

Oral Submission – End of Life Choice Bill

Justice select committee – 11 June 2018, 3:35pm

Julianne

Ngā mihi nui ki a koutou katoa. Thank you for the opportunity to speak to you on this very important issue.

My name is Julianne Hickey. I am the Director of Caritas Aotearoa New Zealand and with me is Mikaele Teofilo (Lay Pastoral Leader), and Teresa Thorp (our Advocacy & Research Manager). We represent Caritas Aotearoa New Zealand, the Catholic agency for justice, peace and development. For us, this bill must be seen through the lens of social justice.

We are social justice advocates who listen to the experiences and understand the realities facing people and communities living in this country. We are experienced in working with and listening to the poor, disabled and vulnerable people, and those with physical and mental challenges. Our submission is informed by this reality.

As an agency committed to overcoming poverty and injustice, the issues that mostly bring us to Parliament are those affecting people living with poverty and other forms of disadvantage – people living on benefits, low income workers, tenants, people in prison, people living with the impact of climate change, refugees and people seeking asylum.

As much as many of us would like to think of New Zealand being an equal society, we know all too well that there are power imbalances in many households, workplaces, neighbourhoods and communities. Some people are confident to speak, and confident that their voices will be heard. However, others are afraid to speak and when they do, they feel their opinions and views are overlooked or ignored.

4 years ago I was diagnosed with an aggressive breast cancer, Grade 3, Stage 3 – and in my lymph nodes. I entered the medical system:

- Educated to degree level
- A CEO of a social justice advocacy agency
- With previous work experience in health care systems and regulation in the UK
- An English speaker, with financial resources
- With a family and community to support me

Then numerous tests, 2 rounds of surgery, 6 months of chemotherapy and several weeks of radiation; I was quite unwell. And I felt unable to challenge, question or even understand my care pathways. I was vulnerable, and I felt like I had no power – despite my background and resources.

Now, take some of my advantages away – imagine someone not able to speak English, or not having a support person to question the medical options or being a beneficiary with limited financial resources. They will be vulnerable and will lack power – particularly in regard to making choices and decisions. People lose power when they are sick and in pain.

Power imbalances not only occur in hospitals, they occur in families, in rest homes and in the broader community. Some people may feel confident that they themselves, and no one else, will make fundamental choices concerning the most significant decisions they will make about life and death. But we know, from experience, unfair treatment by others cannot be prevented. Many people have little or no power when faced with financial, emotional or even physical pressure by others.

We are here to remind you of these people. These are the faces and the voices that you must see as you consider the questions of euthanasia and choice.

I now pass you to Teresa who will speak further about power imbalance and choice.

Teresa

Our experience is that laws don't keep people safe.

Despite legal protections and specialised organisations working to prevent exploitation, our written submission highlights many examples where people are exploited in our country. Sometimes exploitation is presented as being a matter of consent or mutual agreement; for example, a worker signs an employment agreement which includes sub-standard pay and conditions; or a tenant signs a tenancy agreement for a cold, mouldy, leaky home.

In reality though, a migrant worker may be choosing between unemployment or poor working conditions; the poor may be choosing between a poor home and homelessness. With the abuse of migrant workers, or the abuse of tenants, the problem isn't always the substance of the law. Irrespective of the law, we live in a society that often struggles to uphold the law.

Removing the current legal requirements which provide protection against taking human life will create many new situations where people may seemingly make the choice to end their life prematurely when this is not what they really want.

Our whole society is affected when situations of abuse and exploitation are revealed.

In certain circumstances, the wellbeing of society therefore requires that we set standards which apply to all, because apparent "choice" for a few creates the conditions of harm for many.

In respect of this bill, there can never be sufficient safeguards. This bill cannot be implemented safely.

Just because safeguards have been passed in Parliament does not mean they work in practice. In theory, laws work; in an ideal world, safeguards work; but, as our experience working with the poor and vulnerable shows, putting safeguards into law does not always stop abuse.

We're here to talk about the practicalities facing all New Zealanders; and to demonstrate how exploitation removes real choice and autonomy from the most vulnerable. From our experience, poverty is a factor in the increasing suffering of many seriously ill people. People may also suffer when they live in isolation; have difficulty accessing health care because of distance or lack of transport; are living with inadequate food or heating; are cut off from society; and, if they feel they are a burden on their community or whanau.

In times of illness or disability, people are particularly vulnerable. Abuse and undue pressure often take advantage of vulnerability. It is naïve to assume equal power between a terminally ill patient and a doctor; or between an elderly sick person and his or her family. But this bill seemingly does just that: it tries to simplify reality by making unrealistic and uncontrollable assumptions.

Poverty and a lack of access are two of the worse reasons to be forced into euthanasia. If any issue calls for a careful, considered, and cautionary approach, this is the one.

History also shows it is important that Parliament hears Māori, Pacific and other perspectives and viewpoints. If there is not a representative sample of these viewpoints generated by the Select Committee submission process, it is vital for you to proactively seek out these perspectives. Mikaele Teofilo shares some of these.

Mika

Respect for life is one of the common factors right across the Pacific. From the time we are born we are encouraged to look after those who are vulnerable. Children, the sick and the elderly are valued because they all have something to contribute to society. The elderly, in particular, also have something to contribute; and, have already contributed to the well-being of the family and community. We value the care we provide for vulnerable people because of the importance of life.

This Bill challenges cultural convention that centres on the value of life. Indeed, there is no word or phrase for Euthanasia in any Pacific language. During our consultation with communities we needed to translate this issue so that it could be understood by those whose first language is not English. To illustrate how foreign this concept is we had to use direct transliteration when talking about euthanasia in Samoan.

The transliteration is "Eutanasia" because, in Samoan, there is no word that even comes close to the concept of euthanasia. The fact that it doesn't exist, even as a concept, supports the view that culturally, such a thing would not, and must not, be considered.

Euthanasia also has the potential for causing major disruption in families who have to deal with the end of life choice that someone makes. It removes the hope for loving families who only want to provide the best care. The lack of real choices to provide care, together with the burden and pressure of euthanasia, would make a recipe for injustice.

During our consultation with tangata whenua we were guided by the words of our friends from Wairoa who have been discussing the End of Life Choice Bill with their people. They

came back to us with a consensus on value of life by sharing the words, “he tapu te tinana, te tamaiti, te whare tangata”. The body, the child and the origin of humankind is sacred.

In their opinion, as informed by a Māori worldview, all aspects of a person’s life is sacred.

It is also their opinion that this bill doesn’t reflect the spiritual and ancestral understanding that this kaupapa requires in order to properly look out for the most vulnerable members of their whānau and family connections.

In fact, this very way of hearing submissions brings into question the best way for ensuring Māori and Pacifica have a say. There are other ways of engaging that are more inclusive and consider the dynamics of local communities.

Julianne

We work with disenfranchised people and communities here and overseas. We know that context matters – People do not make “choices” in a vacuum. They are influenced by factors such as poverty and neglect. They are influenced by the views society has of them – and if some people in society regard others as worthless and a burden, they themselves will feel themselves to be worthless and a burden. We know that the impact of such contexts on people who are powerless insofar that it can lead to bad outcomes.

As we have seen and heard, despite all the goodwill in the world, our current legislation in many respects is unable to keep people safe.

We must be absolutely certain that the powerlessness, exploitation and lack of choice that many New Zealanders face in homes, workplaces and communities is not present in the hour of their death.

We oppose legalising euthanasia and assisted suicide, and we therefore oppose this bill.