# dying reviews



The first 500

Dedicated to those who gave their precious time and energy to provide these first valuable reviews. You leave the legacy of real-world change, that will benefit all those who come after you.

Thank you for this gift.

As you read this, there are 34,000 people in New Zealand living with the knowledge that they're in their final phase of life.

For each of these people, there are more supporting them, emotionally and practically. About one in five of us are navigating the dying process at any one time.

So, when you read these results, know that we will all be directly affected by what they say. No one is exempt from this reality.

We all hope that when our time comes, we will be treated with dignity, compassion and empathy. That people's humanity will lead, giving us the grace of holding our last years, months, or days with care.

These reviews are just the start. Let's use this world-first Dying Reviews platform to help get us there, year by year. To be open to learning, adapting, and designing better; to put this very human part of life back into living.

If you would like to write a review, go to dyingreviews.org

**Wayne Naylor** 

**Chief Executive Officer** 

Hospice New Zealand, Te Kahu Pairuri o Aotearoa

The first 500 Dying Reviews provide an unfiltered look at how people experience everyday services in New Zealand while facing death - their own or that of someone they love.

It reveals a simple truth: the systems we rely on are not well designed for the realities of dying, but where empathy exists, it makes all the difference.

Across nearly 500 accounts, the most powerful experiences were not about what was delivered, but how it was delivered. Organisations that showed flexibility, compassion, and human connection stood out - regardless of industry. Whether waiving a bill, holding a door, or calling to check in, these moments made people feel seen.

Yet these moments were the exception. Many respondents described being overwhelmed by fragmented systems, rigid rules, and digital-first processes that excluded them. People spoke of having to fight for care, pretend to be a dying relative just to cancel a subscription, or queue at a bank for a signature with someone who is dying. It was not uncommon to receive both a 5-star and a 1-star story about the same company, highlighting how much experience depends on the person you happen to deal with - not the organisation itself.

The data surfaces a quiet but urgent challenge: while many organisations have policies for customers in crisis, few have embedded literacy around dealing with people who are dying, or introduced bereavement processes. This is not a niche issue - it affects every sector and every New Zealander eventually.

What stands out is not just what needs fixing, but what is already working. Some organisations are leading by example: fast-tracking claims, accepting scanned documents, coordinating care teams, and allowing whānau to stay overnight. These acts show it is possible to build systems around dignity, not just efficiency.

Despite dying being a natural part of life, no institution in the world has ever led a cross-sector, people focused review of dying experiences. Dying Reviews is a world-first initiative launched in Aotearoa and backed by Hospice New Zealand.

The first 500 Dying Reviews are not just a record of what is broken - they are a roadmap. The insights here are an opportunity to rethink how we design services for people at their most vulnerable. When systems meet grief with compassion, they don't just function better - they honour life itself.

**Dying Review**,

It seems as though we give death very little thought these days. Society seems very far removed from it. I wonder how we could better incorporate the dying process into 'normal life' again like it once was.

## Our starting point is



## **Interpreting New Zealand Ratings**

While we do not have a definitive global study placing New Zealand on a 'generosity index' the available evidence suggests we are likely to be more moderate than some of our Western counterparts but more expressive than many Asian cultures.

For a mediocre service, a 3-star rating from a New Zealander is a very plausible outcome, where in other cultures it might indeed be a 1 or 2.

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### 1. Compassion over process

Across all sectors, experiences that stood out most positively were those where staff treated people with empathy, flexibility, and kindness. Even small, human gestures made an enormous difference. People didn't always remember what was done – but they remembered how it made them feel. In contrast, impersonal or rigid interactions, even when technically correct, felt cold and upsetting.

## 2. Systems not designed for death

Many standard procedures – from closing accounts to cancelling services – are not built with the complexities of dying in mind. Processes are often designed for business-as-usual scenarios and fail to adapt when someone is terminally ill or has died. This leads to confusion, delay, or distress when people are already vulnerable.

# Overall cross-sector themes

## 3. Support is fragmented and repetitive

People often had to deal with multiple departments, agencies, or service providers separately, repeating the same difficult story each time. This duplication added emotional strain, especially when contacting government or financial services. There was a strong desire for better coordination, shared records, or single points of contact to ease the administrative burden.

## 4. Digital-first systems leave people behind

A heavy reliance on online services and digital-only processes (apps, email, online forms) disadvantaged those who were elderly, very ill, or had limited digital access. Many systems offered no alternative to digital self-service – and few made it easy to speak to a real person. As a result, important matters were delayed or never resolved.

### 5. Experience varies within the same organisation

The same banks, insurance providers, and aged care facilities appeared in both the most positive and most negative feedback. This inconsistency suggests a lack of standardised staff training or organisational values being embedded in practice. Instead, quality often came down to the individual staff member and their personal approach.

#### 6. Administrative burden adds to emotional strain

Fulfilling documentation requirements, chasing updates, managing long wait times, or being asked for the same information repeatedly created a disproportionate burden on grieving or caregiving individuals. People were often forced to spend time and energy fighting for services or entitlements when they were least able to do so.

# Overall cross-sector themes

#### 7. Words and tone matter

The way organisations communicated - in letters, emails, and on the phone - made a significant difference. Cold or insensitive language was experienced as dehumanising, while warmth and acknowledgment of a person's situation was deeply appreciated. Even small details, like addressing someone by name or expressing condolences, helped people feel seen.

## 8. Families want choice, time, and dignity

In some cases, families felt rushed into decisions, excluded from planning, or pushed into unwanted outcomes (like rest home transfers or hospital discharges). In contrast, when people were given time, space, and clear information, they were more likely to feel in control and at peace with the choices made for their loved one.

### 1. Rigid identity and access policies

Many organisations required original documents, physical signatures, or in-person visits to authorise changes. These rules, though intended to protect security, often created impossible situations for those who were seriously ill, lacked transport, or were acting on behalf of someone else.

## 2. Lack of joined-up communication

Agencies - especially government and health services - often failed to share information internally or across departments. Families had to repeat information or re-prove circumstances multiple times. This created a sense of inefficiency and added emotional toll, especially when dealing with serious illness or death.

# Systemic pain points and frictions

### 3. Automated systems with no empathy

Many systems triggered automatic messages or standard responses that failed to account for someone's death or serious condition. This included bills, follow-up notices, or customer service replies that felt thoughtless or even cruel. The lack of human oversight led to emotional distress for many.

### 4. Exclusion through digital-first models

Customers who were not able to use websites, email, or phone apps - due to age, illness, or disability - often had no viable alternative. This particularly affected those managing someone else's affairs or those in their dying phase of life. Some even had to impersonate a loved one to get help.

## 5. Delays in financial or legal processes

People experienced long wait times for certificates, approvals, insurance payouts, and KiwiSaver access. These delays caused additional stress and sometimes financial hardship. A more streamlined, compassionate approach to timesensitive processes is needed.

## 6. Inflexibility from workplaces

Some employees facing serious illness, or acting as caregivers, were unsupported or penalised. In a few cases, people were dismissed or pressured to resign. Others found it difficult to get time off or adjust hours to care for someone dying. This was often linked to inconsistent HR practices or lack of leadership understanding.

# Systemic pain points and frictions

### 7. Inconsistent service within organisations

The most glaring issue was inconsistent service across teams, branches, or individuals. One staff member might go above and beyond, while another refused basic support. This lack of consistency undermines trust in the organisation and leaves outcomes to chance.

## 8. When someone does die, there's no central death notification process

Families were required to notify dozens of services and organisations individually, repeating documentation and context over and over. There is no unified, government-supported way to inform all relevant services of a death or terminal diagnosis. This fragmented approach increases workload and emotional fatigue.

## 1. Home visits and mobile support

Organisations that offered in-home appointments, arranged transport, or visited customers showed a deep understanding of accessibility. This was particularly important for those unable to travel due to illness, age, or disability.

## 2. Fast-tracking time-sensitive processes

Some insurers, banks, and government departments expedited approvals or payments once they understood someone was terminally ill. This helped reduce stress and allowed families to plan or spend quality time together without financial pressure.

## Best practice behaviours across organisations

## 3. Fee waivers and administrative flexibility

Waiving charges, accepting scanned documentation, or simplifying account closures showed awareness of the situation. These adjustments made people feel cared for rather than penalised for being in crisis.

## 4. Allowing family presence and involvement

Hospitals, rest homes, and retirement villages that welcomed families around the clock, provided extra beds, or included whānau in decisions made a profound difference to the dying experience.

### 5. Clear, proactive communication

Best-in-class services guided people through what to expect, helped them prepare documents, and checked in at key points. This proactive support prevented confusion and helped people feel in control.

## 6. Continuity of care and relationships

When people were able to deal with the same staff member or team across time, it created trust, reduced repetition, and provided emotional comfort. This was especially important in healthcare, legal services, and home care.

## Best practice behaviours across organisations

## 7. Cultural awareness and personalisation

Some organisations showed deep respect for different cultural practices, values, and beliefs. Where staff adjusted to the person's worldview - rather than enforcing uniform rules - the experience felt safer and more inclusive.

## Sector breakdowns



## Banking

2.93 STARS *n56* 



Banks like ANZ, ASB, and Westpac were all named in both the most positive and most negative feedback. This inconsistency highlights a key issue: experiences often depend on the individual staff member or branch, rather than a clearly embedded process. Where banking staff were flexible, compassionate, and proactive, families felt supported. Where rigid protocols were enforced - even when Enduring Power of Attorney was in place - families were left feeling distressed and disrespected.

## What made it so positive

Positive feedback reflected compassionate, respectful support and clear, efficient processes. Respondents valued proactive help, empathy, and the removal of financial stress during the dying phase of life and also bereavement.

#### Bank

We were treated with kindness and compassion. I believe this helped put my husband's mind at ease knowing we would be okay.





#### Bank

No private room to discuss a very difficult and upsetting situation.



## How it could be improved

Negative feedback commonly reflected difficulty accessing or managing accounts, especially when acting on behalf of someone dying. Respondents noted rigid processes, lack of empathy, and poor communication during sensitive times, often leading to frustration, delays, or distress.

#### Onehunga

I gave up, I did empty the account, but was not prepared to stand in a crowd for ages unvaccinated even in a mask. As far as I know the account still exists.



#### **Bank**

They made it so difficult to get things transferred over into my mum's name. Even though she did everything right. They took their time, and it isn't something someone who's grieving should go through.



#### **Bank**

No reliable transport to nearest branch now 60km away for person without own transport.



#### Bank

My mother and myself went into the bank and set up my signing for her documents as she had a dementia diagnosis. A year later when she was in a rest home I went into the bank to access her money. had no record of our setting up of signing rights. Very embarrassing and was totally unacceptable.



No understanding, compassion and empathy.



#### Bank

This organisation kept sending information even after receiving the death certificate which felt really cruel.



#### Bank

All I got on 2 separate occasions was 'no they couldn't do anything for me'. It felt so insulting.



#### **Bank**

Not understanding and poor compassion.
Hard to talk to a person.



Silly little people on personal power trips need more training in realistic client service solutions. It is hard when one's remaining dignity is compromised by entities who are meant to help.



#### Bank

Lots of legal red tape.



#### Bank

It was a challenging time to change names over closing accounts and proving it.



#### Bank

Banking - Hard to deal with.



#### Bank

More empathy.



#### **KiwiSaver**

The person I dealt with was officious and inflexible. Insisted my specialist use a rubber stamp which she didn't have, gave an unreasonable deadline and throughout her email referred to me as 'member' rather than using personal pronouns or my name.



#### **Bank**

Everything is so difficult to sort out.



#### Bank

Person was not treated with respect during the final days by the financial institution. Was made to visit branch physically to confirm his identity.



#### Bank

No private room to discuss a very difficult and upsetting situation.



I waited in a long queue during lunch hour, only to find I need to make prior appointment.



#### Bank

Account not accepting the info of partner to the terminally ill person.



#### Bank

Just being more available to people in more remote areas whose illness does not allow them to access services as normal people do.



#### Bank

Difficult to gain access to accounts after passing.



They need a set of procedures you can sit down and study before going into the bank and not have to do it on the fly. Be prepared.



#### Bank

Even though my mother's lawyer had explained that her bank accounts would be frozen, I hadn't appreciated that it would happen immediately and that having authority over her account and having financial power of attorney would make no difference.



#### **Bank**

Better support needed.



#### **Bank**

Simple more empathy.



#### **Bank**

When someone is too ill to get to the bank and does not do internet banking, and the bank needs the person to renew a bank card by coming to a branch. Bank won't allow a family member or friend to do it for them.



They sorted my sisters finances out in the last three months of her life ensuring loved ones were looked after.



#### **Bank**

Although our questions and queries were responded to, it was a difficult and awkward interaction.



#### Bank

I had the EPOA for my dying husband and needed to be able to access his account. The lawyer had sent a photocopy with an affirmation stamp and legal signature saying it was true and correct. I was told they needed a 'wet' copy, which I picked up from the lawyer. This wasn't enough and I had to get my husband to come with me to a JP to get his signature witnessed. It was the last time he left the house.



#### Bank

Difficulty closing accounts and transferring funds out.



was able to help ensure that full access is available to the accounts so that financial matters were able to be promptly sorted.



#### **Bank**

They helped my family member release their KiwiSaver so they could spend it before passing away. This was done so quickly.



#### Bank

My bank was very helpful - they did everything they could.



#### Bank

It was easy with help from a bank to manage paying bills until my relative died.



You need someone to help you manage your affairs and provide emotional help.



#### **Bank**

My Mother's bank offered home visits when she couldn't go to a branch. They created a positive relationship between them, me and her during her journey so she could always access her money or get me to do anything she needed. They made our banking journey so easy which took all that worry and pressure off all of us.



#### Bank

They made sure that my loved one was secure in their last days.



#### Bank

After them explaining the process and me providing everything, it all ran smoothly.



#### **BANKING - FULL COMMENTS**

#### **Bank**

were so respectful, helpful, kind & understanding. Each person at that my Mum & I spoke with was consistently kind & effective in getting Mum's finances in order, as she was dying. It was very important that all her finances were in order, & they were very respectful of that goal, & were efficient.



#### Bank

Exceptional customer service, very understanding, compassionate and fair.



#### Bank

I found the organisation really good to deal with once they knew I had EPOA and my husband had end stage dementia.



#### Bank

We were treated with kindness and compassion. I believe this helped put my husband's mind at ease knowing we would be okay.



Work
3.63 STARS
n38



Workplaces stood out as either exceptional or deeply disappointing. Supportive employers maintained pay, allowed flexible hours or remote work, and checked in personally with both dying employees and caregivers. These experiences left a lasting positive impression. In contrast, several respondents were dismissed, doubted, or penalised for taking time off - often following a management change. This sector shows a clear gap in systematising compassion in HR practices, especially for caregivers and the terminally ill.

## What made it so positive

Positive experiences highlighted empathetic employers who offered flexibility, financial security, and ongoing connection. Respondents appreciated full sick leave entitlements, work-fromhome options, and compassionate managers who respected their situation. Acts of kindness from colleagues and organisations that valued employees beyond their diagnosis left a lasting impression.

Workplace

Kindness and support. They checked in with my husband regularly and colleagues came to visit him at home. He was given the opportunity to contribute and work from home when he felt able. There was no pressure on him and it was his choice when he felt he should stop work.





#### Workplace

I wanted to return to work after first chemo round and was told to wait until I felt better. After a month was visited by the GM and CFO and pressured to leave as I was going to have too much time off. They wanted to talk to my Haematologist and then when I asked if there would be a job for me if I improved, they said 'No. We were told you are dying!'

## How it could be improved

Improvement areas included a lack of empathy, inflexible leave policies, and poor communication from management. Several respondents described being forced out of work or unsupported when needing time off to care for someone terminally ill. Others cited dismissive treatment, lack of understanding about terminal diagnoses, and emotionally distressing behaviour from employers during bereavement.



When my mother-in-law contacted her boss again to advise symptoms were coming back and that she was concerned, she was told 'it won't kill you'. Turns out, it did. She and was completely let down by him and his manner, with her at the end, was as if she was a hassle to him.



#### Workplace

## They treated my father terribly. Stressed him badly.



### Workplace

I notified the area manager that my husband was dying and I needed to be home looking after him. That was ok, but due to the fact I was a relieving manager at a care facility I was requested to keep my work phone on as a backup.



#### **Workplace**

I wanted to return to work after first chemo round and was told to wait until I felt better. After a month was visited by the GM and CFO and pressured to leave as I was going to have too much time off. They wanted to talk to my Haematologist and then when I asked if there would be a job for me if I improved, they said 'No. We were told you are dying!'



## Wish I could have more time off.



#### **Workplace**

She had to give up work due to the terminal illness. There was little help from employers but her colleagues at a community choir rallied round.



#### Workplace

Made it difficult to reduce hours of work to help cope with the fatigue.



### Workplace

New managers did not know me. Leaving my job for times to take care of my husband was an issue, I believe they thought I was making it up to take time off.



#### Workplace

He was in building and construction. He couldn't complete tasks. He needed a younger person to help him.



Great support, but could have been more helpful in steps toward employment being terminated.



Workplace

It was good overall. I was able to take the time needed.



#### Workplace

Have more people check in on the farmer and check on the farm, because our farmer finds it hard to leave the farm.



### Workplace

Could not have been more caring. My sister was on full pay for the rest of her time and many individual staff members did so much for her, including meals, baking, etc.



Caring and positive.



Workplace

Flexible schedule - best understanding boss.



Workplace

Worked for company for 36 years and were amazingly kind and supportive when cancer diagnosed.



Workplace

He was there for his last months and was treated like a king. They took real good care of him.



While his illness was progressing and was becoming unable to work they paid him a percentage of salary to help keep his family comfortable and would regularly check in with his wife to see how they could assist her.



#### Workplace

Kindness and support. They checked in with my husband regularly and colleagues came to visit him at home. He was given the opportunity to contribute and work from home when he felt able. There was no pressure on him and it was his choice when he felt he should stop work.



#### Workplace

I was kept on full sick leave during my tests and procedures plus an additional 2 weeks enabling me to sort out paperwork for Kiwisaver etc. and try to process my terminal diagnosis. Then I was able to medically retire and given 65 days' pay. Finding joy in the life left takes time. I can't believe some people have to continue working through this adjustment period. Knowing you're going to die is an emotional washing machine.



#### Workplace

They were very supportive of mum after her cancer diagnosis, and wanted to offer my mum part time work, to help her manage her symptoms.



As soon as she was diagnosed, the head of their union organised for her wages & insurance & leave owed to be paid out so less for to worry about.



#### Workplace

They hired me knowing my diagnosis. They have been supportive from day dot and have seen beyond the diagnosis. They weren't afraid of my incurable diagnosis and had confidence in me to perform the role. I have been with since October last year, and recently moved into a different role as my fixed term contract had ended. I'm so appreciative of the team and the culture that has been nurtured. There is no judgement, only aroha and compassion. I wish all employers and colleagues had this perspective. When I was diagnosed, I was working in Mental Health and they pretty much restructured me out. I tried to apply for other jobs, but the issue of the diagnosis kept coming up. I was going to be transparent, because the diagnosis was my reality and I did not want to hide it. I wish employers would realise, that at the end of the day, no one gets out alive, and none of us know when our time is up.



#### **Workplace**

Very grateful to the employer who understands what this family is going through and allowing the husband to take days off work to care for their dying spouse.



#### Workplace

They are looking after my friend so that he can work the hours he wants. My friend is still trying to juggle between working and chemo and the business is supporting him in everything.



## Insurance company / Policies

3.16 STARS n38



Experiences with life and health insurers were polarising. On one end, some providers were commended for quick, compassionate payouts - particularly for terminal illness claims - which provided enormous relief and dignity. On the other end, families described needing to submit excessive documentation, facing long delays, or dealing with cold and disbelieving communication.

The ability to act with both efficiency and humanity was a key differentiator in this sector.

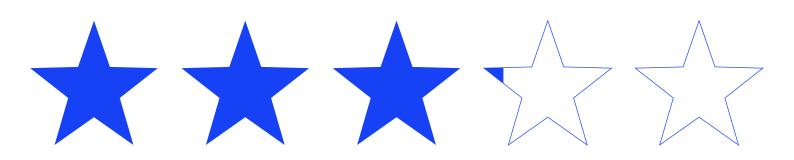
## What made it so positive

Respondents valued fast, compassionate handling of claims, especially when terminal illness allowed for early payouts. The availability of funds during a stressful time offered significant relief and enabled families to focus on making the most of their remaining time together. Simple, efficient processes and empathetic communication were particularly appreciated.

#### Insurance

They were great at sorting the insurance and I am so grateful we had no financial issues through what was the hardest time of our life. They were fast and efficient which helped us make the most of the last 12 months as a family.





#### Insurance

I visited the insurance broker we had been with for many years. After completing the necessary forms I asked if he was the person I should contact on the off chance there were any problems. He wiped his hands together and said 'my job is done, any problems contact head office'.



## How it could be improved

Common frustrations included delays, excessive paperwork, and insensitive or impersonal communication. Proving terminal illness was often a burden, with repeated demands for documentation and limited flexibility. Some felt unsupported or even disbelieved, and others described distressing interactions during already overwhelming times. Improved sensitivity and simpler procedures were key areas for improvement.

#### Insurance

So this is bizarre. My Dad used to work in financial services so is really particular about this – when the spouse of a beneficiary dies you have to advise the company. They could find no record of Dad in their system. I was put on hold repeatedly repeating the story to strangers of Mum's death while Dad listens in and gets a little sadder with each telling. Dad's pension continues to be paid, as it should, but I have no idea how (or whether) we will shut this down once Dad dies. Unbelievable.



#### Insurance

Very difficult and slow to deal with, they make it sound easy but it is not. They need to approach this with compassion and understanding. Families could do without this hassle.



#### insurance

The paperwork needed is unclear and very complicated.



#### Insurance

Be more better in the payment.



There's no option to go directly through to a human which would have been so helpful for my dad instead of multiple screening questions and waiting indefinitely in a queue. He just became more stressed.



#### Insurance

Having to wait in queue even if you are seriously ill.



## Insurance

It's a battle we are going through at the moment.



### Insurance

I visited the insurance broker we had been with for many years. After completing the necessary forms I asked if he was the person I should contact on the off chance there were any problems. He wiped his hands together and said 'my job is done, any problems contact head office'.



We had difficulties dealing with the claim.



### Insurance

Sometimes big companies need to show a bit more understanding and compassion. It is not always possible to give a definite length for the remainder of a person's life.



### **Insurance**

Need to be a little better. Be more on the active side and provide more support.



### **Insurance**

It seems a quick payout is a fallacy, just adds stress to family at a bad time.



Have staff that are more sensitive. Once people know you're dying that is all they can see. Not the person.



## Insurance

Trying to understand if early payment was possible. Telephone support service no help and needed opinion of an underwriter. They were reluctant to put us in contact but eventually we did manage to get some contact details, but it was hard work.



#### Insurance

Onerous at a stressful time.



#### **Insurance**

Stressful as required lots of medical paperwork to prove my terminal cancer but once done, the funds were put promptly deposited in bank account.



### Insurance

Communication can be better improved.



# Resolved after they realised the person was not yet deceased.



## Insurance

Life insurance company assisted in paying out life insurance in advance so my husband could use the money while he was still here.



## Insurance

They were so easy to deal with which provided substantial funds available quickly which was a great help to her and her family at this terrible time.



#### Insurance

They were great at sorting the insurance and I am so grateful we had no financial issues through what was the hardest time of our life. They were fast and efficient which helped us make the most of the last 12 months as a family.



## Utilities / Bills and payments

3.12 STARS *n17* 



This sector featured a stark divide between companies who streamlined account closures and those who clung to inflexible rules. Some providers were praised for waiving final charges, offering empathy, and making things simple after a death. Others refused to act without formal documents, even when the customer had died – causing frustration and delays. Digital-first processes often compounded the problem, especially when grieving families struggled to find ways to speak to someone directly.

## What made it so positive

Positive experiences reflected prompt, empathetic customer service and streamlined account closures. Respondents appreciated providers who acted with compassion, offered flexibility, and made difficult situations easier by waiving fees or simplifying processes while they were dying or after a loved one's death.

They were no fuss, understood the situation. They showed me kindness & empathy.





## Telco & Subscription

I had to do it all for my dad, he was unable to concentrate & too weak to hold the phone or iPad in his last few months. As everything is preferred to be done online these days it is not helpful to someone who is dying!



# How it could be improved

Many reported inflexible systems, slow responses, and barriers to closing or managing accounts, especially online.

Requirements like death certificates, formal ID, and long phone queues created distress.

A lack of compassion and understanding, especially for the dying phase of life or bereavement, made navigating basic utilities unnecessarily difficult.

## Power/Energy

Almost impossible to deal with. Some companies are much better than others to deal with.



## Telco

They're shit and inconsiderate to give leeway for someone who is dying and unable to work or pay.



## **Utilities**

## Difficult time -More empathy needed.



## Power/Energy

We rang to disconnect power after my father-in-law died. They would not accept our call as they needed to speak with the account holder. I tried to explain that the account holder was dead. They had no way of dealing with this. We had to wait until the death certificate came through which was difficult as the flat lease was up and we couldn't afford to keep paying for the line rental etc.



## **Utilities**

Make the process to get names taken off bills easier. A how to guide would be good.



## Power/Energy

## Be kinder and more compassionate.



## Power/Energy

They could have answered in a much timelier manner. Took 3 emails and 2 calls to be able to give dad's last power reading.



## Telco

Very difficult as a family member had to assist with an issue on the bill. More support is needed for family members assisting the dying to manage legal requirements.



## Power/Energy

## No understanding.



## Telco & Subscription

I had to do it all for my dad, he was unable to concentrate & too weak to hold the phone or iPad in his last few months. As everything is preferred to be done online these days it is not helpful to someone who is dying! People need to understand that much more support is needed to ensure people can live as happily as possibly with their illness whilst dying.



## Power/Energy

The process to take names off things is a pain in the butt. It should be simple 'ok, no worries'.



Power/Energy & Telco

She struggled to pay due to not being able to work.



## Power/Energy

It was a great experience, they have been very accommodating and very transparent about what happens in the case that a household no longer needs their services.



## Power/Energy

I think being more mindful of customers situations when dealing with account issues, I just found their experience to be a bit impersonal.



## Power/Energy

They provided great care for my dying relative.



## Power

## Ensuring life support power was maintained.



## Power

They were no fuss, understood the situation. They showed me kindness & empathy.



## Telco

His bill after his passing was kindly waived off with customer service agent being very sympathetic.



## Clubs and other community groups

4.10 STARS

n29



Informal groups (e.g. walking clubs, dog groups, local churches) were described as incredibly supportive, offering emotional connection and practical help like food or companionship. Formal clubs, however, sometimes struggled to adapt when members became too unwell to fulfill roles or obligations. In some cases, people were sidelined or excluded entirely. The most impactful experiences came from communities that stayed connected, regardless of a person's ability to "contribute" in traditional ways.

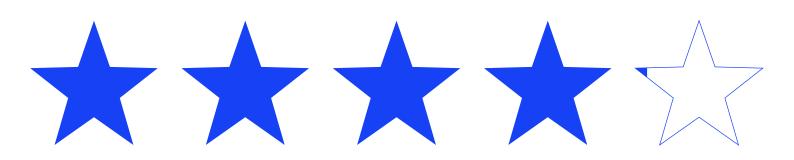
## What made it so positive

Supportive clubs and groups provided emotional connection, practical help, and a sense of belonging. Respondents valued the kindness, respect, and personal attention they or their loved ones received - from home visits and food drops to community memorials and informal support from walking or dog groups.

Club

Club were solid.
Rostered drivers took hubby daily to his treatment - They looked after him so I could just be his partner not driver, medic, banker etc.





Church

Ignoring their frailty. Never mentioning illness or opening up conversations about their fears and need for support.



## How it could be improved

Some clubs struggled to respond appropriately to members' deteriorating health. Issues included poor communication, cultural insensitivity, and emotional disconnect. A few felt excluded or unsupported when they could no longer meet obligations or keep up socially, pointing to a need for greater awareness and flexibility in community spaces.

## Church

Ignoring their frailty. Never mentioning illness or opening up conversations about their fears and need for support.



## **Organisation**

My wife had been in contact with over a year ago in preparation for her passing. She wanted to donate her corneas as she knew they wouldn't be affected by her cancer. They said, to contact her closer to the time of passing. She did so and they said there is now a series of questions that need to be completed but by then she was too exhausted to do so, therefore the donation could not proceed.



**Organisation** 

Just treated me normal.



**Organisation** 

Lack of sympathy.



## Organisation

## Promises made, delivery not executed.



## Club

They had difficulty coping with my brother-in-law after his first surgery and several members wanted him out stating that he couldn't keep up with his commitment to the secretarial job. In the end he walked away very disheartened by the club's actions.



## Group

This group of people who had come to live in NZ from other countries, rallied around my friend and supported her in many ways in her last weeks.



## **Organisation**

More prompt communication would have been nice.



## **Organisation**

## The assistance provided by the , AMAZING!



## Club

I think it's good for dementia sufferers to hang out together. It gives grandad some time off.



## Organisation

Without this service it would've been difficult as I would've had to leave work to prepare meals etc.



## **Organisation**

Free accommodation including providing some meals, if needed. Was very useful.



## Club

How people are treated.



## **Community Group**

My mum loved being involved in this group for the exercise and the social contact.



## **Organisation**

The provided a lot of helpful information on how the cancer diagnosis, treatment and future processes work. Sadly Dad didn't live long enough to make use of their services but they would have been very helpful had he needed them.



## Church

Church were very supportive and accommodated with home visits and dropping off food parcels.



### Church

Prayers given for her.



## Church

Good support.



## Club

Dad had cancer of the Pancreas but was able to go to his and Croquet Clubs and the people involved helped keep his spirits up.



### Club

They were awesome and put on a memorial for my husband free of charge as he was a very involved member.



#### Club

An informal group of people with dogs used to walk my friend's dog too, voluntarily. Her dog was very important to her, she didn't have to worry about him when they walked him.



### Club

Rallied around my family and provided support.



## Club

They were very supportive both before the death and after.



## CLUBS AND OTHER COMMUNITY GROUPS - FULL COMMENTS

## Group

The community around was very supportive and helped in all the possible way they could during the difficult situation we were facing. The help we received from the community was too much.



## **Organisation**

Gave the very best service and support in the early days of my mother's dementia when she could no longer drive. My mother loved the sea and they would always take the route home alongside the sea. Sometimes stopping the clock to stand on the shore and watch the waves come in. They would always carry the groceries, books back up to the house and sometimes stopped for a cup of tea. They went above and beyond. Personal, caring and very compassionate.



## **Organisation**

The support they provided was amazing to both my brother and his partner.



## **Organisation**

Instrumental at such a hard time.



Club

Club were solid. Rostered drivers took hubby daily to his treatment – His mates looked after him so I could just be his partner not driver, medic, banker etc.



## Education

4.0 STARS n4

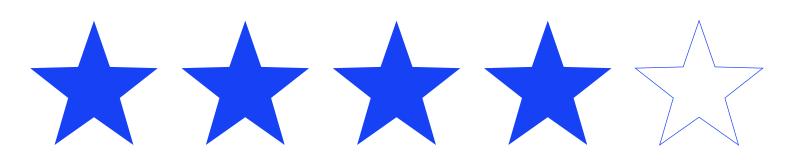


Education providers were mentioned infrequently, but when they appeared, the contrast was clear. The most positive experiences came from universities and schools that showed understanding and flexibility – adapting learning requirements for students facing illness or bereavement. However, some respondents described having to repeatedly advocate for themselves or their family members to receive support. The emotional burden of self-advocacy in these situations points to a need for better pastoral care and clearly signposted support pathways for students navigating terminal illness or grief.

## What made it so positive

Positive experiences reflected understanding and flexible support from educational providers. Lecturers and teachers who adapted to unpredictable attendance or physical limitations enabled continued learning.





Secondary school

Constantly having to advocate for yourself can be hard.



# How it could be improved

Challenges included lack of financial support and the emotional burden of self-advocacy.

## Secondary school

Constantly having to advocate for yourself can be hard.



Secondary school

Provide more financial aid of students whose family members are suffering.



Primary school

Great support.





The lecturers were very accommodating in facilitating learning outcomes for a mobility challenged student and one who had unpredictable attendance to lectures and labs.



## Government agencies / Public services

2.5 STARS n40



Government agencies - especially WINZ, IRD, and ACC - received a mix of praise and strong criticism. Compassionate, proactive case managers made a huge difference, particularly when they helped families navigate financial support and housing needs. However, many found these systems exhausting to deal with, citing long wait times, confusing criteria, and the emotional toll of proving their terminal illness repeatedly. There is a clear need for more consistent case management, shared information between departments, and a simplified, humane process for notifying multiple agencies of a death.

## What made it so positive

Positive feedback acknowledged compassionate, efficient assistance from agencies. Respondents appreciated when staff took initiative to resolve housing, benefits, or financial issues with minimal stress, allowing families to focus on care and grief.

## **Govt Agency**

Claim was handled efficiently and with compassion. We all carried on as best we could and provided care and support at all times to my ill daughter throughout her struggles.





### Govt Agency

I wasn't sure of what I would be entitled to and trying to find out is a mission impossible. When I asked, the woman on the phone said I'm not entitled to it because it's for those with a serious illness....by this point I had already mentioned that I have an incurable diagnosis.... so I asked, 'What's more serious than a terminal diagnosis?'



## How it could be improved

Negative experiences reflected bureaucratic hurdles, impersonal systems, and a lack of joined-up communication across agencies. Respondents were exhausted by repeating their story, facing long call wait times, and constantly proving terminal illness. Compassionate case management, simplified processes, and cross-agency coordination were urgently needed.

Provide case management to suit the client, don't just treat everyone the same.



## **Govt Agency**

I have lost most of my accumulated sick leave as I cared for my dying father, dying mother, dying daughter, dying husband. I am now in my 60's with limited sick leave. Perhaps ACC-type support could be applied for on an 80% of salary for up 3? 4? months. No one is looking for handouts just some kind of dignified recognition that during these profoundly challenging times the fundamental financial well-being is provided for as of right and not just for those who can afford insurances to cover such times.



#### Council

This was an upsetting and stressful incident. I believe it is revenue gathering.



## Govt Agency

Agency would not cancel my child support payments even though I was sole beneficiary of the will, so I was basically paying into an account that was to become mine.



# Ensure that their systems are working properly.



## & Govt Agencies

Every year we get an letter saying mum is on the wrong tax code. The letter says talk to your employer and have them fix this issue. She has received the pension for ten years, pays her benefit and her rest homes, how do they not know how to fix this? We can't change it for mum as neither office has power of attorney documents on file and we just cannot be fucked with the rigmarole.



## Govt Agency

More empathy.



## Govt Agency

Renting out a wheelchair is a nightmare.



## Govt Agency

Nothing available for financial help. Lack of clarity around Financial support available.



I wasn't sure of what I would be entitled to and trying to find out is a mission impossible. When I asked about the accommodation supplement or might have been the disability allowance, the woman on the phone said I'm not entitled to it because it's for those with a serious illness....by this point I had already mentioned that I have an incurable diagnosis....so I asked, 'What's more serious than a terminal diagnosis?'



## **Govt Agency**

and Community organisations it's often transport or costs that are highly stressful - there's little support prior to serious effects from illness.



## **Govt Agency**

has no sympathy. My mum has cancer and needed transport which could have been provided by but no such luck.



## Council

Council made mistakes in all billing and you cannot call to talk to a person.



## Absolutely no help what so ever, it's a joke.



## Govt Agency

Didn't meet the qualifications for assistance. Had nowhere else to go and felt abandoned without any further advice or guidance what to do next. It's expensive to stay alive. It's also expensive to die.



## and Govt Agencies

You end up telling your story multiple times to multiple agencies. It's emotionally draining repeating to strangers that your mum has just died while your Dad weeps next to you. How about an 0800 number dedicated to notifying these agencies of a bereavement?



## and Govt Agencies

Prior to his death, we had to use our tax fund, (GST) to give my darling a leaving party, then fund his funeral. were helpful initially with the funeral grant but I'm still struggling and frightened by



## and Govt Agencies

The day after Mum died, Dad wanted to sort out all the admin. The wait times are excessive, so you ask for callbacks. We then had , and all calling at the same time and had to make a call in the moment as to, for example, hanging up on mid-convo and telling them we'll have to call back, then taking the call from to switch off Govt Super. Which puts you at the back of the queue again for ...



## **Govt Agency**

# have been understanding however there's a lot of paperwork.



## DHB Govt Agencies

I supported my dad dying with terminal bowel cancer for 15 months until he died 2 weeks ago. It was hugely difficult & time consuming to undertake all the applications & to organise him to be assessed etc. In my opinion there is no way an elderly, dying person could navigate all this themselves, so if they don't have family support it would just be too hard!!



## **Govt Agency**

Not very clear about what they are saying.



## and Govt Agencies

and were a little bit frustrating to deal with. We had to go through a few hoops and it wasn't as straight forward as one hoped. More awareness of the process of how to do it is needed so it makes it easier to complete.



## **Govt Agency**

## The level of compassion towards others.



## Govt Agency

It was so hard to get information that he wanted to know; he couldn't manage lengthy waits on phone lines or get help from experienced staff who understood his situation. One said, 'Don't worry, it will all come out in the normal course of things.' But he didn't have that time ahead of him. The staff member was perhaps trying to help but he wanted to 'tidy' his business affairs himself.



## **Govt Agency**

It took a long time to get response. People need more engagement when they are dying.



## Hospital and Govt Agency

Care was good but the bureaucratic wrangling over how to pay for things between agencies seems inefficient and a waste of resources.



## Govt Agency

I watched my chatting extrovert father withdraw & become lonely, he felt embarrassed about his illness & wasn't able to go out much. I gave up working to care. 'Well' people need to understand that much more support is needed to ensure people can live as happily as possibly with their illness whilst dying. If my GP had not signed me off on medical leave, would have been on my back to apply for jobs at a time that I couldn't do it (there needs to be a separate benefit for caregivers of terminal patients).



## Govt Agency

are one of the most insensitive organisations to deal with when terminally ill. You have to prove every 3 months by visiting your doctor or specialist, that you are still 'terminally ill'. The question asked is, 'Are you still terminally ill or dying and has anything changed?'



## Govt Agency

While the process was a little long winded and somewhat stressful for the immediate family, they were excellent with a really focused and supportive staff member and support package. A clearer pathway would have taken away some weeks of stress about on going care.



They approved mum's sickness benefit quickly and her husband was paid to look after her at home.



## **Govt Agency**

Claim was handled efficiently and with compassion. We all carried on as best we could and provided care and support at all times to my ill daughter throughout her struggles.



## **Govt Agency**

Had no issues at all, they did everything expected of them and with compassion.



## **Govt Agency**

Support worker helped negotiate with the landlord, since income had changed.



## Healthcare

2.77 STARS *n*65



Healthcare was the most emotionally loaded sector - showing both extraordinary care and deep distress. Palliative nurses, hospice teams, and certain GPs were celebrated for their kindness, respect, and ability to make people feel safe and comfortable. However, respondents also described hospitals as noisy, impersonal, or even neglectful. A recurring issue was patients being treated as cases rather than people - particularly the elderly or those with dementia. The healthcare system showed signs of strain, with overworked staff and fragmented care, highlighting the need for better integration, communication, and training across services.

## What made it so positive

Respondents deeply valued respectful, compassionate care, particularly from palliative teams, nurses, and specialist services. Positive stories often involved healthcare workers going above and beyond to provide dignity, comfort, and support for both patients and families during the final stages of life.

### DHB

The nurses were absolutely fantastic in the care they provided to my friend. They treated her with the utmost care and respect at the worst time of her life.





### Hospital

We could see he was wasting away, but no one was honest about his state and they kept talking about the future. We and he wanted to have him at home. He died alone. How it could be better: be honest, provide options based on the wishes of the patient and the family. I'm still upset and angry four years later.



## How it could be improved

Experiences varied widely, with many citing poor communication, dismissive attitudes, and delays in accessing appropriate care. Gaps in coordination, emotional support, and respect for patient preferences were common. Families often felt they had to fight for care or navigate the system alone - especially when dealing with age-related decline or cognitive issues.

## Hospital

## They were put in a single room at the far end of a general ward.



### Healthcare Provider

My dad was sent home to die after chemo and lymphoma on the liver.

came every morning but not always!!!!! Often late, paid for 1 hour, but sometimes only there 25mins. Dad was passive so didn't complain. On the weekends sometimes no-one came.



## **Hospital**

To have been let in to see our mother to be able to offer her the basics like water and food, which she was missing out on a huge amount! Feeling not seen/heard and often in mixed sex rooms which is uncomfortable for people. Keeping people at home as much as possible is often what is preferred.



## **Hospital**

You are just a number and treated like a burden...so little respect for a person's life.



## **HEALTHCARE - FULL COMMENTS**

## Hospital and Hospital

My husband had a brain tumor, he had seizures, he could not drive. We live in but needed services in \_\_\_\_\_\_. The transport service was unhelpful, unkind, aggressive, unsupportive, I could not drive him there alone, his seizures were violent and long lasting, the journey takes you through no signal areas. He was terrified of flying alone. They would not fly me as a support person. He was scared, lonely and it was unnecessary.



## **Hospital**

My mother was profoundly deaf and used hearing aides but relied mainly on lip reading. This was on her notes but no one seemed to know and often turned away while giving her instructions. I was always repeating the instructions or asking if I could write on the bed about her hearing. And was told 'no'.



## **Hospital**

## A horrible experience.



## Hospital.

There was a level of rudeness and impatience that astonished me. It was almost as though they wished he would hurry up and die or get out of there. The bright lights stayed on, loud patient alarms for completed drips etc. were not attended to quickly, staff didn't get his name right and, they too often talked to me instead of him. I felt it was unsafe to leave him there. This was not an isolated experience. A cousin and a friend and similar and horrible experiences with their parents in the same hospital. I just really wish it hadn't been so hard.



#### Hospital

### Terrible.



#### & Hospitals

I utterly dislike both hospitals because of the unkind treatment they gave my mother. The health system needs to be more caring as I don't think it really is at all.



#### Hospital

We could see he was wasting away, but no one was honest about his state and they kept talking about the future. We and he wanted to have him at home. He died alone. How it could be better: be honest, provide options based on the wishes of the patient and the family. We would've paid for help at home. I'm still upset and angry four years later.



#### DHB

They explained the system, but it didn't happen as they had said. Neither his wishes, nor mine were respected. More regular conversations with the relevant professionals about the process of dying are needed.



#### DBH

So many promises, so little delivery. It's like a flow diagram – once you are in the system there are no options.



#### **Hospital**

The community and medical system are not well set up to care for the dying at home. GPs are not available for home visits. Getting my father to and from the GP was a major exercise. The general medical system demands everyone will come to them, even when they know the challenges the patient faces. When I think of the time it took and what it cost his energy each time, it breaks my heart. It wasn't fair on him or on me.

In reality, it's simpler and quicker for hospitals and GPs if patients leave home to go into private hospital care settings. This is the clear message communicated to patients and families, despite official lines of home-based support. In the end, my father did die at home. I regard it as one of our combined greatest achievements because it was where he wanted to be. I just really wish it hadn't been so hard.



#### **Hospital**

Hospitals are not the place to go. They seem to want to hurry things along.



#### DBH

Some departments were exceptional, however we had a terrible experience of the health system over the 12 months my husband was dying. Improve the health system and staffing levels for all support services including in home care workers.



#### **Hospital**

It was awful, dirty, and unpleasant atmosphere for very unwell people. Wish there was more support. The whole process of people dying is so hard.



#### Hospital

The nurses at the hospital need to be taught empathy. My grandmother had an accident (wet herself) and while my sister and me waited on the other side of the curtain we heard how disgusting they treated her.



#### DHB

Reception staff not checking my file and either continually trying to phone despite my file saying I cannot communicate verbally.



#### DHB

## Informing of more than just saying family member is dying.



#### DHB

Disappointed with the District nurses. Supplies were put on the doorstep and there was never any interaction with the patient.



#### Hospital

My sister was phoned by her oncologist and told she only had weeks to live. No consideration for the impact and distress of being told this news alone in a hospital room, without the option to have a support person with her.



#### **Hospital**

## Needs to be a more open discussion.



#### **Hospital**

They are terrible to talk to. Treated her like crap during her last moments alive, didn't look after her properly or provide her with enough information or equipment during this time.



#### DBH

They didn't look after her in her time of need and she ended up with bed sores.



#### Medical Centre

### GP didn't provide much information.



#### **Hospital**

Staff at the hospital were ill informed about power of attorney, even those working in the older persons unit. Often I had to explain to them how it worked, having gone through the process a couple of years earlier with my father.



#### at Hospital

Some of the occupational people I saw were lovely but on the other hand, they had me caring for my dying husband at home in the last few days of his life. I had no experience in dealing with morphine pumps etc.



#### **Hospital**

They need training on how to care for a dying person, how to support family, for example, when I wanted to stay with my husband for the night, they said I could not use the ward toilet but would have to go out to the corridor and use the toilet by the lift. When I said I had a medical condition and would need the toilet regular they didn't care. I was unable to stay with him during the nights. I was offered the floor to sleep on also. Can you imagine sleeping on the floor for 2 weeks!!!!!! They completed end of life documents which were never discussed with us.

As a carer, you are forced to stop being the wife, the lover, you have to become a carer, stand up for their dignity, be their voice, fight a system and try and manage your own self too. It's lonely, very lonely.



#### Medical Clinic & Pharmacy

Shopping is fine. It's the doctor to chemist that's hopeless. The doctor writes a prescription but they say they can only fax it to the chemist. Not give a hard copy. Then you go to pick up the prescription, often for antibiotics, and it's not done. Sometimes a few days can go by before the chemist receives them. This is very frustrating to say the least.



#### DBH

No support on taking care of her wounds.



#### DHB

I have had to fight for the right treatment and care for my mother. If I didn't ring and badger the Mum would have simply 'fallen between the cracks'. No follow ups ever done, no communication, no checking of conditions or medications. If not for me, my Mum would have died by now - my whole family agrees. Without a strong advocate fighting for their right to dignity & care the elderly are dying badly in NZ!



#### DBH

No family support at a doctors meeting. Patient has impaired hearing and some cognitive decline. No information was given to the family about this meeting.



#### **Hospital**

My Dad was left alone for many hours, he wasn't allowed mom to visit him while he was there.



#### **Hospital**

My father had to walk a long way to the appointment.



#### Hospital

My father was going through terminal cancer. Often he was left for days until someone could visit him at his house in and in some cases, would be advised to go into Hospital instead.



#### **Hospital**

It felt like the staff didn't want Mum to die at the hospital, and they wanted to quickly transfer her to the local hospice to die. I felt as if Mum was seen as a burden.



#### **Hospital**

Very mixed messages from 'people in charge'. For example, the specialist at the hospital says 'sorry, there's nothing more we can do, we recommend a transfer to Hospice services' and then the GP says 'oh no, you don't need that, you need more tests'. It's unsettling and confusing.



#### Hospital

I used to like going to hospital (take the pain away!) but now I'm scared to go back.



Hospital & Medical Centre

I paid privately to see an Oncologist who was very good. The Gastro surgeons were upbeat and positive. The anaesthetists were super caring and also made me laugh. The Palliative care team are exceptionally good. My GP has also been outstanding.



#### DHB

Good care, but my dad felt abandoned for his last 6 months after being discharged because there was nothing further they could do, we had lots of hurdles & new things to deal with.



#### Hospital

Had our own separate room for them, were protected and comforted during the stay.



#### Medical Centre

More empathy and choices.



#### Hospital

They took good care of her and I don't think there's much they could have done to improve.



#### **Hospital**

The clinical nurse specialist has been a great navigator. New Zealand is opening up to the dying conversation. Māori have taught us a lot about grieving openly.



#### DBH

How I felt during my experience with healthcare was an experience/journey that can never be forgotten. The healthcare provided us with all the information we needed during this time, tests and results that needed to be done, a helping hand or shoulder to cry when needed. The service they gave was exceptional though I feel that what could be improved is the doctors' explanation to patients when providing them with information could be broken into terminology that patients, who have a language barrier, understand. Just showing that patient the understanding you have towards them definitely makes a difference.



#### Hospital

My father had multiple hospital visits in the last year of his life. In almost every instance he expressed how grateful he was for the quality of the care he received, particularly the nursing staff. Many nurses were willing to allow someone on the ward early enough for my father to have someone present but it is outside policy and not a given.

The aspects that were challenging for an 80 year old man who was dying were:

- The ED. long waits in a public area while chronically unwell were a major deterrent to seeking hospital care.
- Access to palliative care information. I practically had to insist that the doctors arrange a visit from that team. And some doctors questioned why.
- There seemed to be a complete lack of awareness by clinicians of the value of preparing to die.



#### **Hospital**

I'd summarise to say that 50% of the clinical team were great and 50% were terrible. Improvement would be patience, and acknowledging the persons reality, not ignoring fear and grief. But some of the team were exceptional, and as a whānau, we acknowledged them.



#### Hospital

I really appreciated the palliative care our Dad received before dying.



#### **Hospital**

Amazing staff, incredibly understanding and knowledgeable.



#### Hospital

The level of respect and care we got plus the way they were with him was really good.



#### DHB

The nurses were absolutely fantastic in the care they provided to my friend. They treated her with the utmost care and respect at the worst time of her life.



#### DHB

The important thing is family and carers being able to access help when needed. There are real issues with carer burnout when family do not understand what help can be sourced, do not know how to go about accessing it and / or cannot get traction with timely referrals via GP.



#### **Hospital**

### So friendly. Above my expectations:)



#### Medical Centre

Doctor went above and beyond leading up to end of life as well as afterwards.



#### Ambulance

They treated Mum like an individual, with respect & kindness, despite her being obviously very unwell & struggling with decision making.



### Legal / Accounting

3.43 STARS *n23* 



Positive legal experiences were typically tied to clear, compassionate communication, reasonable pricing, and timely support with wills, EPAs, and probate. Some lawyers took the time to explain processes in plain language and worked at the client's pace - which was highly valued. On the negative side, people described delays, cold treatment, and a lack of follow-through. Some legal firms failed to consider the emotional weight of the situation, treating dying as just another transaction. There's an opportunity here for firms to embed empathy into services when dealing with dying or death.

## What made it so positive

Respondents appreciated professional, compassionate legal support that was timely, clear, and reasonably priced. Lawyers who communicated in plain language, explained complex processes, and offered flexibility made estate planning and probate less daunting.

Law firm

Absolutely fantastic. Absolutely no nonsense, no-frills just good common sense advice - Down to earth approach, totally understandable and listened to the real me not the sick version of me other people speak down to.







Was very inconsiderate. Insisted on meeting at the office when he could have come to the house.



## How it could be improved

Frustrations included delays, lack of empathy, and poor communication.

Some felt rushed, unsupported, or left to manage logistics alone. Suggestions included more proactive service, better coordination with other agencies, and greater kindness during grief or vulnerability.

#### Law Firm

Was very inconsiderate with the children. Insisted on meeting at the office when he could have come to the house.



Law Firm

Little spiritual support.



Law Firm

A 'How to' guide would be good.



Law Firm

Executing a will - Was a very difficult process.



Law Firm

Be more kind and compassionate towards a dying family member.



Law Firm

It was a stressful time that lingered longer than it should have.



Law Firm

They used plain English.



Law Firm

It was a pretty straight forward. Maybe some closer personal contact could have helped.



Law Firm

The lawyer was very considerate and easy to work with but didn't always get back to my husband in a reasonable timeframe and this caused him stress.



Firm

Very supportive and caring.



Law Firm

## One of the best - I really got gold service.



#### Law firm

They were very good. Provided lots of help and advice.



#### Law firm

Our lawyer helped us go through the process in a professional manner.



#### Law firm

Process was clearly explained. There was no pressure or rush at any time and work was done at our pace.



#### and Law firm

## Clear guidance. Prompt access and good advice offered.



#### Law firm

Absolutely fantastic. Absolutely no nonsense, no-frills just good common sense advice – Down to earth approach, totally understandable and listened to the real me not the sick version of me other people speak down to.



### Memberships / Subscriptions

2.5 STARS n10



This sector reflected the hidden emotional toll of everyday admin. Cancelling gym memberships, food deliveries, magazines, or online subscriptions became distressing and difficult - especially when companies required the dying person to speak or respond directly. Some services made people jump through unnecessary hoops or sent repeated marketing materials after a death had been reported. These small but cumulative stressors revealed a lack of dying-awareness in standard customer experience processes. Allowing trusted representatives to manage accounts and training staff in bereavement sensitivity would go a long way.

## What made it so positive

No themes can be identified due to low sample size.

#### Subscription

I found the organisation really good to deal with once they knew I had EPOA and my husband had end stage dementia.





#### Subscription

Aggressive advertising, almost impossible to close the account, I had to pay for a lawyer to write a letter requesting immediate removal from all subscriptions. I had sent more than 3 emails and left messages, posted 2 letters. It took time, energy and money. It was exhausting.



## How it could be improved

Respondents often faced impersonal systems, unhelpful customer service, and complicated cancellation processes. Many found it distressing to repeatedly explain a loved one's death or pretend to be the account holder just to manage or cancel a service.

#### Subscription

Needed to cancel credit facility of the dying family member. Business would not cancel the facility. Only way was to cut the card in half and return to the business.



#### Subscription

Aggressive advertising, almost impossible to close the account, I had to pay for a lawyer to write a letter requesting immediate removal from all subscriptions. I had sent more than 3 emails and left messages, posted 2 letters. It took time, energy and money. It was exhausting.



#### Subscription

Was a real hassle to cancel as my person was unable to speak on phone for themselves or to give me authority to speak for them. In the end I had to pretend to be them to get it done. I understand the security aspect of it but other people need to be able to act on dying person's behalf.



Magazine & Paper Subscription

These were very difficult to change address for.



#### online Subscription

### Really hard to cancel an online service. It sucks.



#### & Credit Service

Letting them know that their health was deteriorating and I was going to stop any future attempts at buying items. After their last breath, going through the process of proving they were no longer alive was very impersonal.



#### **Membership**

Provide flexible membership to put on hold for people who are struggling.



#### Magazine & Paper Subscription

# It was pretty easy, you explain what you need and procedures to follow.

### \*\*\*

#### **Subscription**

I found the organisation really good to deal with once they knew I had EPOA and my husband had end stage dementia.



### Rest homes / retirement villages

3.33 STARS *n82* 



This sector revealed some of the most contrasting experiences in the entire dataset. Many families described deeply compassionate care, where staff treated residents and relatives with dignity and warmth. Facilities that allowed families to stay overnight, supported dying people's wishes, or maintained continuity of care were especially valued. However, others shared stories of poor communication, understaffing, slow medical response, or emotionally distressing policies. Some homes seemed focused on profit over people - pushing residents to upgrade services unnecessarily or failing to explain care options. The most meaningful care came from individual staff members, while systemic shortcomings often led to trauma and regret.

### What made it so positive

Positive experiences were often driven by kind, compassionate staff who kept families informed and made loved ones feel comfortable and cared for. Facilities that enabled loved ones to stay together, offered flexibility, and supported peaceful moments were especially valued. Long-term familiarity with staff and surroundings also contributed to a strong sense of comfort.

#### Retirement Village in

In all instances I have been impressed and overwhelmed by the levels of care, support and attention that have been available to those I have known in the terminal stages of life. The willingness of all to include family in the total process has been appreciated.





#### Retirement Village

Quite negative towards those dying. Biggest problem is food. I have Bile Duct Cancer and have been advised to keep away from red meat and animal fats, including bacon, ham, sausages, etc. The RV considers this is a personal preference.



## How it could be improved

Concerns included understaffing, outdated facilities, limited medical oversight, and poor communication around dying. Some felt pressured into decisions or excluded from planning. A lack of warmth from management and inflexibility in care packages were also mentioned, as was a perceived focus on profit over people in some retirement villages.

#### REST HOMES / RETIREMENT VILLAGES - FULL COMMENTS

#### Rest home

With Mum it was hard to find the right support when she needed it. We must say she did get support in the end but only because she had me and my sister to stand up and fight for her. We saw others who had no one who got left on the sidelines with no support. These people don't have the energy to research everything and push for what they need. They have enough to deal with. It seems those who have family to do all that for them, get the support. Those who don't have family get forgotten. That is so sad and unfair.



#### Retirement Village

Lack of staff. No supervision. My relative often missed care due to no staff. We would never use this home again.



#### Retirement Village

My grandmother was moved from a hospital to a for end of life care. They weren't really equipped to do this. Staff were very busy looking after other residents, extremely understaffed at night, and meds ran out on more than one occasion with no one coming when we rang the bell.



#### Retirement Village

The management were appalling. Heartless and almost cruel when Mum was admitted - the first thing they told us was that Mum was the worst patient they'd ever admitted and implied they were thinking of not accepting her into care. For context, Mum had been in for five days after suffering a fall, was now having to leave the care of her husband of 66 years, was in year 4 of having an inoperable Gastro Intestinal Stromal Tumour, and as a former nurse who hadn't lost her mind (at 88) also knew when she was receiving sub-optimal care from the nursing team. She wasn't rude, she wasn't violent, she wasn't nasty. My sister bore the brunt of management and if we'd been able to find another care facility for Mum that was close to where Dad lives, we'd have moved her out immediately. Unfortunately, that wasn't to be.



#### Rest Home

### Better care needed.



#### Rest Home

Understaffed under resourced. Focus of management on profit. Failure to deal with complaints.

No attention to palliative care in retirement village although they marketed as providing it. Opposed my family member's written and verbal wish to voluntary stop eating and drinking at the end of his life once very frail. Forced food and drink onto his mouth.



#### Rest Home

The service levels, the food and the experiences - the overall care did not match or even remotely compare with the promises made. The management were invisible, the staff training was nonexistent, the attention given to individual needs was nonexistent, there was a lack of a systematic way of doing things.



#### Rest Home

Terrible staff. No knowledge of the illness. No privacy. Absolutely shocking care.



#### Rest home

My friend has Alzheimer's and has also only months to live. The care and attention is not what we would expect.



#### Retirement Village

## Was really awful caring in end days.



#### Rest Home

Not a pleasant atmosphere for visitors, we were not given the option by the hospital for my family member to be transferred to hospice which is where we would have liked her to be in her final weeks. We were not given any options of where she was to be sent as the only option we were given was this one rest home and felt rushed to make the decision to send her there as the hospital needed the bed. I feel people should have the choice of where they go for end of life care and given time to make decisions and not rushed into things. Family need time to take in bad news like this and don't need the added pressure to make big decisions all in one day. There needs to be more support and understanding of individual needs.



#### Retirement Village in

When it came time for end of life care there was too much red tape to get Dad into the hospice for Palliative Care. A better social program & liaison by staff when the resident is fit & well and less red tape when EOL care is needed.



#### Retirement Home

I feel it could help if when a request for a doctor to review the situation they could get one in a timely manner. Not in a week's time or not by video call with a family member. All the while Dad is not in a good place with pain.



#### Rest Home

The rest home was old and not in the best of condition. To me it was not up to standard, and it felt more like a zoo than a pleasant place to live.



#### Retirement Village

Not particularly supportive of family members staying with our loved one as their condition deteriorated. Not helpful that GPs insisted on face-to-face visits to clinic when clearly Mum was less and less able to. This was very stressful and undignifying.



#### Rest home

Staff did their best but the facilities needed updating.



#### Rest home

### Not to be so pressuring.



#### **Rest Home**

Lack of personal care and presentation – everything seemed too much of a bother. There needs to be a better understanding of how the elderly think. They don't want to be a bother and when asked 'Do you want ...' they will often say no. Questions needs to be phrased differently.



#### Rest Home

Not enough nurses and they didn't give a shit.



#### retirement village

Poor care and understanding.



#### Rest Home

Generally good care of my father. Had difficulty dealing with some of his changes as MND progressed though, eg when unable to press call bell. Didn't tell us he developed pneumonia, which was what killed him. I wasn't capable at the time of making the complaint I wish I had. Phoned me when he died, not my mother. We should have been told when his health worsened.



#### Lifecare

Was too scared to complain in case of retaliation of care.



#### Rest Home

Not enough experienced carers, bad communication. She needed much more care and family couldn't pay privately.



#### Homecare

Show up ... Have some passion.



#### **Dementia Care**

Staff were close to my mother. At the time of death and leaving the facility we were surprised. We needed to manage our own grief, but found ourselves caring for staff. We were surprised and taken aback when staff took photos as we wheeled mum on the trolley through to the hearse. This wasn't culturally appropriate for Māori. In our stunned state we just weren't able to address it at the time. Their care, manaaki and relationship with mum and our whānau in the previous part of her stay was just stellar. It was an awkward way to leave.

A lack of kaupapa Māori respite and end of life care facility was hard. Māori space with Māori kai, carers and residents would have been beautiful for our mother.



#### Retirement Village

Quite negative towards those dying. Biggest problem is food. I have Bile Duct Cancer and have been advised to keep away from red meat and animal fats, including bacon, ham, sausages, etc. The RV considers this is a personal preference.



#### Retirement Home

It was very morbid and didn't seem like a very positive uplifting place.



#### Retirement Village

Had to move 4 days before her death as they had no hospital facilities. Very upsetting for her having to leave the Apartment she had been in for over five years. Shouldn't you be able to live out your last days in familiar surroundings?



#### Retirement Village

## They were good with him. Very caring.



#### Rest Home

The rooms were dated. They were also extremely hot, in fact so hot that we had to purchase a portable air conditioner, the windows didn't open and no fans.



#### Rest Home

When you are dying it's nice to be in a lovely room not an old, outdated room. Not only for the person dying but family members have to remember the dull old room with the memory of that person passing away.



#### Rest Home

The room didn't have enough furniture and was not inviting.



#### Rest Home

I was unsure on the score I should give for this as some of the staff were absolutely incredible while others were horrible to deal with. Better screening when hiring staff and closer monitoring to ensure these staff are doing what they should be and treating the elderly respectively.



#### Rest Home

The rest home my grandfather was at before he died was very kind but their staff were very unreliable and incompetent. Most people are kind to people who are dying and old. But there are lots of others who would take advantage of their situation.



#### Rest home

Food was awful. Savories and Cheerios most days for lunch and sandwiches for dinner. Doctor was only available 1-2 days per week. Having a doctor or qualified nurse available at all times would be a huge improvement.



#### Rest home

The people were kind, but it seemed unfulfilling. I would just hope that NZ could provide something more fulfilling than watching tv.



#### Rest Home

Our Rest Home experiences with an extremely ill, slightly befuddled person with constant pain, was not great.



Rest Home

### More sympathy.



#### Retirement Village

I have Bile Duct Cancer Stage 4 with metastases intrahepatic. I have researched nutrition, primarily through the US Cholangiocarcinoma Foundation. Red meat and animal fats are definitely not recommended.

package of care includes meals with no adjustment allowed. Trying to find vegetarian food is almost impossible.



Rest Home



#### Rest Home

My spouse is a tetraplegic/Locked in Syndrome. The situation is ever changing and unbelievably difficult and exhausting. I couldn't cope without the wonderful caring Carers.



#### Retirement Village

### Caring staff. ★★★★



The day she was dying family were with her and it wasn't till late in the day they thought of giving her a wash. When family went to collect her belongings they were given her teeth so she was buried without them.



#### Retirement Village

Very good care, but difficult to be of sound mind with a failing body amongst people who looked comatose and dribbling in the lounge. After a serious accident my older family member was worked on for over an hour by when she was 'not for resuscitation' as she had decided she was ready to go and OK with that. I wish we could have spared her that horrible final few hours and let her go peacefully but I don't think can see her records which stated no interventions at the end.



#### Rest Home

Lack of apparent facilities in small communities that are distanced from larger centers.



#### Retirement Home

My grandmother spent her last week there. The staff were very kind and hospitable. Having more regular medical care from trained doctors or nurses would have been helpful.



They were very supportive of the families wishes to surround her.



#### Rest home

Hard to see some folk living with the best they can, while next door your loved one is dying. It's all a strange situation really.



### Rest home

Supportive caring staff but ultimately not enough of them. Services are very underfunded.



# Rest home

Thoughtful caring staff who responded quickly to family needs.



#### Rest Home

Most of the time we had the same carer which was great as she was lovely.



I was really surprised at the lack of end of life conversations that were had with Nana and the family, and that despite declining health and a number of strokes, the staff seemed to encourage an ambulance to be called so she could die in hospital as opposed to at her home in hospital level care. Nana with support from the family, chose to stay at home.

It was greatly appreciated the roll-away bed that was made available for family to stay overnight.



# Retirement Village

Why do specialists give you a terminal diagnosis (February 2023) with a prognosis of 6 months and maybe to the end of 2023. I did my last Mother's Day, my last birthday, and my last Christmas. Now in 2024 I'm doing it all again. I'm told I'm depressed but I am waiting to die.



### Care Home

People with dire situations need that extra care with meals, meds and taking out for a walk etc. Just make sure people are cared for with respect.



#### Resthome

My family member was well looked after and the family was shown empathy and compassion in the final hours/days of my family member that passed life.



# Friendly and helpful staff who were always there to help.



#### Care Centre

Staff were amazing, so caring and kept us informed every step of the way.



# Retirement Village

Mum had lived in the Village for over 9 years and it became her home. All the gardening & maintenance staff continued to call by her room to say hi or wave out from the gardening areas. Fabulous really. The nurses, care associates, kitchen & cleaning staff were simply amazing and gave her the most wonderful care in her last months. Forever grateful.



### Resthome

My Dad was happy, and comfortable.



# **Health Centre**

Compassionate caring staff.



#### Care Centre

The care and attention the staff and doctors provided during mum's last few weeks on earth was amazing.



# Retirement Village

They gave him the care he needed in his last few months.



# Retirement Centre

Staff and management were so helpful and understanding.



#### Resthome

Wonderful people to deal with. They fully understand the impact on family dealing with a parent with dementia. Excellent facilities and care. When mum passed away they looked after her with dignity and respect.



#### Rest Home

It was a traumatic experience for me personally. The staff at were so compassionate and caring and made this time more bearable.



Rest home

The staff were so caring right until the end.



Rest home

They took good care of my grandmother and made her comfortable.



Rest Home

The staff and carers have been amazing. They are so caring.

\*\*\*\*\*\*



Excellent care they provide. Thank you for all the effort and hard work.



# Retirement village

Once my Mum was made palliative, the village staff worked extremely quickly and set Mum and Dad up with hospital beds in their own apartment and provided the necessary care in their own apartment so they could be together until they both died within 24 hours of each other. The care the staff provided was wonderful and they were so helpful and supportive to me and my family afterwards.



# Retirement village

The staff at the complex were wonderful in how they supported my Grandpa throughout and after Nana's journey. It was wonderful knowing how much they genuinely cared about both my grandparents. We have several nurses in the extended family and they were able to support Nana through the cancer and palliative care journey, and to help translate and communicate with Grandpa. Navigating the health system isn't easy if you don't know the right questions.



# Retirement Village

The staff were wonderful from the time the person entered the building, until their demise one month later. I believe that all the staff associated with this industry are all very genuine, and try to assist you to make your views put into place, whilst still living.



# Constant care and allowing family to stay 24/7.



# Retirement Village in

A family member was admitted with level 5 care requirements. The facilities were well suited to his needs and the staff were really, good and totally committed to his care. In all instances I have been impressed and overwhelmed by the levels of care, support and attention that have been available to those I have known in the terminal stages of life. The willingness of all to include family in the total process has been appreciated.



#### Rest Home

My father received palliative care at for his last 3 days after transfer from hospital. The manager went out of her way to help me and the family, was contactable 24/7 and followed up after Dad passed. Our family were welcomed and included, and great hospital level care was provided.



# Restaurants / Movie theatres / Events

4.55 STARS

n11



Positive experiences in this sector were small but powerful often hinging on acts of quiet kindness. Staff who accommodated mobility aids, relaxed dress codes, or simply treated someone as a person (not a problem) created lasting memories for families. Some waived costs, made special arrangements, or just showed respect during difficult times. There were few negative stories, but those that existed pointed to a lack of accessibility (e.g. narrow layouts, missing ramps) or missed opportunities for inclusive service. Overall, this was one of the more consistently positive sectors - with emotional impact far greater than the transactional nature of the service might suggest.

# What made it so positive

Respondents recalled small acts of kindness that made a big difference, from accommodating clothing or mobility needs to quietly waiving costs. Staff who treated people with dignity and care created meaningful, lasting memories during a vulnerable time.



My family member was treated beautifully for a concert she wished to go to. This was in the last few months before she died. They did their upmost to make her have an exceptional experience by allowing to go towards the front and in her wheelchair. It made her day. She spoke of the occasion numerous times after.





#### Restaurant

Everyone needs to be respected and loved no matter what stage in life we are at.



# How it could be improved

Some respondents called for better physical accessibility, including ramps and wider spaces for mobility aids. Others noted the importance of staff awareness and patience when serving customers with visible or invisible health challenges.

### Restaurant

Satisfactory without being fantastic. Everyone needs to be respected and loved no matter what stage in life we are at.



#### Restaurant

# More accessible for those in wheelchairs.



# Working Men's club

We go to the same place as the space is excellent for a wheelchair-powerchair user. It's a large space and my spouse can navigate the area in his power chair and it's a very relaxed environment. But there isn't a permanent wheelchair ramp to the lovely outdoor area.



# Venue

We had a great time, it was the last time I saw my close family member and it was an experience I won't forget in a while. She had the time of her life too.



### RESTAURANTS / MOVIE THEATRES / EVENTS - FULL COMMENTS

#### Restaurant in

We took my father-in-law out for dinner for his birthday a few days before he died. He desperately wanted spring rolls. The restaurant didn't flinch when he arrived in pj bottoms, a beanie and sweatshirt with slippers. He was so unwell he could barely stand and it was such an effort changing him we took him out 'as is'. They were amazing and we actually got the spring rolls for free.



#### Theatres

# Great wheelchair access.



#### cafe

Before she was diagnosed with cancer my sister and I had a very regular coffee catch up at my local cafe. We did this for years. When she became visibly unwell, but we were still able to meet, our coffee suddenly became free. When she became house bound, I would stop by the cafe and pick up one for her – still free. Such kindness was never expected.



#### Restaurant

My spouse is in a wheelchair as he can't mobilise. The staff move a chair so I could push his chair in under the table. On arriving to inquire if we could eat there as I had a person in a wheelchair they showed me where the ramp was even though I knew where it was. We were offered several tables we could sit at. When leaving the bar person held the door open so it was easier to exit.



### Cinema

# The food, cocktails and reclining chairs.



#### Arena

My family member was treated beautifully for a concert she wished to go to. This was in the last few months before she died. They did their upmost to make her have an exceptional experience by allowing to go towards the front and in her wheelchair. It made her day. She spoke of the occasion numerous times after.



#### Restaurant

The wait-staff were lovely. You don't realize how kind people are until you need assistance for so much.



#### Restaurant

They were super accommodating considering I can barely walk.



# Shopping / Groceries / Pharmacy

4.08 STARS *n37* 



Pharmacies stood out as some of the most consistent providers of compassionate care. Many respondents spoke of staff who knew them by name, checked in regularly, or helped simplify complex medication routines. Pharmacies that delivered medication or offered holistic advice were especially appreciated. In contrast, a few experiences involved poor communication, delays, or insensitive comments - which caused unnecessary distress. Supermarkets and retail staff were generally kind, but accessibility was an issue. Narrow aisles, obstructive online shopping setups, or rushed service made it hard for people who were unwell to feel safe and supported. Like restaurants, simple human kindness went a long way.

# What made it so positive

Respondents praised caring pharmacy staff and accessible supermarkets. They valued help with medication, delivery services, and thoughtful gestures during shopping. Many noted how these everyday experiences provided comfort, routine, and community connection in the dying phase of life.

Pharmacy

My husband broke down in tears in the pharmacy. They have been so caring and forthcoming with advice and suggested useful medicines. They've provided a holistic service to both of us and shared their own experiences and been extremely empathetic.





#### Pharmacy

They texted to say they had my medication (a great service) but when I arrived they couldn't find it. It was very hot and very busy and there was nowhere for me to sit. I had to leave without my meds.



# How it could be improved

Improvements were needed in accessibility, customer sensitivity, and service consistency.
Issues included inaccessible store layouts, insensitive comments, and miscommunications at pharmacies. Respondents highlighted the need for seating, clear processes, and staff training to better serve those with limited mobility or terminal diagnoses.

# **Pharmacy**

I was with my friend when he went to pick up a prescription. He is 80 years old and frail. The pharmacist treated him poorly. He told my friend he had to wait while he served a lady that came to the counter after us and bought a box of gloves. He then went out back and ignored us for almost 10 minutes at which point I called him back and told him not to be so rude. If you go to work in a bad mood remember it isn't the customers fault. We don't want it taken out on us.



# Clothes Shop in

# Shop assistant gave no compassion or sympathy.



# **Pharmacy**

They texted to say they had my medication (a great service) but when I arrived they couldn't find it. It was very hot and very busy and there was nowhere for me to sit. I had to leave without my meds.



### **Pharmacy**

We took the prescription form into our local pharmacy. The drug was one they had to order in especially. When we went in to collect it the pharmacist said 'This is a very expensive medication, did you know it costs \$XXXX a month?' I did, because the doctor who prescribed it told us, also that my husband would only qualify while it was effective. I wondered why the pharmacist said that, quite unnecessary. Were we supposed to express gratitude, or feel guilty that the government was funding it?



# Supermarket

# More delivery options that are accessible to all.



# Supermarket

Can't get a wheelchair around store due to online order trolleys.



# Supermarket + local shops

Needs to be more accessible for those with walking difficulties, and things need to be within reach.



# Pharmacy Pha

All the staff are very friendly and helpful.



# **Pharmacy**

Home delivery of medication!



### SHOPPING / GROCERIES / PHARMACY - FULL COMMENTS

#### Retailer

The very kind and friendly staff showed considerable empathy and kindness towards my dying father by always chatting with him and understanding he needed time to complete his shopping due to his illness.



# **Supermarket**

Groceries getting delivered were always timely and accurate - absolutely wonderful.



# **Pharmacy**

Unfortunately my partner is quite private about his condition so he got mad when asked by the pharmacist about it. Being the first time he met this guy I think less in-depth or personal information could of made things smoother. Had he met the pharmacist on occasions previously I think my partner wouldn't of got so aggravated.



# **Pharmacy**

Pharmacy were incredibly caring and helpful and ensured at short notice much needed medicine was available.



# **Pharmacy**

They made it so easy to have her medication arranged.



# **Supermarket**

Despite her terminal illness my wife still received excellent and helpful service from the Supermarket.



# Supermarket

Ordered everything online – it made life much easier.



# **Pharmacy**

Was always convenient and had no issues picking up his medication on such a regular basis. One staff member went above and beyond and said he hopes we're taking care of ourselves.



# **Pharmacy**

All medications and supplements were ready on time.



### SHOPPING / GROCERIES / PHARMACY - FULL COMMENTS

# **Pharmacy**

My husband broke down in tears in the pharmacy. They have been so caring and forthcoming with advice and suggested useful medicines. They've provided a holistic service to both of us and shared their own experiences and been extremely empathetic.



# **Pharmacy**

The regular supply of medications, for my late wife, required adjustments being made every day.



# Supermarket

When I went to the supermarket with my aunty who was dying, the staff were very accommodating of her slow movement around the store and even had a wheelchair available. This meant we did not have to rush.



# Pharmacy Pha

Our Pharmacist is very helpful and understanding with my cancer treatment. They always have time for a quick chat and ask how I am. Just a real positive feel from them.



# Supermarket

Shopping is really enjoyable at our local supermarket, because they have very capable staff walking around the store assisting people, the aisles are very wide and their checkout staff always are very courteous and have a pleasant smile whilst serving us.



# Pharmacy

They made sure my family member was looked after and had all the correct pain relief.



# **Pharmacy**

The pharmacy would ensure that my dad had the correct medication delivered each week.



# pharmacy

They know her name, they ask how she is. Very helpful.



# **Pharmacy**

Very understanding and willing to go out of their way to accommodate and track down certain special foods etc for my mum. Would check in to see if there was anything we needed.



#### Retailer

Good open space and wide aisles for power wheelchair. Easy to navigate, and relaxed atmosphere.



# Supermarket

Whilst doing the shopping, which I would always do with my late wife, if she was not feeling the best and needed to sit down while I finished the shopping, the staff especially a couple of the young ladies would always keep an eye on her or keep her company. I knew that my wife was going to be ok whilst I rushed around getting the final bits we needed (Yes my wife could have stayed home but she wouldn't - her choice).



# Supermarket

Local staff were very positive and welcoming as these visits became a special way to experience the community.



# Supermarket

'Click and Collect' was a godsend once she became too unsteady to drive, as she could order the groceries she needed and a family member was able to pick them up for her.



# Travel / Public transport

3.58 STARS *n26* 



Airlines and transport providers were most appreciated when they were flexible, empathetic, and fast to act - especially in emergencies or after a death. Air New Zealand was repeatedly praised for refunding non-refundable tickets and handling bereavement with care. Taxi services and mobility schemes made a difference when they were easy to access and physically comfortable. However, digital barriers were common - apps were often the only way to book, leaving older or less tech-savvy users stranded. Public transport also lacked tailored support for the dying or recently bereaved. In a sector focused on logistics, the providers who stood out were those who remembered the human.

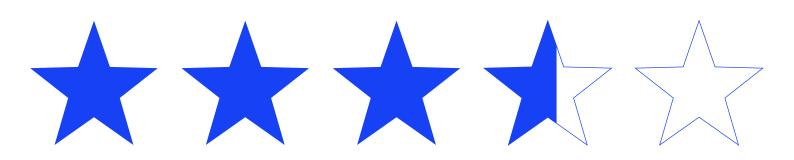
# What made it so positive

Respondents appreciated empathetic and flexible travel services, especially when dealing with bereavement or terminal illness. Airlines and transport providers who waived fees, accommodated special needs, or offered fast, compassionate support made difficult trips easier.

Taxi business

Just having a nice driver who communicated with my sick friend.





**Bus Service** 

requires use of an App, for someone who has impaired sight this is challenging. So there is transport that goes by the door, literally, on a daily basis that they can't use. A non-app option needs to be included.



# How it could be improved

Feedback suggested a need for more accessible vehicles, better affordability, and clearer communication. Respondents described systems that were impersonal, difficult to navigate, or unsuitable for those with physical or cognitive limitations. Some also noted distress caused by thoughtless automated communications after a death.

# TRAVEL / PUBLIC TRANSPORT - FULL COMMENTS

# **Transport**

After my mum's death, I guess removed her from the list of super-annuitants who were eligible for the SuperGold Card (free transport). This resulted in sending automated messages about 'your eligibility has changed' and please get in touch if you think we've got the wrong info. This is unnecessary, heartless, and comes across as antagonistic. For SuperGold card, surely the main reason that 'eligibility' would change is them dying. Surely it is incredibly common and must happen every time someone over 65 (who uses public transport) in dies. Surely it would be very quick for to have a slightly different automated email for these cases that says 'sorry for your loss' or something. It is just unnecessary to cause this extra stress.



# Transport

Transporting someone to the hospital to receive treatment. It takes 2 hours one way to drive to the hospital and 2 hours back which is very exhausting.



#### Bus Service

requires use of an App, for someone who has impaired sight this is challenging. So there is transport that goes by the door, literally, on a daily basis that they can't use. A non-app option needs to be included.



# Airline

Airline companies need to advise airpoint owners how and when the timeline is to claim a loved one's airpoints. After my husband died of cancer the airline said bad luck lady. The airpoints can't be swapped to a family member now. That needs to be done before the person passes away!



# **Transport Agency**

Surrendered driver's license, no issues. But good to have close family to trust and lean on.



# Transport Service

I really appreciated that my father had a Total Mobility card, which enabled him to receive half-price taxi fares. Having access to this was essential when it was difficult for him to move in and out of a car. However, the fares are still astronomically expensive and I think probably prohibitive for many. I think there should be a way for the trips to be free when going to or from a GP or another health care provider.



## Airline

Frontline staff sighed and showed annoyance in front of my father-in-law due to taking time to check in.



# Transport

They don't advise when some of their buses are not working.



## **Airline**

The airline was accommodating to my family member's needs on a flight to Australia.



### **Airline**

It's amazing, they really helped me on my last year of life do everything I wish to do with the little time I have left.



# Airline

It was fine. We booked a ticket in a hurry to be with grandmum.



#### Airline

very good - Consideration in travel is important. Beverly was wheelchair bound for many years prior to dying and the ability to manage wheelchair travel is critical to wellbeing.



#### Taxi

They were very good for the most of it, although they didn't try hard enough to talk with her.



# Public Transport

The cost of the public transport needs to be reduced so that people who are struggling financially are able to use the service.



# Travel Business

Caring for the passengers and handling difficult situations. Customer services need training and improvement.



# Travel & Resort

Since I know that he was mostly lying in his bed & watching TV. We decided to travel him via SUV. We can see in his face that he was happy as he didn't sleep during the travel. He just looking on the sides. Rented an accommodation in a resort, he was happy for the new environment. He appreciated everything. Resort that we rented is ok but need to improve the facilities, that is, wheelchair accessibility. Not only in the accommodation but it will be nice if there's a way to bring the wheelchair to go around the yard or can see a view.



Public Transport

Free transport.



# Wheelchair Taxi Vans

Some newer vans are really good esp for power chairs with more secure clipping/straps to hold the w/chair secure and in place. Older vans have less robust fittings and the chair and person in it (esp a tetraplegic) move about and feel unsafe.



# Transport

My family member often used the bus to travel from her home to the supermarket and other shops. I felt like the service was often rushed and she was expected to get on to the bus quickly which was difficult for her.



### Airline

We had about 8 separate return flights booked, some non-refundable. I phoned to inform them that my husband had died, and while I was on the phone to them they requested I email a copy of his death certificate which I did, they received it and within the one phone call everything was sorted. They separated him off all our bookings so I could still fly (if I wished to, they asked me first) and then fully refunded every single one of his fares, even the non-refundable ones. I was overwhelmed by their compassion and kindness.



### Airline

Service they provided during my holiday.



## **Airline**

were marvelous in getting us emergency seats to get to mum as quickly as possible - Helped me get my family to Christchurch in 4 hours.



# **Bus Service**

The people I spoke/met with were all lovely and efficient.



# Taxi business

Just having a nice driver who communicated with my sick friend.



#### Airline

They changed my flights without charging me extra.



#### Airline

It was a good flight just could've used more space.



# Objectives & Methodology

# **Objectives**

The first 500 Dying Reviews set out to understand how people in Aotearoa are treated by everyday businesses and organisations during one of life's most vulnerable phases - dying.

Unlike most research around dying, this initiative extends far beyond the healthcare system. It invites people to reflect on experiences across all areas of day-to-day life, from supermarkets and government agencies to gyms, banks, and community groups, recognising that dying is still living, and life doesn't stop interacting with systems and services.

By collecting real, unfiltered feedback directly from people who are dying, or who have supported someone who was, the project seeks to:

- Give voice to experiences that are often hidden or overlooked
- Empower participants to reflect on and validate their own experiences
- Identify practical, actionable ways organisations can better support people who are in their dying phase of life
- Build public understanding and empathy by sharing real stories
- Establish a baseline for service standards rooted in dignity, accessibility, and compassion.

# Methodology

An open, self-reporting review form is hosted online and promoted via Hospice New Zealand networks, social media, and word of mouth. It's designed to be inclusive and flexible: participants can review any kind of service or interaction, and submit as many entries as they like. No experience is too small to be counted.

Each review includes a star rating (1 to 5) and opentext comment field. Participants are encouraged to speak freely, sharing both what helps and what harms. Demographic questions (e.g. age, gender, ethnicity, region) are included but optional, and respondents are reminded they can remain anonymous or use a pseudonym.

To date, 481 reviews have been submitted by 380 individuals - of these, 74 unique individuals came through the Dying Reviews website, while 306 were sourced via the Pureprofile research panel. Many participants reviewed multiple organisations or experiences.

The feedback spans a broad cross-section of sectors, highlighting both structural issues and deeply human moments of care. Data was analysed thematically to surface cross-sector insights, systemic pain points, and examples of best practice. Quantitative averages were used to contextualise findings, but the true value lies in the richness of the stories shared - many of them detailed, moving, and candid.

All responses are treated with care and responsibility. Anonymised quotes may be used to inform reporting, advocacy, or service design recommendations, but no identifying information is published without consent.

# WHO WE SPOKE TO

Gender		
Female	62%	
Male	38%	
Prefer to self-describe	1%	

Age		
18 to 24 years	4%	
25 to 34 years	11%	
35 to 44 years	18%	
45 to 54 years	18%	
55 to 64 years	18%	
65 to 74 years	16%	
75 to 84 years	10%	
85 year or more	5%	

Region		
Auckland	35%	
Bay of Plenty	5%	
Canterbury	15%	
Manawatū - Whanganui	4%	
Northland	5%	
Otago	4%	
Other North Island	4%	
Southland	0%	
Taranaki	2%	
Tasman / Nelson / Marlborough	1%	
Waikato	6%	
Wellington	16%	
West Coast	2%	

# WHO WE SPOKE TO

Ethnicity		
NZ European/New Zealander of European descent	75%	
Māori / New Zealander of Māori descent	10%	
Other European	6%	
Chinese	4%	
Indian, Pakistani or Sri Lankan	4%	
Other Asian group	2%	
Other	2%	
Cook Islands Māori	1%	
Samoan	1%	
Korean	1%	
African	1%	
Rather not say	1%	

# **RATINGS**

Overall			
Category	N=	Rating	
OVERALL	481	3.28	
Restaurants   Movie theatres   Events*	11	4.55	
Clubs and other community groups	29	4.10	
Shopping   Groceries   Pharmacy	37	4.08	
Education*	4	4.00	
Work	38	3.63	
Travel   Public transport	26	3.58	
Legal   Accounting	23	3.43	
Rest Homes   Retirement Villages	82	3.33	
Insurance company   Policies	38	3.16	
Utilities   Bills & Payments	17	3.12	
Banking	56	2.93	
Healthcare	65	2.77	
Government agencies   Public services	40	2.50	
Memberships   Subscriptions*	10	2.50	

<sup>\*</sup>Small base sizes

# RATINGS BY DEMOGRAPHICS

Note: we did not capture demographics on all participants, some skipped the questions.

Rating		
Gender	N=	Rating
Male	159	3.46
Female	259	3.21

When looking by age, ratings tended to decrease as age increased.

Rating		
Age	N=	Rating
Under 35 years	57	3.67
35-44 years	78	3.38
45-54 years	66	3.35
55-64 years	85	3.15
65-74 years	63	3.30
75 years+	67	3.01

Thank you for taking the time to read this.

If you would like to write a review go to dyingreviews.org



