Service description for assisted dying service for primary and private services (non-DHB funded)

1. Purpose of this document

1.1. The assisted dying service supports people with a terminal illness to request medical assistance to end their lives.

This service description sets a framework for the requirements for the assisted dying service that will be claimed for under the section 88 notice[1]. It provides context and details of the process of providing the assisted dying service, including what health practitioners are expected to complete for the overall service and for each payment module.

This includes the assessment of eligibility and the process that follows, noting that this process depends upon the outcome of the assessment of eligibility and the ongoing decisions of the person requesting assisted dying.

2. The End of Life Choice Act 2019

2.1. The purpose of the End of Life Choice Act 2019 (the Act) is to give a person who has a terminal illness and who meets certain criteria the option of requesting medical assistance to end their life. The Act establishes a lawful process for assisting eligible persons who exercise that option.

The Act contains multiple safeguards for the person requesting assisted dying, including the ability to stop or defer their request at any stage prior to the administration of the medication. Ongoing consent is verbally requested throughout the assessment and service delivery process. If consent is withdrawn or pressure (coercion) is suspected the process must stop immediately.

Eligibility must be confirmed by two medical practitioners. This includes assessing if a person is competent to make an informed decision – competence is not presumed under the Act. If either or both medical practitioners feel the person would be eligible but have questions about the competence of the person requesting assisted dying to make an informed decision, a psychiatrist can be asked to provide an opinion of competence.

2.2. The Act is prescriptive in how the assisted dying service should be delivered. This service description provides further detail to the process outlined in the Act, in the same way that a Service Specification may provide for other health services. The service description intends to break down each step of the assisted dying process so that practitioners know what is involved and how they may be reimbursed for providing these services.

[1] The section 88 Assisted Dying Notice is a notice under section 88 of the New Zealand Public Health and Disability Act 2000.

3. The objectives of the assisted dying service are to:

3.1. enable people to exercise their right to request assisted dying

3.2. provide a safe, timely and effective service for accessing an assisted death

3.3. ensure appropriate safeguards are in place, including that informed consent is present throughout the process and the person is aware they can change their mind at any stage prior to the administration of the medication

3.4. provide an assisted dying service that administers medication that hastens death in a way that reflects the culture and values of the person being delivered assisted dying services and/or reflects a Māori worldview of health and is framed by Te Tiriti o Waitangi

3.5. ensure that a health practitioner delivering assisted dying services does so in a way that embraces, supports, and encourages a Māori worldview of health and provides high-quality, equitable, and effective assisted dying services for Māori framed by Te Tiriti o Waitangi. In the context of assisting dying services, this may include:

3.5.1. health practitioners having strategies in place to understand and address beliefs and values regarding physical, psychological, spiritual and cultural needs of Māori and their whānau

3.5.2. taking a more whānau-centred approach where the health practitioner asks the person seeking, or eligible for, assisted dying services what role the person would like their whānau to have in the assisted dying process

3.5.3. supporting access and equity to assisted dying services by enabling the health practitioner to travel to meet the person's needs in some cases.

4. Definitions/glossary for the purpose of the assisted dying service

4.1. **assisted dying** – means the act of a medical practitioner or nurse practitioner giving a person medication to relieve their suffering by bringing on their death or the taking of medication by the person to relieve their suffering by bringing on their death

4.2. **assisted dying process** – means the steps outlined in the Act that must occur as part of a person accessing assisted dying

4.3. **request for assisted dying** – means the clear request that a person would like to start the assisted dying process, noting that some conversations related to assisted dying may have taken place ahead of this request

4.4. **administration of the medication** – means the act of providing the medication on the day of the assisted death by one of the four methods as outlined in the Act

4.5. **the person** – means the person who has requested assisted dying

4.6. **attending medical practitioner (AMP)** – means the medical practitioner who provides the first eligibility assessment, delivers the opinion on eligibility and prepares and administers the medications.

4.7. **independent medical practitioner (IMP)** – means the medical practitioner who provides the second eligibility assessment. The IMP is provided by the SCENZ Group

4.8. **replacement AMP** – means the medical practitioner who agrees to take over responsibility for the provision of the assisted dying service if the medical practitioner to whom the request is made is not able to provide/complete the service. The replacement AMP is provided by the SCENZ Group. Once the replacement AMP has started providing assisted dying care they are known as the AMP

4.9. **attending nurse practitioner (ANP)** – means the nurse practitioner who administers the medications.

5. Statutory bodies and role

5.1. There are three statutory bodies provided for by the Act that will all have a role in providing quality standards, reporting information and in ensuring accountability for assisted dying services.

5.2. **Support and Consultation for End of Life in New Zealand (SCENZ) Group**

The SCENZ Group is established by the Director-General of Health. It includes:

- two members with an awareness of Te Ao Māori and an understanding of Tikanga Māori
- three members who are practising medical practitioners
- one member who is a practising psychiatrist
- one member who is a practising pharmacist
- one member who is a practising nurse practitioner
- one member with knowledge of ethics and law
- one member with a disability perspective
- one member who represents the views of patients, whānau and community.

The SCENZ Group makes and maintains a list of health practitioners who are willing to act as an AMP, a replacement AMP, an IMP, a pharmacist or a psychiatrist as part of the provision of assisted dying services. These lists will be privately held.

The SCENZ Group also prepares standards of care, advises on the required medical and legal procedures, and provides practical assistance if requested.

A practitioner is required to have completed specified training to receive funding through the section 88 notice for providing assisted dying services.

Medical or nurse practitioners who want to access this training can do so through the SCENZ Secretariat. The SCENZ Secretariat will sit within the Ministry of Health.

5.3. The Review Committee

The Review Committee is appointed by the Minister of Health. It includes:

- a medical ethicist
- two health practitioners, one of whom must be a medical practitioner who practises in the area of end-of-life care.

The purpose of the Review Committee is to consider the assisted death reports it receives and report back to the Registrar. It will direct the Registrar to follow up on any aspects of an assisted death report that does not show satisfactory compliance.

The secretariat for the Review Committee will sit within the Ministry of Health.

5.4. The Registrar (assisted dying)

The Registrar is a Ministry employee, nominated by the Director-General of Health. The Registrar will check that the processes required by the Act have been followed and notify the AMP of whether the process can continue.

In addition, their role is to establish and maintain a register recording the following:

- approved forms held by the Registrar
- the Review Committee's reports to the Registrar
- the Registrar's reports to the Minister.

The Registrar may also receive complaints about the provision of assisted dying services, including the conduct of health practitioners, and, if necessary, refer the complaint to the Health and Disability Commissioner, the practitioner's responsible authority, or the Police as appropriate.

6. Fee for service funding for assisted dying services

6.1. Medical practitioners, nurse practitioners and psychiatrists who are involved in providing assisted dying services can all claim for funding for providing assisted dying services through the section 88 notice. Each practitioner must hold an individual section 88 Assisted Dying notice. LINK

6.1.1. A medical practitioner acting as an AMP can choose whether they wish to offer the assisted dying service to their own patients and/or to register themselves on the list held by the SCENZ Group as being available as a replacement AMP, if available/practical to do so.

6.1.2. A medical practitioner acting as an IMP must be on the list held by the SCENZ Group and registered as being willing to provide an independent assessment if requested, and if available/practical to do so.

6.1.3. A nurse practitioner acting as an ANP can administer the assisted dying medication 'acting under the instruction of an attending medical practitioner'.

6.1.4. A psychiatrist providing a competency assessment as part of the assisted dying process must be on the list held by the SCENZ Group and registered as being willing to provide a competency assessment when requested, and if available/practical to do so.

6.2. Services provided by pharmacists will be contracted for under a separate contract.

6.3. An individual section 88 notice can be obtained by lodging the first payment claim or applied for beforehand. Obtaining a notice only needs to be done once. LINK to application process

6.4. To be eligible for a section 88 notice the practitioner must have completed (and be up-to-date with) the Ministry's required training and have recorded this with the SCENZ Group Link. The training will consist of online and practical learning that can be completed remotely.

6.5. To receive payment under the section 88 notice, a practitioner cannot charge the person a co-payment for an appointment that is part of the assisted dying process. A co-payment may be charged for the first appointment in which assisted dying is raised with a practitioner as this is not yet part of the assisted dying process.

7. Reporting and payment

7.1. The service is divided into five payment modules in the section 88 notice, reflecting each step of the process. Electronic forms for reporting and claiming in each module will be hosted on a secure IT platform. When the reporting forms are completed, an invoice[2] is automatically generated, so claiming and subsequent payment will occur automatically if the documentation has been completed correctly.

7.2. Where possible, electronic signatures will be used in the assisted dying service. An exception process will be available to print and sign forms. These forms will then be scanned and uploaded to the assisted dying application.

7.3. This reporting sits alongside the practitioner's usual professional obligations for clinical records. Forms needed for the assisted dying process record, such as the patient's signed consent form, can be downloaded from the assisted dying platform as pdfs for uploading into the practitioner's Patient Management system.

7.4. If at any point during the delivery of a module, the practitioner ceases to deliver assisted dying services due to the patient rescinding their decision, being declared ineligible, or pressure detected, payment occurs as if that module had been completed. Reasons for ceasing delivery of services may be because the person defers or rescinds their decision to receive assisted dying services, if pressure is suspected or if the person dies.

[2] buyer created tax invoice – only for people who are GST registered. If not GST registered they will be able to claim a GST exclusive amount.

8. Requests for assisted dying

8.1. Assisted dying conversations must not be initiated by a health practitioner. A person who wishes to exercise the option of receiving assisted dying must inform a medical practitioner of their wish.

8.2. An initial conversation about assisted dying may occur during a routine primary care appointment and a co-payment can be charged for this. If this conversation leads to the person wanting to make a formal request and start the assisted dying process, it is recommended a longer appointment is then scheduled to give further information and start the assessment process.

8.3. Health practitioners do not have to be involved in assisted dying services. Regardless of personal beliefs, practitioners should meet professional standards by not inhibiting a person's access to lawful medical treatment and ensure that continuity of care is maintained for a person requesting assisted dying.

8.3.1. **Conscientious objection:** If a medical practitioner with a conscientious objection is asked by a patient about assisted dying, they must inform the person of their objection, and tell the person that the person has the right to ask the SCENZ Group for the name and contact details of a medical practitioner who is willing to participate in assisted dying.

8.3.2. **Other reasons:** Practitioners may also have personal or practical reasons for not wanting to be involved in providing assisted dying services, this may include having the appropriate skills or experience to provide this care. Medical practitioners should consider their ability to be an AMP and to provide the full service before they start the assessment process. If a person requests assisted dying from a medical practitioner who feels they are unable to provide the service for reasons other than conscientious objection, they have a responsibility to ensure that the person can access this care and can provide the person with SCENZ contact details.

9. Eligibility for assisted dying

9.1 A person is only eligible for assisted dying if they are:

- aged 18 years or over, and,
- suffering from a terminal illness that is likely to end the person's life within six months, and,
- in an advanced state of irreversible decline in physical capability, and,
- experiencing unbearable suffering that cannot be relieved in a manner that the person considers tolerable, and,
- competent to make an informed decision about assisted dying.

9.2. A person is competent to make an informed decision about assisted dying if they can:

- understand information about the nature of assisted dying that is relevant to the decision
- retain that information to the extent necessary to make the decision
- use or weigh that information as part of the process of making the decision
- communicate the decision in some way.

10. Module One: first eligibility assessment – to be claimed by AMP

10.1. **Discussing the request:** As part of the first eligibility assessment, the AMP must:

- give the person information about the prognosis of their terminal illness, the irreversible nature of assisted dying and the anticipated impacts of assisted dying
- regularly communicate (by any means - can be telephone or email) with the person about their wishes at intervals determined by the progress of the person's terminal illness
- ensure that the person understands all of their options for end-of-life care, including palliative care, which may continue alongside the assisted dying process
- ensure that the person knows they can withdraw from the process at any time before the administration of the medication
- encourage the person to discuss their wishes with their friends and whānau and ensure they have time to do so
- ensure that they also have time to discuss their wishes with others they may choose to, such as carers or support workers, counsellors, spiritual or cultural support
- check they are aware that they are not obliged to discuss their decisions with anyone
- do their best to ensure that the person is not under pressure in their request for assisted dying. This may include conferring with other health practitioners who are in regular contact with the person or discussing with whānau members if this is agreed by the person
- record the actions they have taken in the first part of the approved form that requests the option of receiving assisted dying.

10.2. **Confirming the request:** The AMP should confirm if the person wants to make a formal request for assisted dying.

If the person wishes to proceed, the person must sign and date their section of this form, in the AMP's presence.

If the person needs someone else to sign on their behalf, for instance if they are unable to write, they can nominate someone, who signs in the presence of the AMP and the person requesting the assisted dying service. The AMP must submit the completed form to the Registrar.

10.3. **Completing the first assessment:** The AMP should determine whether a person meets the eligibility criteria (as outlined in 9).

The AMP will undertake an assessment of the person's eligibility for assisted dying which will include reviewing the person's clinical record, examining them and reaching an opinion. At the end of the process, the AMP will reach the opinion that the person requesting the option of receiving assisted dying is:

- eligible for assisted dying or
- is not eligible for assisted dying or
- would be eligible for assisted dying if competency is established.

The AMP must discuss their opinion with the person and explain the next steps.

If the AMP's opinion is that the person is ineligible, where relevant, they must refer them back to their GP. If the AMP's opinion is that the person is ineligible due to not being competent, they should share this decision with the person's support person, with consent.

10.4. Reporting and claiming

The AMP must complete an approved form recording their opinion and send the completed form to the Registrar. If the person is considered by the AMP to be ineligible, the process ends at this point.

If the person is judged eligible by the AMP, the completed form will notify the SCENZ Group that the process for the second opinion can start and it will provide the name and contact details of an IMP.

This is the end of Module One of the section 88 notice and completion of the form will generate payment for Module One.

If a Replacement AMP is required at any stage, they may need to complete the first opinion again: this is dependent upon the circumstances and will be decided following discussion with the Registrar. If they do complete the reporting and claiming for Module One and payment will be made accordingly.

The Pricing Schedule for Modules One to Four contains options for practitioners claiming travel to visit a patient if the practitioner considers it desirable to do so.

11. Module Two: second eligibility assessment – to be claimed by IMP

11.1 Assessment

The person's clinical record will be collated by the Ministry of Health. The IMP must read the person's clinical record, examine them and will reach the opinion that the person:

- is eligible for assisted dying, or
- is not eligible for assisted dying or
- would be eligible for assisted dying if competency established to make an informed decision about assisted dying.

The IMP must share their opinion with the person.

If the IMP's opinion is that the person is ineligible due to not being competent, they should share this decision with the person's support person, with consent.

There may be a need or an opportunity for a collaborative discussion between the AMP and IMP at this point. If necessary, the Registrar should facilitate this for them.

11.2 Reporting and claiming

The IMP must complete an approved form recording their opinion, send the completed form to the Registrar, copied to the AMP. This is the end of Module Two of the section 88 notice and completion of the form will generate payment for Module Two.

12. Module Three – competency assessment – to be claimed by psychiatrist (optional)

12.1. Assessment

If the AMP and IMP agree that a person would be eligible for assisted dying, but have concerns over the person's competence, they can request that a psychiatrist completes a competency assessment.

The SCENZ Group, notified by the completion of the electronic form, will facilitate the process for the psychiatrist's opinion on whether the person requesting the option of receiving assisted dying is competent to make an informed decision about assisted dying.

The psychiatrist must read the person's clinical record and assess the person. They will reach the opinion that either the person is competent or not competent to make an informed decision about assisted dying, noting their role is to determine competence and not other eligibility.

The psychiatrist must share their opinion with the person. If they deem the person not competent, they should share this decision with the person's support person, with consent.

12.2 Reporting and claiming

The psychiatrist must complete the approved form recording their opinion and send the completed form to the Registrar, which will be automatically sent to the AMP and IMP. This is the end of Module Three of the section 88 notice and completion of the form will generate payment for Module Three.

13. Module Four – opinion on eligibility – to be claimed by AMP

13.1. Opinion is reached that the person is not eligible for assisted dying

If the AMP, IMP or psychiatrist reach an opinion that the person is not eligible for assisted dying, they must explain the reasons to the person requesting the service. The IMP or psychiatrist must also inform the AMP of their reasoning as soon as is reasonably practical.

The AMP will have a further conversation with the person who is ineligible including providing some information about the options available to them, and possibly identifying the circumstances where the person might be able to re-apply for assisted dying services. To ensure continuity of care:

- if the AMP is not the person's usual general practitioner (GP), they will formally transfer care back to the GP
- if the AMP is the person's usual GP, this concludes their role as an AMP
- if the person has no GP, the AMP should notify the Registrar who will support the person to enrol with a GP if this is wanted by the person.

All subsequent conversations between the GP and the person can incur a co-payment.

13.2. Reporting and claiming

The AMP must complete the approved form recording this and send the completed form to the Registrar. This is part of Module Four and the end of the module if the person is ineligible.

13.3. Opinion is reached that the person is eligible for assisted dying

If the AMP, IMP (with or without the psychiatrist) agree that the person is eligible for assisted dying, including being competent to make an informed choice, the AMP must advise the person they are eligible for assisted dying. The AMP will discuss with the person the progress of their terminal illness and have a conversation about the likely timing for the administration of the medication.

The AMP then gives the person the form to complete to choose the date and time for the administration of the medication – this can be no more than six months in the future. The system will allow for both electronic via the secure IT platform, and manual forms – with electronic preferred where possible unless for instance there is poor connectivity in a rural location.

At this time the AMP may also want to discuss with the person what they would like their assisted death to look like so the person can start making appropriate preparations. This may include location, when family members who are wanted to be there are available and any spiritual or cultural decisions around what happens. It may also be an opportunity to manage expectations about AMP availability, travel implications.

13.3.1 Reporting and claiming

The AMP must complete an approved form recording the combined opinion and send the completed form to the Registrar, which will be copied electronically to the IMP and psychiatrist. This is part of Module Four.

13.4. Eligible person to choose date and time for administration of Medication

Not all eligible people will choose to proceed with the process at this point. They may wish to make a decision about time and date later (no more than six months ahead) or rescind.

If an eligible person wishes to receive assisted dying, the person must complete the approved form and return the completed form to the AMP.

Each time (if any) that an eligible person decides to defer the date for receiving the medication to a date later than on the form they must complete a replacement form stating the new date and time chosen on the form.

13.5. Reporting and Claiming

After the completed form is received, the AMP must send the form to the Registrar. This is part of Module Four.

13.6. Provisional arrangements for administration of medication

Before the date chosen for the administration of the medication by the eligible person, the AMP must explain the available options for administration. Under the Act these are:

(i) ingestion, triggered by the person
(ii) intravenous, triggered by the person
(iii) ingestion through a tube, triggered by the AMP or ANP
(iv) intravenous administration by the AMP or ANP

The decision of route chosen, rests with the person, but they are likely to seek guidance from the AMP. The AMP should ask the person to choose one of these methods and remind the person that at any time after completing the approved form they may decide to not receive the medication, to defer the time and date for receiving the medication, or to change their chosen administration route.

If they do choose to defer and the new time and date is six months or less than the original time chosen, only part of the process needs to be repeated. At no point in the process can the date be deferred for more than six months beyond the date first chosen. If this occurs an entirely new assessment process needs to be started.

At this point the AMP can make provisional arrangements for the administration of the medication on the chosen day and time and this is also an opportunity to discuss practical issues such as speaking with a Funeral Director, ensuring there are no unexpected visitors on that day, etc.

13.7. At least 48 hours before the chosen time for the administration of the medication

The AMP or ANP must write the prescription for the eligible person. Although the legislation states at least 48 hours prior to the chosen time, the AMP or ANP should give consideration to allow adequate time for approval, dispensing and the delivery of the medication kit to the AMP.

13.8. Reporting and Claiming

The AMP or ANP must advise the Registrar of the method and of the date and time chosen for the administration of the medication. The Registrar will check the processes have been complied with and if satisfied, will notify the AMP or ANP. This is the end of Module Four of the section 88 notice and completion of the form will generate payment for Module Four.

14. Module Five – the administration of medication – to be claimed by the AMP or the ANP

14.1. All medication will be provided pursuant to a prescription. Once the AMP has received notification from the Registrar that the process has been approved, the prescription is dispensed. The Registrar will send the approved prescription to the dispensing pharmacy.

14.2. Assisted dying medication and administration equipment will be delivered securely in a standard kit to the prescribing AMP / ANP.

Two medications kits will be available. Provision will be based on the person's choice of medication administration (and the prescription):

a. Oral kit – containing oral medication (suitable for oral or feeding tube administration), a back-up set of intravenous medication provided in case the oral / tube route is compromised, plus administration equipment for all routes.

b. Intravenous kit – containing two sets of intravenous medication; the second set provided in case the first set is compromised, plus administration equipment.

Intraosseous needles will also be provided in case the intravenous route is compromised.

Intraosseous needles and feeding tubes (with associated accessories) will be ordered, as needed, from the supplying pharmacy separately to the medication kits.

14.3. Pharmacists will prepare assisted dying medications in accordance with the Pharmacy services Standard (NZS 8134.7:2010) that defines the quality and safety requirements for the provision of community and hospital-based pharmacy services.

14.4. All practitioners delivering assisted dying services must comply with the standard for the administration of assisted dying medication that is issued by the SCENZ Group.

14.5. Prior to the administration of the medication, the AMP or ANP must assess their competence to provide consent.

14.6. At the chosen time for the administration of the medication, the AMP/ ANP must ask the eligible person if they choose:

- to receive the medication at that time; or
- not to receive the medication at that time, but to receive the medication at a later date no more than 6 months after the date initially chosen; or
- not to receive the medication at that time, and to rescind their request to exercise the option of assisted dying.

14.7. **If the eligible person chooses to receive the medication** the AMP or ANP must provide or administer the medication to the person by the agreed method. The AMP or ANP must remain available to the person until death occurs or arrange for another medical practitioner or ANP to be available to the person until the person dies**.**

14.8. **Reporting and Claiming** see 'Death to be reported' (14.15).

Travel reimbursement is included in Module Five claiming and will be described in the pricing schedule, arranged in time bands. There are additional options for out of area travel and these claims will be considered and payment will be at the Ministry's discretion. This includes requests for flights and accommodation which need to be pre-approved.

Supervision: The pricing schedule also allows for an AMP or ANP to supervise an AMP or ANP who is administering medication under the Act for the first time.

14.9. **If person defers their chosen date and time to receive assisted dying,** the AMP/ANP must immediately take the medication away from the person returning the complete medication kit to the supplying pharmacy as soon as practicable or destroy the prescription. The person can receive the medication at a later date no more than 6 months after the date initially chosen for the administration of the medication under the same application. A new prescription and medication kit will be required.

14.10. Reporting and claiming - if the person chooses not to receive the medication at the chosen time, the AMP or ANP completes the approved form and sends it to the Registrar. This is part of Module Five.

14.11. If person rescinds their request for assisted dying the AMP/ ANP must immediately take the medication away from the person, returning the complete medication kit to the supplying pharmacy as soon as practicable, or destroy the prescription. No further action is to be taken. If at any subsequent time the person wishes to again request assisted dying, they may make a new request.

14.12. Reporting and claiming - if the person rescinds their request for assisted dying the AMP or ANP completes the approved form and sends it to the Registrar. This is part of Module Five.

14.13. If pressure is suspected, the AMP or ANP must immediately take the medication away from the person or destroy the prescription. No further action is to be taken.

14.14. Reporting and claiming - if pressure is suspected the AMP or ANP completes the approved form and sends it to the Registrar. This is part of Module Five.

All unused medication and administration equipment must be taken away from the person and returned to the supplying pharmacy using signature required courier as soon as practicable.

14.15. Death to be reported

Immediately after person's death as a result of assisted dying the AMP or the ANP who provided or administered the medication must provide a certificate of cause of death, unless a Coroner has opened an inquiry into the death.

The certificate of cause of death, in the case of a death by assisted dying, includes information about:

- the terminal illness that gave rise to the person's eligibility for assisted dying
- the fact that the person died as a result of assisted dying under that Act
- the interval between the onset of the cause of death and the death
- the interval between the onset of the terminal illness that gave rise to the person's eligibility for assisted dying and the person's death by assisted dying.

Within fourteen working days of a person's death as a result of the assisted dying service, the AMP or the ANP who provided or administered the medication must also send the Registrar a report in the approved form. This is part of Module Five.