



# Hospice New Zealand Breakfast Lecture Series

*Holding the Space Between: How End of Life Doulas Complement Palliative Care*

## Questions and Answers

Thank you to everyone who joined our Hospice New Zealand Breakfast Lecture Series presentation, *Holding the Space Between: How End of Life Doulas Complement Palliative Care*.

We received many thoughtful questions and were not able to answer them all during the session. We have grouped responses below to continue the conversation and provide clearer information about End of Life Doula practice, training, scope, funding and how Doulas can work alongside individuals, whānau, hospice, palliative care and other healthcare professionals across Aotearoa.

End of Life Doulas do not replace hospice, palliative care or clinical services. They complement existing care by supporting the emotional, practical, relational, spiritual and planning needs that sit around the person and their whānau at end of life.

### Why End of Life Doulas Matter

**Q: Gaylene, would the increasing workload of Nursing & the focus becoming more medically & clinically modelled. Was this one of the reasons you chose to become a Doula?**

In short, yes. Unfortunately, with the increase in workload for nurses, the consequence is often that once the medical and clinical aspects of the role are completed, there is very little, if any, time left to consider the spiritual, emotional, practical and relational dimensions of care. I feel these aspects are just as important as the clinical.

### Finding and Accessing an End of Life Doula

**Q: Is there a contact for Doulas in the Otago district?**

Yes. ELDAA currently has Professional Member End of Life Doulas based in the Otago region, with others in training.

The easiest way to find a Doula is through the [ELDAA website directory](#). You can also contact ELDAA directly at [info@eldaa.org.nz](mailto:info@eldaa.org.nz) and we will happily help connect you with a Doula in your area where possible.

**Q: Is Doula support available in provincial towns or only larger cities?**

End of Life Doula support is becoming increasingly available across Aotearoa. While more Doulas are based in larger centres, many also support people in provincial and rural communities, including through flexible or blended ways of working.

**Q: How does one find an End of Life Doula?**

The easiest way is through the [ELDAA website](#), where you can search the directory of Professional Members across Aotearoa and read their bios.

If you are unsure who might be the best fit, you are welcome to contact ELDA directly at [info@eldaa.org.nz](mailto:info@eldaa.org.nz) and we can help point you in the right direction.

**Q: Is it self-referral? Or does a GP need to send a referral?**

No formal referral is required. Individuals and whānau can contact an End of Life Doula directly.

Referrals may also come from a GP, hospice, hospital team, community organisation, aged residential care provider or another healthcare professional. We welcome these conversations and are always happy to discuss how End of Life Doula support can complement existing care.

**Q: I see on the ELDA website there is a list of Doulas across Aotearoa.**

Yes. The [ELDA directory](#) lists our Professional Members throughout Aotearoa.

## Funding, Fees and Availability

**Q: Is End of Life Doula support a pay for use service or a voluntary service? What about negotiating recompense?**

Most End of Life Doulas are self-employed and charge directly for their services, although many offer a free initial conversation so people and whānau can understand what support may be helpful.

Fees and arrangements vary. Many Doulas offer sliding scale fees, koha arrangements, reduced rates or pro bono support where they can. ELDA recognises the importance of equitable access, while also acknowledging that sustainable funding is needed if more people and whānau are to benefit from this care.

As awareness grows, we would welcome conversations with hospice, palliative care, community organisations, funders and health providers about collaborative models that improve access to End of Life Doula support across Aotearoa.

**Q: Where does funding come from for the Doula service?**

Please see the funding answer above.

At present, most End of Life Doula services are paid for privately, although some Doulas offer reduced fees, koha, sliding scale or pro bono support where possible. ELDA would welcome future funding models that improve equitable access while recognising the value Doulas can bring alongside existing health and community services.

**Q: Do End of Life Doulas get paid and if so, how does this work?**

Please see the funding answer above.

**Q: The role of Doulas sounds very valuable. How are Doulas funded?**

Please see the funding answer above.

**Q: How easy is it to access? What is the general time given to each client?**

Access varies depending on location and Doula availability, but people and whānau can contact a Doula directly through the [ELDA directory](#) or by [contacting ELDA](#).

There is no set amount of time allocated to each person. One of the strengths of the Doula role is its flexibility. Support may range from a few planning conversations through to ongoing support over weeks or months, bedside presence, vigil support and after death care.

**Q: Valuable and worthwhile enterprise. My questions echo those above around funding, access and referral. Also, is this available 24/7? As a Paramedic we pick up from most services after hours. Is this another example of this?**

A Doula's availability is discussed openly with the person and whānau from the outset, so expectations are clear. Some Doulas offer evening, overnight, weekend or short notice support where possible, but availability varies.

End of Life Doulas do not replace urgent clinical care, hospice services, primary care or emergency services. If clinical concerns arise, our role is to encourage the person or whānau to contact the appropriate healthcare provider.

Where appropriate, and with permission, we can support that communication and continue providing non-clinical, emotional, practical and whānau-centred support.

## Training, Standards and Public Protection

**Q: What training do Doulas have, both as preparation for the role and during the role?**

End of Life Doula training varies internationally, which is why ELDAAs has developed clear Professional Standards for its Professional Members.

To become an ELDAAs Professional Member, Doulas must complete recognised training through an ELDAAs Education Partner and demonstrate readiness to support people and whānau safely and ethically. This includes palliative care foundations, Advance Care Planning, communication, professional boundaries, cultural responsiveness, ethics and an understanding of New Zealand's assisted dying legislation.

End of Life Doula practice is not currently regulated in New Zealand. ELDAAs's role is to strengthen safety, accountability and consistency through its Scope of Practice, Code of Ethics, Core Competencies, Professional Standards, ongoing professional development and mentorship.

**Q: As an unregulated role, how are the public protected?**

End of Life Doula practice is not currently regulated in New Zealand, so ELDAAs has established safeguards to support safe, ethical and accountable practice.

Professional Members are expected to meet eligibility criteria, demonstrate ELDAAs's Core Competencies, practise within our Scope of Practice, Code of Ethics and Professional Standards, and commit to ongoing professional development and mentorship.

Professional Members also use written service agreements so expectations, roles and boundaries are clear from the outset. ELDAAs has a complaints process, and many Professional Members also hold professional indemnity insurance.

**Q: You mentioned earlier what doesn't sit within the scope of an End of Life Doula. What does New Zealand specific cultural safety, risk management and boundaries training look like for End of Life Doulas? And if risk arises, where does this responsibility sit, given Doulas may be working in contracted roles?**

Cultural safety, professional boundaries and risk management are core parts of ELDAAs's Professional Standards.

We recognise Te Tiriti o Waitangi as Aotearoa's founding document, and our understanding of wellbeing is informed by Te Whare Tapa Whā. We also recognise that every person's culture,

beliefs and traditions are unique. Doulas are expected to approach each person and whānau with curiosity, openness and humility, taking time to understand what matters most to them.

Doulas are also expected to understand their scope, recognise when something sits outside it, and know when to involve the appropriate healthcare professionals.

If concerns arise that are clinical in nature, responsibility remains with the appropriate healthcare provider. The Doula's role is to recognise the concern, support timely communication with the healthcare team where appropriate, and continue providing non-clinical support.

Clear roles, mutual respect and open communication help End of Life Doulas and healthcare professionals work safely and collaboratively in the best interests of the person and their whānau.

#### **Q: Is there any thought to include training for Doulas under the NZQA umbrella?**

As the profession continues to grow in Aotearoa, conversations like this are likely to continue.

ELDAA's current focus is on ensuring Professional Members are well trained, practise safely and ethically, and meet our Professional Standards. Whether or not training eventually sits within the NZQA framework, our priority will remain high quality education that prepares Doulas well for practice and reflects the New Zealand context.

### **Working Alongside Hospice, Palliative Care and Clinical Teams**

#### **Q: Question for Gaylene - was Hospice involved in the situation of the man discharged home for EOL care?**

Yes, they were and because of this, the necessary home equipment such as a hospital bed was already in place. My phone call for this man occurred on a Friday and it was late on the Friday afternoon before he returned to the family home. Thus, out of hours for the local hospice to provide support. By the time the RN arrived on Saturday, he had already passed.

#### **Q: If Hospice is involved and you get a call about clinical concerns, do you contact Hospice or advise the whānau to do this?**

If a clinical concern arises, our first step is to encourage the person or whānau to contact the appropriate healthcare provider. If hospice is already involved, that will often be the right place to start.

With the person's permission, a Doula may support the whānau to make that contact or liaise with the healthcare team. However, clinical responsibility remains with the appropriate healthcare provider.

The Doula's role is to recognise when something sits outside our scope, support timely communication, and continue providing non-clinical support.

#### **Q: Will a Doula give medication that has been provided at home to use PRN?**

No. Administering medication is outside the Scope of Practice of an End of Life Doula.

Medication should only be administered by an appropriate healthcare professional, or by a family member or caregiver who has been authorised and instructed to do so by the healthcare team.

**Q: How do you work in a situation when, after the person is no longer able to speak for themselves, the family does not want to uphold the person's wishes?**

This can be one of the most challenging situations for everyone involved, which is why End of Life Doulas encourage early conversations about values, preferences and Advance Care Planning.

Where appropriate, we encourage people to appoint an Enduring Power of Attorney for Personal Care and Welfare, ensuring someone they trust can make decisions on their behalf if they lose capacity.

If differences arise after a person is no longer able to speak for themselves, our role is not to make decisions or mediate legal disputes. We can help facilitate respectful conversations, remind people of the person's previously expressed wishes where appropriate, and encourage involvement of the healthcare team. Any decisions must be made within the relevant legal and clinical frameworks.

Throughout, our role is to support the person and their whānau with compassion while helping maintain communication and relationships wherever possible.

**Q: How is this space created within a long-term care facility? How, as an RN, do I facilitate this?**

It is wonderful to hear you are thinking about how to create more of this where you work.

We are seeing growing interest from long-term care facilities in how End of Life Doulas can complement the care already being provided. One place to start is by connecting with your local End of Life Doula to explore how they might support your facility through education, workshops or conversations with staff and management.

End of Life Doulas can work alongside care teams by supporting planning, communication, whānau conversations, emotional and spiritual support, vigil presence and after death care, while respecting the clinical role and responsibilities of the facility team.

## Cultural, Spiritual and Whānau Support

**Q: Tell us about connections with Christian, Muslim, Hindu, Buddhist supporters.**

End of Life Doulas support people of all faiths, cultures and worldviews. Our role is to understand what matters most to the person and whānau, and to support the beliefs, traditions, rituals and communities that are important to them.

Where helpful, we can work alongside ministers, priests, chaplains, kaumātua, imams, monks, celebrants and other spiritual or cultural leaders.

Where we are unfamiliar with a particular practice, we seek guidance and support rather than making assumptions.

**Q: Does ELDA cover the whole lifespan?**

Yes. End of Life Doula support can be provided at any stage of life.

This may include people who are well and wish to complete Advance Care Planning or document their end of life wishes, through to supporting infants, children, adults and older people with life-limiting illness.

Douglas may also provide support to whānau following a sudden death.

### **Q: How early in the end of life journey can a Doula provide support?**

End of Life Doula support can begin whenever it is needed.

In our experience, the earlier we become involved, the greater the opportunity to build relationships, have important conversations before there is a crisis, plan ahead and support people to make informed choices about what matters most to them.

We may also become involved during the final days or hours of life, or following a sudden or unexpected death to support whānau.

We are there to meet people wherever they are in their journey.

## **Research, Numbers and Future Models**

### **Q: Thank you for supporting patient choice and autonomy in dying, through your support with both natural and assisted death. Are you capturing any research in this area?**

Research into End of Life Doula practice, including support provided alongside assisted dying, is still emerging both internationally and here in Aotearoa.

There is a growing body of [international qualitative research](#), alongside feedback from individuals, whānau and healthcare professionals describing the positive impact End of Life Doula support can have.

ELDAA is not currently undertaking formal research. However, we would welcome opportunities to contribute to future research and evaluation in Aotearoa and would love to hear from anyone interested in exploring this further.

### **Q: How many Doulas do you believe there are in Ōtautahi or nationwide?**

At the time of writing, ELDAA has four Professional Members practising across Ōtautahi and North Canterbury.

Nationally, we currently have around 30 ELDAA Professional Members, along with a growing number of Associate Members undertaking further training, experience and mentorship as they work towards Professional Membership.

There are also other End of Life Doulas practising throughout Aotearoa who are not members of ELDAA, so it is difficult to know the total number nationwide. What we are seeing, however, is growing interest in End of Life Doula practice and increasing demand for this support across Aotearoa.

### **Q: What models are you aware of that you believe will be the future of Doula care in New Zealand?**

Internationally, a range of End of Life Doula models are emerging. In some places, Doulas work alongside hospice and palliative care teams, while in others they focus on education, workforce support and strengthening community approaches to end of life care.

In Aotearoa, we hope to see a variety of models develop rather than a one size fits all approach. We see End of Life Doulas as a valued, complementary part of the wider health and community system, working alongside existing services to strengthen person and whānau centred care.

As awareness and demand continue to grow, we hope to see sustainable funding models that improve equitable access while recognising the value End of Life Doulas bring. We are encouraged by the growing interest from healthcare providers and community organisations,

and welcome opportunities to explore innovative models, collaborative partnerships and other approaches that help make End of Life Doula support accessible to more people across Aotearoa.

## Continuing the Conversation

Thank you again to everyone who joined us and for your thoughtful questions.

We hope these responses have been helpful and that they continue the conversation about how End of Life Doulas can complement hospice, palliative care, community care and whānau support across Aotearoa.

If you would like to connect with an End of Life Doula, explore collaboration, discuss how Doulas can complement your service, or share your ideas and feedback, we would love to hear from you.

### Contact ELDA

End of Life Doula Alliance Aotearoa

[info@eldaa.org.nz](mailto:info@eldaa.org.nz)

[www.eldaa.org.nz](http://www.eldaa.org.nz)

