientious objection to involvement in the AD process (see section **0**).

5. Responsibilities to Te Tiriti o Waitangi

ODNZ respects the mana of Te Tiriti o Waitangi within Aotearoa New Zealand and seeks to honour its responsibilities to Māori, as tangata whenua, that arise from Te Tiriti. Specifically, the ADD process will strive to uphold:

- **Kāwanatanga** – ODNZ will ensure good governance and meaningful Māori participation through inclusion in the ADD design and review process. ODNZ will monitor outcomes to ensure ADD meets Māori needs for health and wellbeing. And continually work towards equitable outcomes within the scope of ADD.

- **Rangatiratanga** – ADD will seek to preserve autonomy and self-determination for Māori and will engage with worldviews central to Te Ao Māori, keeping in mind what this may mean for each individual and their situation.

- **Ōritetanga** – ADD philosophy will advocate for health equity for Māori and strive for equitable access to the opportunity to donate.

Additionally, ODNZ recognises the need to specifically address:

- **Wairuatanga** – ADD will respect Māori worldviews, cultural values and spiritual beliefs around the process of death. Ongoing consultation and development will occur on ways of upholding tikanga and kawa that would normally apply to the process of death (Moeke-Maxwell et al, 2018).

- **Kaitiakitanga** – ODNZ recognises its responsibilities as a custodian of the donation process and donated tissues, as well as towards stewardship of the common good. Data sovereignty must be explored and addressed as part of ODNZ governance.

It is noted that the ethical concepts and principles addressed in this framework largely derive from Western cultures, as do the legal principles. Reference is made to concepts within Te Ao Māori that are similar, but it is recognised that these sets of concepts are not exactly equivalent as the worldviews differ in important ways – the intention is to bring the concepts into respectful conversation with each other without diminishing one worldview. A full exploration of the concepts of Te Ao Māori and how they relate to organ donation is beyond the scope of this document.

6. Respect for Cultural Safety

ODNZ recognises that engaging in culturally safe processes is essential to addressing ethical issues within the context of existing health inequities within Aotearoa New Zealand (Curtis, et al., 2019).

Recent work in Aotearoa New Zealand (Curtis et al, 2025 Refining the definitions of cultural safety, cultural competency and Indigenous health: lessons from Aotearoa New Zealand, 2025) has defined cultural safety as requiring health professionals to examine themselves and the potential impact of their own identities and culture on their practice. This requires health professionals to acknowledge and address their own power, privilege, biases, attitude, stereotypes, prejudices that may affect the quality of care that they provide.

Cultural safety involves developing critical consciousness and engaging in ongoing self-reflection, with health professionals holding themselves accountable to standards of care defined by patients and their communities. Cultural safety focuses on benefits for all patients and communities as reflected by their indigenous status, age or generation, gender, sexual orientation, socio-economic status, ethnicity, religious or spiritual beliefs and disability.

ODNZ is mindful that cultures, religions, and worldviews are diverse rather than homogenous, and that respectful, open, and flexible engagement with each patient and whānau is essential. Healthcare providers involved in ADD should engage in critical reflexivity to identify potential biases they may hold, as well as to recognise inherent power differentials in healthcare interactions. This includes awareness of the impact of structural and interpersonal racism, as well as the risk of systemic ableism and exclusion of other cultural frameworks.

The ADD process should strive to be free of bias and discrimination in interactions with individuals undergoing AD. It is important that this process of reflection is actively included in the ADD framework, and in critical analysis after each interaction.

7. Legal Considerations for Aotearoa New Zealand

The HTA 2008 delineates legal consent for deceased organ and tissue donation, in which a competent person's informed consent, given prior to their death, provides legal authorisation for the collection and use of tissue after their death. This consent is not affected in law by the person requesting Assisted Dying according to the EOLCA 2019. Legal competency for the decision to pursue Assisted Dying is essentially no different from the competency required to consent to donation of tissue. The requirements for informed consent laid out in the HTA 2008 are that:

(a) consent is:

(i) specific to the relevant collection and use of the tissue (i.e., not a general consent, such as general agreement through the driver licence system to being an organ donor)

(ii) given freely, and in the light of all information that a reasonable person, in that person's circumstances, needed to give informed consent

(iii) given in accordance with specific requirements under the HTA, including that:

> (1) the person giving consent must take into account and consider the weight that they wish to give to the cultural and spiritual needs, values and beliefs of their immediate family; and
>
> (2) the consent is given in writing (with or without witnesses), or orally in the presence of two or more witnesses present at the same time; and

(iv) not later revoked; and

(b) the person must be capable to give consent. "Capable" is defined as having the capacity to understand the nature and foresee the consequences of the decision and communicate the decision.

Assessment of capacity is a nuanced process, and in-depth discussion is beyond the scope of this document. It will need to be conducted in accordance with sound medical and legal practice.

Consent given by the individual prior to death has the highest priority in the HTA 2008 and cannot be overturned by an "informed objection". However, health practitioners collecting and using human tissue must take into account, to the extent known to them, the cultural and spiritual needs, values and beliefs of the deceased person's immediate family. Although consent may have been given, the individual health practitioners are not obliged by law to collect or use tissue if they believe there are reasons the consent should not be acted on.

In the case of an individual with disability, where that person's communication is atypical, it would be of paramount importance to involve an independent disability advocate to ensure supported decision making. Consent for ADD is required to be first person - there is no instance where a guardian or EPOA would legally be able to make a decision on behalf of an individual.

8. International Experience with Donation After Assisted Dying

Organ donation following AD has been legally undertaken in Belgium since 2005, in the Netherlands since 2012, Canada since 2016 (Mulder et al., 2022) and Spain since 2021. These countries have the most experience with ADD and have national or provincial practice guidelines pertaining to ADD which include safeguards for patients and health care professionals. More recently there have been a small number of cases in Australia.

In Canada a national guidance document for managing deceased organ donation in conscious, competent donors (including those undergoing AD) was published in 2019 (Downar et al., 2019) and updated in 2023 (Wiebe et al., 2023). This document was produced as a result of a forum including medical, legal and bio-ethics experts. Preliminary work in advance of this forum showed broad public approval of allowing conscious, competent patients to donate after AD although concerns regarding coercion and the interaction of the two decisions were expressed. The national guidance document outlined clinical pathways for organ donation in this context including approaches to the donation conversation and safeguards for patients. In 2021, 8% of all deceased organ donors in Canada were through Assisted Dying. A review of ADD in Quebec between 2018 and 2022 showed an increase in this form of deceased donation over the first 5 years of implementation in line with the increase in numbers of people choosing Assisted Dying (Weiss et al., 2024).

In Australia state-based Donate Life organ donation agencies have developed guidelines for the conduct of donation after Voluntary Assisted Dying. Several cases of donation have occurred in Victoria, Queensland and New South Wales.

9. Identification of Pathways Involved in End-of-Life Care in the Context of Donation

Three overlapping care pathways can be identified in current practice for deceased donation and transplantation, irrespective of the type of donation (Mulder et al., 2022). These pathways consist of a death pathway, a donor pathway and a recipient pathway. The death pathway leads to the donor's death; the donor pathway leads to deceased organ donation as a result of this death; and the recipient pathway leads to transplantation of donated organs or tissues to recipients on transplant waiting lists. This document will largely consider the first two pathways only.

The HTA (2008) requires that collection of human tissue for the purposes of deceased donation can only occur after "a qualified person is satisfied, by personal examination of the body, that the individual concerned is dead". Current practice involves the donation of organs and tissues following two different methods of determining that death has occurred. **Donation after brain death (DBD)** uses specific neurological criteria and **donation after circulatory death (DCD)** requires permanent cessation of circulatory function. DCD is the method relevant to consideration of ADD.

DCD is an ethically accepted form of donation globally (UK Donation Ethics Committee, 2015) and has been occurring in Aotearoa New Zealand since 2008. While many parts of the process for DCD would be the same in ADD, some specific interactions between the death and donation pathways exist in ADD that require additional ethical consideration.

10. The Current Process for Assisted Dying

Strict eligibility criteria for AD exist. A person must meet all criteria to be eligible for AD. The person must be:

- Aged 18 years or over and a citizen or permanent resident of Aotearoa New Zealand.
- Suffering from a terminal illness with an anticipated life expectancy of six months or less.
- In an advanced state of irreversible decline in physical capacity.
- Experiencing unbearable suffering that cannot be relieved in a manner that the person considers tolerable.
- Competent to make an informed decision on assisted dying.

The following safeguards are currently part of the AD process:

1. Autonomous first-person consent must be obtained and retained without coercion. The consent process must include sufficient and unbiased information on AD.
2. Medical practitioners may not discuss assisted dying with a person prior to the person themselves raising it as a consideration.
3. Attending medical practitioners must satisfy themselves that the decision is free from coercion and may consult the person's regular health practitioner and whānau (with the person's consent).
4. Eligibility is assessed by two independent medical practitioners and, if necessary, a psychiatrist may be required to assess whether the person is competent to give informed consent.
5. If a person loses competence to make an informed decision prior to the final administration of AD medication, then they are no longer eligible for AD.
6. Consent to pursue assisted dying may be revoked at any time. The attending medical practitioner must ask the person again immediately prior to administration of AD medication if they still wish to proceed.

A Registrar for Assisted Dying has overall responsibility to ensure that the correct processes have been followed.

11. The Current Process for Donation After Circulatory Death

DCD currently occurs following withdrawal of life-sustaining therapies (WLST) of patients in the Intensive Care Unit (ICU). Patients are usually, but not always, unconscious with underlying severe illness that has not caused brain death, but for which ongoing provision of life-sustaining treatment is not considered to be in the patient's best interests. The process of reaching this decision involves medical consensus amongst treating specialists and an appropriate period of consultation with whānau. WLST then occurs and death is an anticipated, but not intended, result of WLST.

An internationally accepted ethical standard for deceased donation to occur is known as the "Dead Donor Rule" (Gardiner et al., 2021;Lewis et al., 2023). This requires that the process of organ donation should not cause the death of the donor and therefore donation may only proceed after death has occurred and has been confirmed in accordance with the relevant legal standards. An implication of this rule is that the process of donation should not influence decisions that may result in the death of a person and should not compromise the quality of end-of-life care.

For Aotearoa New Zealand there is no statutory definition of death in law (including within the HTA) but common law recognises that the basis for determining death is good medical practice, as recognised and approved within the medical profession. For deceased organ donation, the relevant standards of good medical practice are contained within the ANZICS Statement on Death and Organ Donation (Australian and New Zealand Intensive Care Society, 2021).

DCD can only proceed with informed consent from surrogate decision makers – the hierarchy of consent is outlined within the HTA. Normally the opportunity to consider donation would only be offered to whānau following discussion and acceptance of the decision to proceed to WLST. This provides an ethical safeguard in that it separates discussion and decision making on WLST from that involved in donation. If consent is obtained, donation surgery only proceeds following confirmation of death following WLST using the above criteria.

Eligibility to be a donor involves assessment of organs or tissues that are medically suitable for transplantation – this means that they must likely be of sufficient function post transplantation to benefit the recipient and to be free of diseases that may cause potential harm to recipients. This assessment involves careful evaluation of the patient records by donation specialists, often in liaison with transplant teams, and additional testing (blood tests and sometimes urine, sputum and radiological tests).

The donation pathway may also alter the death pathway from WLST, in that specific additional pre-mortem investigations (PMIs) and medications may be used and justified, to improve potential organ function for the benefit of the transplant recipient (such as blood thinning medications), which would not be used in the setting of WLST alone. These additional interventions are discussed in the consent procedure.

In rare circumstances DCD could involve first-person consent where patients may be conscious but dependent on life-sustaining treatment and are deemed competent to decide to cease treatment as well as to donate following their death. The same considerations would apply in that the decision to undergo WLST must be discussed and confirmed prior to proceeding with discussion of organ donation.

12. Differences Between Assisted dying and donation and Current Donation After Circulatory Death Processes

A proposed modified DCD pathway for ADD is shown in Figure 1. Broadly the steps involved can be categorised into:

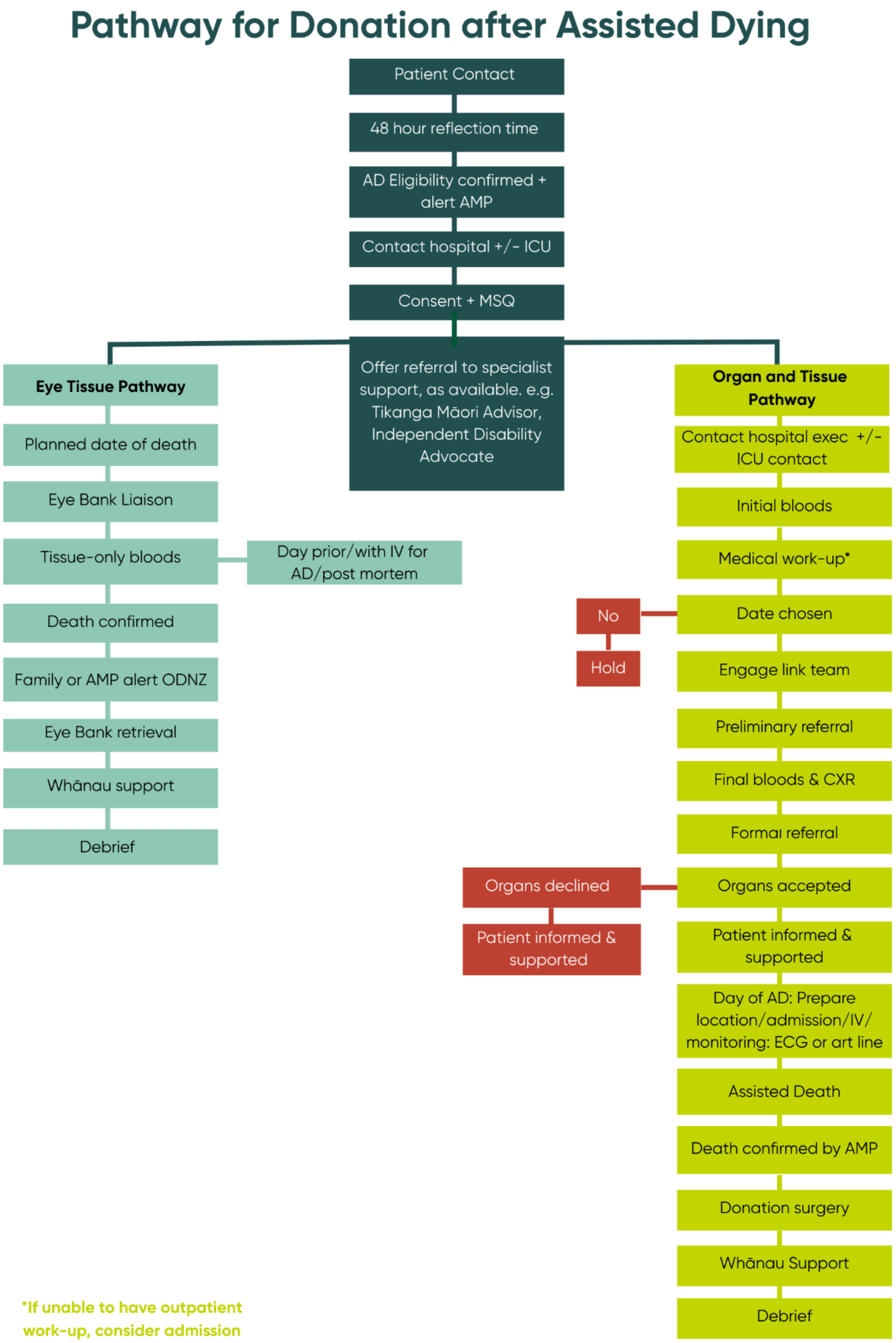
1. The request from an individual for AD, assessment of eligibility and confirmation of the decision, including first-person consent for AD.
2. The referral to ODNZ to consider the patient's wishes to pursue organ donation and assessment of suitability for DCD. This would follow the patient expressing a desire to pursue donation with the AD providers.
3. An approach from ODNZ to the patient and subsequent discussion with organ donation specialists for consent.
4. Premortem investigations.
5. Hospital admission, which may include further investigations and interventions.
6. Provision of AD.
7. Donation surgery following circulatory confirmation of death.

The principal difference between ADD and the normal pathways for DCD are in the interaction between the decision to pursue AD, which leads to the anticipated and intended death of the conscious patient, and the decision to additionally donate organs or tissue following death. These pathways involve the same conscious person. Both pathways require independent provision of autonomous and informed first-person consent.

The main ethical considerations, therefore, in ADD are broadly:

1. Ensuring autonomy for patients undergoing ADD in making decisions at the end-of-life.
2. Ensuring no element of coercion exists, perceived or otherwise, that may adversely influence patient decision-making.
3. Preserving a dignified experience of end-of-life for AD patients and their whānau, such that any benefits of organ donation outweigh any potential harms.
4. Ensuring ADD processes do not influence patient timelines around AD.

Figure 1 Proposed Pathway for Donation After Assisted Dying



*If unable to have outpatient work-up, consider admission

13. Key Ethical Values

A fundamental ethical principle is that of respect for dignity, defined as the inherent worth and equal value of people. In Te Ao Māori, this overlaps with the concept of upholding mana for individuals, though mana is also considered in the context of whanaungatanga (interconnectedness). The following ethical principles are outlined and must be placed within the context of assuring dignity and mana.

a. Autonomy and conflicts of interest

Autonomy represents self-governance in decision making. Respect for autonomy requires that decisions are made with the provision of appropriate information and are free of coercion. Information must be presented in a manner which is accessible and understandable for all. For example, considerations must be made to ensure people with learning difficulties are provided the same content of information as any other participant, but in a form that is considerate of their needs. This may include the provision of supported decision-making processes.

It is important to ensure autonomy is upheld by ensuring that individuals are not consciously or unconsciously coerced into ADD. It is important to design processes that will protect the most vulnerable, which will ensure they are suitable for the entire population. This may also include multiple formats or methods of communication to ensure that equity of access to information is achieved.

Self-governance occurs within the context of an individual's own values, beliefs and preferences. For healthcare this translates to the concept of informed consent.

Similarly, Māori retain the right to self-determine their path through the AD process according to Māori beliefs, values and practices. This right to self-determination is enshrined in Tino Rangatiratanga, article 2 of Te Tiriti o Waitangi.

Consent for ADD would differ from other deceased donation in that it is always first-person and contemporaneous. Advantages are the ability to determine the potential donor's exact wishes without the use of deemed consent or surrogate decision makers. This would include the ability to seek informed consent for additional pre-mortem interventions if necessary.

A specific ethical issue for ADD, however, is the potential for interaction of the AD and Donation pathways once both have been initiated (Sylva et al., 2023; Mulder et al., 2022; Downar et al., 2019; Yazdani et al., 2018). Potential concerns are:

1. The initial and ongoing decision to proceed with AD might be unduly influenced by the person's altruistic decision to donate.

2. The interactions with healthcare providers around the donation process may create a conflict of interest with potential for coercion to continue both pathways. International experience thus far suggests that this concern can be addressed by incorporation of appropriate safeguards in decision-making into policies for ADD.
3. Patients without a suitable place to have an assisted death may choose to pursue ADD in order to be given a place in a hospital for their assisted death.

We propose the following as safeguards for these concerns:

1. Separation of decision-making processes. Discussion and decision making for AD should be separate from, and precede, any discussion of ADD. AD providers who assess eligibility for AD should not be involved in assessing eligibility or obtaining consent for organ donation. If approaches are made to ODNZ prior to the decision to proceed with AD then any further discussion would be respectfully deferred until after the AD process had been confirmed.
2. Separation of roles. The AD and donation pathways should involve different teams. Donation surgery or transplant teams should not be involved in any way with decision making around ADD or the AD death, including confirmation of death (other than providing advice regarding potential eligibility or pre-mortem interventions).
3. AD and organ donation providers must be satisfied that enabling donation is not the principal reason for the individual to choose AD. This will involve consultation between the two sets of providers.
4. A reflection period of a minimum of 48 hours will be provided within the process following the initial conversation with a donation specialist to allow the individual to consider the information they have been given on donation and how the donation process might impact their experience of AD.

A question for consideration is how donation is raised once consent for AD is given (i.e. whether to offer it as an option to all individuals undergoing AD). A conservative approach to this would be to only discuss donation after the patient themselves has raised it with AD providers. However, this may require individuals to have pre-existing knowledge or consideration of the opportunity to donate after death. This may not be equitable and potentially only the most well-informed individuals will have the opportunity to consider donation.

Another conservative, but more equitable, approach is that the opportunity to consider ADD is in the paperwork or a link to written information is provided. This is the current preferred option for Organ Donation New Zealand. The Attending Medical Practitioner for AD would also be provided with basic information regarding the ADD process and would defer all further information sharing to the ODNZ team.

All points where donation is raised—whether in paperwork, conversation or hospital admission - should include accessible communication (Easy Read, NZSL, large print, AAC-compatible digital formats) and the proactive offer of an independent disability advocate.

It may be appropriate to engage the services of Personal Advocacy and Safeguarding Adults Trust (PASAT) at this stage to ensure that the needs of those with learning difficulties are met in this process.

A Tino Rangatiratanga aligned approach may be to consider a verbal kanohi ki te kanohi discussion, utilising wānanga in a respectful and pressure-free way. Where providers are able to raise the possibility of donation with every individual following confirmation of the AD process. This may be seen as the most equitable approach for access to donation as part of end-of-life care, depending on language and resources used, to diminish the effects of health literacy, written language and communication barriers, and access to digital technology. This practice has already been adopted in Ontario and British Columbia but no other Canadian provinces (Sylva, et al., 2023).

The need to maintain consent for both pathways through until the time of AD medication administration raises further potential points of interaction. Additional safeguards proposed are:

5. The recognition by both AD providers and donation specialists that provision of consent is a dynamic process. Patients may revoke consent for AD and/or donation at any time or decide to postpone the AD process.

6. The recognition that decisions to revoke consent for donation will not affect the patient's eligibility to pursue AD at a time or manner of their choosing.

7. Similarly, the decision to postpone AD will not affect the ability to pursue organ or tissue donation at a later date (potentially pending repeated assessment of eligibility closer to that time).

8. If the person loses competence to consent at any point, for example due to worsening of their underlying illness, then neither AD nor ADD would proceed (tissue donation after death would still be possible following standard pathways).

b. Directed Donation

Directed donation (donation to a specific named individual) in deceased organ donation is rarely undertaken and requests for it are only considered on a case-by-case basis by ODNZ and Transplant Services according to an established policy (Directed Donation from Deceased Donors, ODNZ Internal Policy 2012). This policy details the procedural steps and consultation required to respond to a request for directed donation with appropriate ethical safeguards in place.

Directed donation is not permitted to be discriminatory against individuals or groups, or to conflict with urgent allocations on transplant waiting lists. Directed donation could raise the potential for undue influence to maintain consent for both pathways in ADD. This scenario, if undertaken, would require both donation and transplant teams to be assured that no such coercion was present. This may require wider consultation, for example with clinical ethics committees or clinical psychological expertise (Lewis et al., 2023). It may also require legal consultation.

Directed donation would not be offered or encouraged in ADD conversations but could be considered on a similar case-by-case basis as currently occurs. This would align with the principles for consideration of directed donation outlined in Canadian national guidance documents for ADD (Downar et al., 2019).

Any discussions regarding directed donation may need to first occur without the presence or involvement of the potential recipient, or others with a potential conflict of interest, even if they are close family members.

c. Shared Decision-making and Assisted dying and donation

> ***"True ethical autonomy is not achieved by simply offering more choices. It is achieved by ensuring that the conditions surrounding those choices are free from coercion – including internalised coercion. Without this recognition, policy risks validating decisions rooted not in empowerment, but in despair masked as altruism."***

Quote from feedback provided by an Ethics advisor with lived experience of disability.

Healthcare providers should provide information and support for an individual's decisions regarding their own healthcare in a manner that reflects respect for the individual's values and beliefs. A competent person retains full autonomy to make their own decisions, but it is considered good practice to (with appropriate consent of the individual) involve whānau in shared decision making.

With regards to AD there is no legal obligation of the person to inform whānau they are undergoing AD. This right for an individual to keep their decision to pursue AD confidential from others is codified in the EOLCA (2019). Therefore, there would be a responsibility to uphold this within the ADD process also if required, leading to the issue of conflict of the right to self-autonomy with the wishes of family if these are not in alignment. It would be the preference of ODNZ that this scenario does not arise, if possible. ODNZ would be committed to extensive conversations and support to try to have the whānau and patient aligned in their wishes. This would require sensitive management to maintain public trust should the family not be aware of AD and/or ADD occurring.

As opposed to Western centring of individual autonomy, the concept of whanaungatanga is centred in Te Ao Māori, representing the interconnectedness of all things and individual obligations and responsibilities in that regard. A higher emphasis is made on collective decision making by whānau and the individual's place within the whānau. This may create an apparent tension with the principle of absolute individual autonomy in decision making in ADD, if an expectation of distributed autonomy may be the norm. Māori are a diverse people and may have differing degrees of relationship with Te Ao Māori. Therefore, it would be important to explore this relationship in the context of an individual's own values and beliefs, with cultural support advice where appropriate, rather than making generalised assumptions with respect to culture. The issue of distributed autonomy may occur in ethnic groups other than Māori.

Respect for autonomy also requires supported-decision-making (SDM). For individuals with disability, clinicians must presume capacity, exhaust all reasonable accommodations, and document supports provided before declaring a person incapable. It is recommended that an advocate trained in disability rights (PASAT) should sit in every ADD consent meeting with individuals with disabilities to confirm the individual understands that Assisted Dying and organ donation are separate, revocable pathways, and to monitor for subtle altruistic coercion. Their role would also be important as an additional safeguard against internalised oppression as a form of unconscious coercion.

d. Balancing Benefits and Harms

These concepts require weighing potential benefits of ADD against any potential harms and ensuring harms are proportionate to such benefits. These must be discussed in the context of the individual's own values and without bias or influence from healthcare providers.

It is important to acknowledge that framing around altruism is not necessarily neutral and may disproportionally affect marginalised individuals. This is evident not only in the concept of ADD, but also specifically relating to Pre-Mortem interventions.

The best interests of the individual may extend beyond the patient's self-interest in their health and wellbeing to include their altruistic concern for others. They should also be considered to extend beyond the moment of death, as donation may fulfil these concerns. Therefore, a holistic approach balances risk of harm against the individual's autonomous wish to donate. A specific advantage of ADD over other deceased donation is that possible benefits and harms can be discussed with the potential donor.

Potential harms arising from ADD could be considered to include how end-of-life care may be altered by the donation process. These include the need for admission to hospital to facilitate donation surgery, a change in the experience of death for both the individual and whānau and the presence of other healthcare personnel not previously known to the potential donor at the time of death. A specific consideration for Māori is respect for wairuatanga and the need to maintain appropriate tikanga around the process of death and bereavement in the face of the donation process.

In a manner similar to other DCD, there may be pre-mortem interventions (PMIs) proposed that are of no therapeutic benefit to the donor but facilitate eligibility for donation of specific organs or improve likelihood of successful transplantation, thereby benefitting recipients (Then et al, 2023). These may differ in the degree of invasiveness, from blood tests that could be taken at home to investigations that require attendance at a medical facility, or the administration of blood thinning medication. In facilitating successful donation, PMIs may still fulfil a person's strong wish to become a donor, hence the need to discuss them in the context of the patient's values.

Potential safeguards proposed for the process of considering PMIs are:

1. All interventions should be discussed as part of the shared decision-making process of informed consent. This would be in terms of the necessity of interventions to facilitate donation and their potential impact on end-of-life experience. Some interventions may be more acceptable than others to patients. Acceptability to patients will inform further discussion with transplant teams regarding eligibility for donation of specific organs or tissues.

2. The impact of PMIs on the quality of end-of-life care experience can be minimised and tailored to each individual. For example, blood tests can be taken at home visits or investigations can be co-ordinated with admission to hospital immediately prior to AD and donation surgery. This may decrease the burden of travel to medical facilities.

3. The decision to accept or refuse PMIs, where possible, should not impact the ability to undergo AD or affect the quality of the AD process.

4. An all-or-nothing model of PMIs should be avoided. PMIs should be adapted to allow donation to proceed. Declining some PMIs may still allow donation of certain organs.

5. It is important that decisions regarding PMIs are free from coercion, both external and internal. Healthcare professionals involved in assisted dying and donation must be trained in the dynamics of ableism, internalised oppression, and systemic bias, to better assess whether a choice is truly autonomous.

e. Equity and justice

For ADD, equity and social justice concerns require addressing equity in distribution of and access to the benefits of organ and tissue donation, including those that arise from altruistic motivation as outlined above. Requests to donate should be considered for all individuals without prejudice or discrimination based on clinically irrelevant factors such as ethnicity or other social or disability grouping. All interactions should be culturally safe but assumptions about preferences based on cultural affiliation should be avoided and each person treated as an individual with their own values and beliefs. This extends to impartial communication of the risks and benefits of donation to potential donors and may require enlisting Cultural Support or Language Interpretation resources to ensure there are no barriers to the opportunity to make an informed decision about donation.

f. Solidarity and Community Reciprocity

Solidarity can be defined as the commitment to shared values or challenges and recognises the importance of altruism. It is aligned with the concept of reciprocity in that those who may benefit from transplantation have a reciprocal obligation to participate in the opportunity to donate. The principles of solidarity and reciprocity also recognise that transplantation for individuals with organ failures is dependent on preceding organ donation and there is an ongoing unmet need for organ transplantation. Facilitating an individual’s wish to donate after assisted dying fulfils both these ethical principles.

g. Provider Wellbeing

AD and ADD can be for confronting for healthcare professionals (HCP). Initially the process may be particularly emotionally heightened. Donation, hospital and transplant teams will need collegiality, flexibility and support. Pre-briefing of all involved in the process will need to address provider wellbeing. Training on Tikanga Māori, anti-ableism, disability culture, cultural safety and accessible communication should be embedded in pre-briefings alongside psychosocial support. Additional debriefing and peer support for those involved will be required following each interaction and also following donation. This may include issues that arose and any mitigation, as well as reflections on any discomfort or bias staff experienced, allowing for these insights to be included in updates for future practice and education.

h. Conscientious Objection to Assisted Dying

A right of conscientious objection exists within healthcare under which healthcare providers may refuse to participate in provision of certain healthcare processes. This right is conferred on health providers as individuals. It does not preclude an organisation from putting systems in place to support patient access to such healthcare processes, and involving other health providers who do not have a conscientious objection in delivering such services.

Within the AD process conscientious objection is recognised as a right within the EOLCA (2019). No HCP is obliged to participate in AD if it conflicts with their personal moral or ethical values. As this process would involve practitioners other than the AD provider (for example donation specialists and hospital staff), this right would also need to be upheld within the ADD process. This may require contextual discussion with provider staff in the work-up and pre-briefing. Whilst conscientious objection is respected at an individual level, at an organisational level it should not be a barrier to the access of ADD for an individual, or provision of appropriate care of the individual and their whānau at the time of AD.

It is important to clarify that one is not required to be a conscientious objector in order to choose not to be involved. Involvement in the ADD process is entirely voluntary, and in keeping with the principles that underpin the End of Life Choice Act.

It should also be noted that current practice for donation is that donor details are kept anonymous from recipients. Only increased medical risks are disclosed to recipients (such as some infectious diseases). ADD would not in and of itself present an increased medical risk and therefore does not fall within this obligation to disclose (Yazdani, Buchman, Wright , & Chandler, 2018). Additionally, organs may be currently transplanted from donors who have died through suicide. There is no obligation to disclose this to the recipients even though they may have a moral objection to suicide.

14. Implementation of Assisted Dying and Donation

As the national agency for organ and tissue donation in Aotearoa New Zealand, ODNZ will oversee the clinical implementation of ADD in conjunction with Assisted Dying Providers, clinical hospital staff and Transplant Services. Experiences from ADD implementation will inform future updates to clinical and ethical guidance. Oversight for ODNZ practice in ADD will rest initially with the Organ and Tissue Clinical Governance Sub-committee within NZBS. This oversight will include review of clinical guidance and standard operating procedure documents produced for the process, as well as planned review of the first five cases of ADD to ensure the process is being undertaken within the appropriate legal, ethical and clinical standards. Additionally, review will be undertaken with the Support and Consultation for End of Life in New Zealand (SCENZ) Group to ensure AD and ADD pathways are proceeding in a mutually appropriate manner.

It is recognised that a broad range of health care professionals may be involved in ADD: Primary Care Physicians, Assisted Dying Providers, Donation Specialists, Hospital Operating Theatre and ICU staff, Donation Surgical Teams, Tissue Banks and Transplant Teams. Therefore, education and training resources will be provided on ADD processes. Discussions with appropriate clinical forums including SCENZ, Community Primary Care and Chief Medical Officers have been or will be undertaken to support the implementation of the program.

ODNZ recognises that some staff may not yet have made definitive ethical judgments on issues such as ADD. They may face barriers to speaking out due to hierarchical structures within the medical profession. These healthcare professionals may be vulnerable to external influences or participate in actions they find personally uncomfortable or ethically ambiguous. We need to be vigilant for such occurrences. While some may wish to be involved in ADD, our proposed processes are designed to exclude junior staff, thereby safeguarding their ethical autonomy and well-being.

As is standard with current deceased donation, routine follow-up of whānau of donors will be offered.

Additionally, as highlighted above, specific attention will be given to HCP wellbeing in the context of involvement with this process. This will include debriefing of cases and access to clinical supervision and counselling.

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