

How do I talk to my parents about their care wishes?



Have a conversation with your family about your end-of-life wishes while you are healthy. No one wants to have that discussion... but if you do, you'll be giving your loved ones a tremendous gift, since they won't have to guess what your wishes would have been, and it takes the onus of responsibility off of them.

— Jodi Picoult

The sad truth is, we all will finish our laps around the sun and those we love and that love us, will have to say their farewells, grieve, and on top of that, manage our estate.

This is a complex process, one with lots of elements and details to be ironed out so taking time to have our own estates in order, and to encourage those we love to do the same is really important.

When having those conversations with loved ones, the intention is to deeply understand their wishes. That likely means carefully planning and then curating the conversation, managing your own emotionality and asking great questions to really understand what they're wanting. It's a hard conversation to have, yet one that can reduce some of the stress and pressure for the family, at one of life's most difficult times.

This guide is designed to help you. There's some reminders about how to tackle tough conversations, why this conversation in particular is really important, some questions to help you prepare and lead the chat, and we wrap up with some explainers on technical terms and things you may want to research a little more.

We hope this is helpful and please contact us hello@holdmine.com if you have any questions or feedback.



Why Talking About The Tough Stuff Matters

Losing a loved one, no matter how organised you are, really is like a tsunami of emotion and overwhelm, that nothing really prepares you for, so by taking care of some of the details ahead of time, we know it'll allow a little more space to be present with those you love.



How to Talk to Your Parents

CRUCIAL CONVERSATIONS

There's no one way to do this well. It's always going to be a BIG conversation, one that is complex, emotionally heavy and unique to the people involved. The only thing you can do is prepare yourself, go slowly and gently, take notes along the way and lean into the discomfort. And show up for it. It can be easy to put it off for another day, when the timing is right, after x, y or z – but sometimes the first step, committing to having the conversation is the most important step.

Some framing and a tool or two is useful here, so we're drawing on the research from The New York Times and Washington Post bestselling book 'Crucial conversations'.

A crucial conversation is one that is described as "A discussion between two or more people where the stakes are high, opinions vary, and emotions run strong." And typically we handle it one of three ways, we avoid them, do it but do it badly, or we can handle it well.

While even in the best relationships, the opinions may be aligned, there's no doubting that this topic is one that does have high stakes and strong emotions, so with that in mind, aiming to have a good chat isn't enough, some preparation is needed.

Namely, the context and setting, the content, and how it's captured will be important for all parties. No-one likes to be ambushed for a big conversation, let alone one such as this. We've covered off some key steps in the following sections to help prepare you, and your loved one/s, as best as can be.

If you're not a 'let's sit down and talk about it' kind of family, that's where Holdmine can help you work through the detail in a gentler way. Your parents can create their own Holdmine account, add in the details of their wishes, and share it with you as a Trusted Contact, or set you up as a Legacy Contact*. That enables you to view their wishes and details when you need it most, without having a conversation if you or they don't wish to. If you can though, we do recommend it, so as to really understand the nuances of their wishes, the reasoning, the detail, their story around why this matters to them.

By everyone being on the same page, you're all better prepared to honour their wishes and honour your own grief when the difficult moments come.

^{*}A process to be followed to enable Legacy Contacts.



How do I talk to my parents about their care and wishes?

As humans, in many cultures, we have developed a resistance to talking about difficult topics like death. Maybe we think that if we don't acknowledge it, that if we don't talk about it, we won't have to deal with it. Unfortunately, it doesn't work that way.

Western cultures tend to shy away from death—talking about what your parents want when they need care or after their death is essential. Not only can you then honour their wishes, but you can also help your family lighten the load when they are mourning.

But how do you bring it up without scaring them? How do you deal with the overwhelming feelings associated with thinking about losing your loved one? Where do you store the information they give you? It's not easy. You just have to take it one step at a time.



Firstly, it may be helpful to have this conversation when your parents are healthy and able to make decisions on what they want without the fear that comes with being ill. Including your siblings and close extended family and trusted loved ones in the conversation so that they know what the wishes are, and what their responsibilities may be helpful as well. If you can share the conversation with others, that can diffuse the intensity a little, and do chat freely and share ideas and experiences too.

By including everyone in the conversation early, it can help ensure that there are no disputes, disagreements or family issues along the way. Be mindful of how the conversations flows and eb careful not to make your parents feel ganged up on as that is the opposite of what you're intending! Making sure you follow some of the steps below could help the conversation feel more casual and less confronting.

Secondly, be prepared and lead the conversation. If you're the one initiating the discussion, do have some questions and prompts ready and help the conversation flow by leading with these. Also be comfortable taking notes, asking for more detail, calling for breaks as needed.

When it comes to understanding your parents wishes, a good tip is to use open-ended questions to keep the conversation going and we've included some useful ones here in the question guide.

Even at the start, if they decline your request to talk about it, it can be helpful to say and ask "It's important to me to do things right for you, and I'd like to know what concerns you have about having this conversation?" Or if you can manage your tone well, asking "Can you talk me through why you're reluctant to chat about this please?"

If they're stalling, then maybe even "I'm really interested to know so we can all honour and respect your wishes. I hear you're not ready for that conversation, what would you need to feel ready?".

It's important for everyone attending to realise the intention is purely to understand your parents' wishes – that means staying present, calm and genuinely interested in what they're saying. Sometimes, being asked these questions are the first time someone's actually thought about it, and they might need time to land on what they actually want, so be prepared to chat it through in a couple of sessions too.



Thirdly, self-care and self-management is important. Taking on this task is no mean feat. It takes mettle and management. Make sure you've got capacity for it and when the chat happens, it might be harder than you expect too. Even the thought of losing a loved one is emotionally charged and so it makes sense that it's tough to sit in that space and think through the details. It might seem easier to leave it for 'another day' or 'later', but sadly later does come, and there are often problems that occur that are avoidable by having these tough, but important conversations.

Share your views openly, express yourself and why it matters to you to have their wishes understood and use "I statements" while doing so. If the conversation gets stalled, or it's unclear, it's okay to say "I want to get this right for you, can you please explain that again or give me an example?". 'I statements' are impactful.

Lastly, perhaps your parents prefer to get 'the professionals' to handle it so the best you can do is encourage them to talk to their doctor or lawyer about the decisions they need to make and what they do decide. The topics you want to ensure they've discussed could be:

- What they wish to do if they become ill and unable to care for themselves.
- Who they want as their medical and legal power of attorney.
- What they want after their passing and their will.

And then confirming with them the details of the professionals who have records of their wishes when the time comes.

Holdmine is a great place to record this so you have all your parent's wishes and/or the contact details for their professional advisors in one easy to find, safe place.



Question guide

Please feel free to use these to guide the conversation, and to add your own

- Would you like us to have a celebration of your life together soon or at your next milestone birthday?
- If your health were to deteriorate, what would you like to happen?
- What are your end-of-life care wishes if you needed more intensive care?
- Have you designated someone to make healthcare decisions on your behalf in the event that you are unable to do so? Like a Power of Attorney or Guardian?
- What preferences do you have for the kind of funeral or memorial service you would like?
- Do you have a preferred location for your final resting place?
- Do you have a will or an estate plan in place? Who is managing this for you?
- Do you have any specific requests for how you would like your personal belongings or property to be distributed?

- Are there any elements of your will or final wishes that might be complex or would be good for us to discuss in depth now?
 What are your preferences for organ and tissue donation?
- Do you have a life insurance policy or other financial arrangements in place to cover end-of-life or funeral expenses?
- Have you any cultural or spiritual beliefs that you would like to be honoured during your end-of-life care or after your passing? Are there any traditions you would want us to follow on the anniversary of your passing?
- Is there anything specific you would like included or excluded in your obituary and/or service sheet?
- What else is important to you?
- Is there anything I didn't ask that you want to talk about?

The **Best**Question

Melissa completed a Vipassana silent meditation course recently and had the privilege of meeting Sarah, a compassionate and kind woman with a depth of experience in palliative care nursing. In the brief moments they could speak, Sarah shared her guidance for when someone you love is passing or unwell. It's powerful.

If nothing else, please take her advice and ask those you love "What is important to you?" that will then help you support them, and help you find peace as you navigate this difficult terrain with them and for them.



POWER OF ATTORNEY

It may also be a good idea to ask your parents about their medical and legal power of attorney. If they have already sorted this then simply recording the information on Holdmine is quick and easy. Otherwise, you may need to go through what each means and help them pick and finalise who they want for each position.

A legal power of attorney is a document which allows a person to authorise another person to act on their behalf. The appointed attorney might have the authority to make legal, personal, and financial decisions for the principal (person who gives power of attorney to another person).

Also known as an enduring power of attorney EPA, the NZ Govt site sums it up well"

"An EPA comes into effect if you become 'mentally incapable', for example because of an illness or accident. The person you give the decision-making power to is called your attorney. They're often a family member or a trusted friend."

This individual can be anyone as long as they're a New Zealand resident, over the age of twenty, and not in bankruptcy.

A medical power of attorney is a legal document which allows a person to name someone and give them authority to make crucial decisions about medical care. A medical power of attorney is only needed when your doctor says you are not able to make critical decisions for yourself. Typically, medical power of attorney is only for extreme medical situations. Only a doctor can decide when one is needed.

Both documents are legal documents and that need to be completed through a lawyer or trustee corporation. All the forms you need are on the justice.govt.nz page (Link 1). A power of attorney is usually family or friend and must be over 20 years old, must not be bankrupt and must be mentally capable. You can choose the same person for both. You may also select one person as medical power of attorney and multiple people for different aspects of your legal issues and ask that they consult on decisions.

Once you make a decision, you will need a lawyer, a qualified legal executive or someone from a trustee corporation to witness when signing your documents. Filling out your forms and taking all supporting documents with you for your appointment will make the process shorter and therefore cheaper as lawyers can become expensive. Adding a copy of this onto your Holdmine account will help you stay organised and will make it easy for your family to find when they need it.



ADVANCED CARE PLANNING

One way to ensure you get down all the essential information about what your parents want for their end of life care. Questions you may want to include are:

What is important to them, including what should happen to pets, organ donation, burial plans or cremations, where they store important information and who the medical and legal power of attorney is. An advanced caring plan provides a step by step guide on what you may need to cover when having what could be a difficult conversation with your parents. This plan also often includes information on what is essential to the individual at the start to open up the conversation and make it seem less scary.

This plan also provides details on extending life, the dying process, removing tubes and medications, spiritual and religious factors in end of life care, a DNR or do not resuscitate order and the place where the person would like to be when they pass.

Some individuals choose to involve their doctors or other health professionals, especially if there are existing medical issues as these could affect your care later on. Doctors can also talk you through some of the choices you can make about your later life care now. It is also essential that your parents know to update their plans and yearly.

You can find a guide and more information at hqsc.govt.nz (Link 2). All this information can easily be stored through Holdmine so that the data is safe and can be accessed easily from wherever you are.

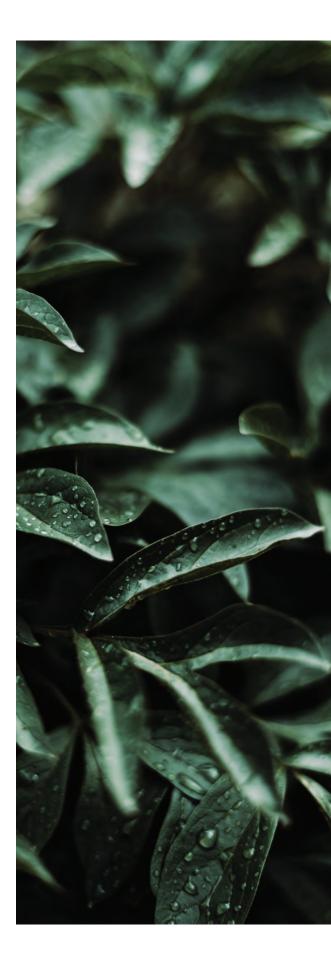
END OF LIFE MEDICAL CARE

This part of the conversation may be particularly difficult as no one wants to think about their loved ones in pain and the tough choices they may have to make. Make sure you don't push the conversation too much and start with an easier topic such as important values and beliefs as stated in the advanced care planning. The things you may want to discuss include the choices your loved one may want for their end of life care.

Firstly, treatment being focused on extending their life as long as possible, with any exceptions. Secondly, focusing treatment on quality of life with tests and treatment being only to help recover or regain quality of life. Here it may be important to get your parents to describe what quality of life looks like to them. A third option would include treatment that looks after comfort and dignity above all else. It may be that your parents don't know and wish for their health care professionals to make the decision while taking into account your and your families wishes.

If none of these options are suitable you may want to write out exactly what your parents want if they were to find themselves in a situation where they cannot make an informed decision themselves. This includes a list of different situations, what treatment should focus on in that particular situation and the treatment they would accept and refuse.

Your parents may also choose to have a DNR (do not resuscitate) in the case where they are seriously or terminally ill. Signing this kind of document and having your parents discuss it with their health professional will make it easier for their health team to follow their wishes.





WHAT DO THEY WANT IF THEY BECOME ILL AND UNABLE TO CARE FOR THEMSELVES?

The following questions can be a good way to start a conversation about later life care. Whether they want to be in a retirement village with assisted living, have a full-time nurse or move in with another family member. Researching these options with your parents might be helpful. You could even consider doing tours of some of the available assisted care living in your area. Talking to the director of the assisted care living facility will help you plan for this if your parents need it. Eldernet is a great webpage that can direct you to retirement villages and residential care options in your area (Link 3).

Another thing you may want to discuss with your parents is hospice care if they develop a life-limiting disorder. It is free of charge and can offer different kinds of support for the whole family. To get more information, head to their website at hospice, org.nz. If only one parent requires care, and while the other remains relatively healthy, this can become more complicated. It may be important to discuss whether or not your parents feel like they would be up for becoming the full-time carer of the other. Talking about set back plans could also be helpful if this is what they would like. For example, discussing the possibility of hiring a nurse if it becomes too much or possible respite options for the healthy partner.

Having a clear and frank conversation about what this may look like is a great start. Money is another more practical issue that can be discussed. Your parents may be eligible for Carer support subsidy, Disability allowances, Lottery grants, support with modifying cars or home and other support and advice. A Carer support subsidy can be used to help pay for another support person to allow your parent to have some time to recuperate. A disability allowance is a weekly payment used for regular ongoing costs such as doctor visits, medication, travel and more.

A lottery grant can help pay for cars and car modification, scooters or other mobility equipment, communication devices and more. Suppose you need to make serious or substantial changes to your house or car. In that case, you can apply for House Modification Funding or Car Modification Funding. More support and advice, in the form of guides, questions and other resources, can be gained from Carers New Zealand (Link 4). Having information ready for if this scenario were to occur may make it easier for you and your parents in a difficult time. There is more information on eligibility and application on govt.nz (Link 5).



AFTER PASSING OPTIONS

Finding out what your loved ones want after they pass can be really helpful in honouring them and in lessening the burden on you and your family when you are grieving. Talking to your parents about what they want and recording this will make a difficult time slightly easier. If they have not thought about it, it might be a good idea to go through the different options with them and help them decide what they would like.

By getting them to consider services they have attended and talking about what they liked and didnt like can be a good way to start this conversation in a way that is not so daunting or confronting. You could also talk about services you have been to in this same way and talk about why you liked or didn't like certain aspects. Some options include: A burial, cremation, organ donation, eco burial, donation to science or a culturally traditional option. It may also be a good idea to talk to them about whether or not they want a service and what they would want their service to look like.

Different options include a funeral, a memorial or a tangi hanga. Who they would like to perform the service and where they would like it to be held is also important information to consider. A memorial service is similar to a funeral, but the main difference is that the body is not present at a memorial service. Not having a body present can open up more location options, from having it in the comforts of your own home to going big and hiring a venue, or to choosing a significant spot. Other things you could ask about any special requests they might want as well. Most funeral homes will accommodate you and your family in pre planning a funeral and will record your parents wishes as well. If going through a

funeral home is what you and your family choose to do then this is a great way to have support from professionals while going through this process.

A funeral director is a professional who will work to provide you and your family in times of emotional need. They will allow you and your whanau to grieve appropriately and express your emotions. At the same time, they will expertly arrange the details of the funeral, from whether there will be a burial or cremation, to which type of flowers, to the location. A funeral director can work hand in hand with you and your family to really understand your needs and be there for you in every step of the way of this daunting task. Many of a funeral director's services include registering the death, transporting the body, arranging the burial or cremation (or other), as well as the funeral service. They can also take care of the legal requirements.

A funeral celebrant is a person who is qualified to conduct a ceremony related to the values, beliefs, and desires of the deceased individual and their family members. They will work with you and your family to create a ceremony that can include aspects of your traditions, beliefs, and customs to ensure that the deceased is honoured adequately according to their wishes.

You may also want to discuss who your parents would want to speak at their funeral and who should say their eulogy. More information on eulogies and how to write them can be found later on in this guide.



FINANCING THEIR PREFERRED OPTION?

If your parents have a plan for the cost of their funeral or service then getting this information and saving through Holdmine will be useful. If not there are plenty of other payment options that you may want to add to the planning as well. More information on funding and support available please see the help guide "What to do when someone dies". This guide will also provide information on the necessary steps you may need to take after your parents have passed.

THEIR WILL

If you parents already have a will then that's great and all you should discuss is who the executor and trustee of their estate is so that you know for when the time comes. If they do not have a will then organising one is really important and you supporting them through this could be very helpful.

You can find a will template online (which may be a cheaper option), however it will still need to be signed and witnessed (Link 6). It may be easier to go through a lawyer or trustee company as if the procedure is not done correctly, the will may not be valid. Some lawyers will draft a will up for free, especially if they are your family lawyer or have done work for your family in the past.

GENERAL

If there are any terms that you need more clarification for please find the FAQ document on the Holdmine website.

ETHICAL WILLS

You may want to talk to your parents about leaving an ethical will as a keepsake for you and your family. The memories you create and leave behind in this world matter. An ethical will is uniquely yours, and unlike a legal will, this type of will is purely voluntary. Also known as a legacy letter, an ethical will is created to communicate things like values, life lessons, experiences, and anything to share with your loved ones.

Questions you could use to prompt the conversation include: What did you learn in this life? What values will you want your children never to forget? This type of message can bring enormous peace of mind and help people achieve closure at times.

Writing a legacy letter can also benefit them, as reflecting on the most significant aspects of their lives could be a tool for self-reflection for the other aspects of the conversation. An ethical will can also be used to distribute personal belongings such as photographs, clothing, recipes, and any objects of great unique value. It can be in the form of a diary, a PowerPoint presentation, a video recording, a poem or a song.

There is no right way of creating a legacy letter, what matters the most is that it's personal and that it communicates what's important to them.

We hope this is **helpful**

Please contact us hello@holdmine.com if you have any questions or feedback.





REFERENCE LIST

PAGE REFERENCES

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LINK 1: https://www.justice.govt.nz/family/powers-to-make-decisions/the-court-and-enduring-power-of-attorney-epa/

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LINK 2: https://www.hqsc.govt.nz/our-programmes/advance-care-planning/publications-and-resources/publication/3212

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LINK 3: https://www.eldernet.co.nz/Home

LINK 4: https://carers.net.nz/

 $LINK\ 5: \ https://www.govt.nz/browse/health/caring-for-someone-with-a-health-condition/$

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 $\textbf{LINK 6:} \ https://www.publictrust.co.nz/personal/online, https://www.lawhawk.nz/online-will-and-enduring-powers-of-attorney. The property of the property$

DOCUMENT RESOURCES

 $LINK\ 7: \ https://www.psychologytoday.com/nz/blog/call/201706/talking-your-parent-about-aging-and-death$

LINK~8: https://www.daughterhood.org/4-tips-for-talking-to-your-parents-about-death/

LINK 9: http://superseniors.msd.govt.nz/finance-planning/enduring-power-of-attorney/

LINK 10: https://sorted.org.nz/guides/protecting-wealth/wills/

LINK~11:~https://www.govt.nz/browse/family-and-whanau/enduring-power-of-attorney-epa-for-personal-care-and-welfare/like and the control of the control of

