

# **Medical Services (Dying with Dignity)**

## **Exposure Draft Bill Submission**

August 2014

Loredana Alessio-Mulhall

## Introduction

This will probably be one of the most important submissions that you will receive.

My friend, Loredana Alessio-Mulhall is 65 years old and she has advanced, progressive multiple sclerosis.

Loredana has had multiple sclerosis for 40 years and is now totally disabled.

Loredana lives in NSW and last year she featured in a campaign video to support Cate Faehrmann's *Rights of the Terminally Ill Bill 2013*.

Some of you may be aware of Loredana's story but if not, please watch the video here:

<http://youtu.be/IYw1wmmtWNg>

Loredana wants law reform so that she can die with dignity at a time of her choosing.

Last year Cate Faehrmann urged all politicians in NSW to contact Loredana to hear her story but not a single person made contact.

Loredana is determined not to give up, so please read this submission, which is taken from an audio interview made recently and please contact Loredana yourself.

Loredana is  
many people  
first-hand just  
current laws



just one of the  
who experience  
how cruel our  
are.

## **Loredana's Submission**

"My name is Loredana Alessio-Mulhall and I have advanced, progressive multiple sclerosis."

"For me there is no turning back. It is too late for me."

"I am totally disabled."

"I can't move anything except my head and my mouth."

"I have had a catheter for 10 years and a colostomy for 15 years."

"I live at home in my unit and I now have a carer for eight hours a day. But that is the maximum allowed."

"They won't allow me to die but they won't allow me more hours. So what do I do?"

"That is a dilemma for people like me."

"I started to think seriously about euthanasia only in the last couple of years."

"People who say they oppose voluntary euthanasia because of the risk to the vulnerable are just using that as an excuse to avoid the subject of death."

"They are too afraid and scared and they just don't want to face it."

"And the reasons why they are like that?"

"Often it is about religion, or sometimes just a deep belief in life, life at the cost of everything."

“But that is all well and good, if everything is going well.”

“Basically people who are against voluntary euthanasia, I find, are very inflexible, very black and white people.”

“It’s either ‘yes’ or ‘no’.”

“They just have no idea and they don’t want to face the reality of my situation, which makes it so much worse and it is so sad.”

“In my television interviews (last year) I asked people to please come and speak to me - politicians, church leaders, anyone, to come and speak to me.”

“Not one person... nobody contacted me.”

“I just asked could they call me, that would be easy, I am available.”

“But no, nobody did.”

“So that proved to me that they just weren’t interested.”

“They just don’t care.”

“They want the status quo and they don’t want anything to change.”

“They can close their eyes but they don’t have the pain and they don’t have the fear.”

“All I want is for voluntary euthanasia to be legalised so that people like me can choose and there are so many people like me.”

“That is why I want to talk, and that is why I do talk, because most sick people, unfortunately, are generally too shy, too scared or don’t have good enough English or whatever, or they are just very private...and that is fine, of course, but I want to talk.”

“I am tenacious and I will never give up.”

“When people say that legalising voluntary euthanasia will change the idea of doctors as healers, I think, what a quantum leap that is.”

“Maybe doctors should not be involved.”

“They are not the carers, nurses are the carers and they support voluntary euthanasia law reform.”

“Doctors don’t see the suffering.”

“Nurses are there, family members are there but doctors don’t see it unless it is someone in their family.”

“I support palliative care but it doesn’t work for everybody.”

“For me palliative care can’t work.”

“I can’t go into hospital because nobody can look after me there.”

“For me to go into hospital is so traumatic because I can’t go with my carers.”

“Nurses don’t know what to do with me, they are not trained by me, to look after me.”

“Life is hard enough here at home but at least it is not traumatic.”

“Here is the best place for me.”

“It is the only place I can be really.”

“I can’t go into hospital and so forget palliative care for me.”

“No one can give me a timeframe because they don’t truly know that, it depends on the person.”

“With MS everything goes, all the muscles go.”

“When the MS affects my voice, I will not be able to communicate with my carers.”

“Nobody is going to say what will happen to me....they don’t want to.”

“But I don’t know anyone with MS who didn’t have a problem and even now my voice is going...sometimes it is really difficult.....it depends how stressed I am at the time.”

“The more useful and the more positive I am, the better I feel.”

“But how can I feel positive when I need more hours and I can’t get them?”

“There is a constant stress.”

“Stress is my enemy.....it’s everyone’s enemy but mine in particular and I just hope my voice can last.”

“At the moment I have already got to the stage where I can’t speak in a room full of people.”

“If lots of people are talking I can’t speak at all...my voice just goes, it literally just goes.”

“People don’t understand that.”

“The average person out there who doesn’t have family members or hasn’t experienced this, just automatically thinks doctors know best.”

“But the people who are pro-euthanasia generally have had a friend, or relative, or somebody close who has been in terrible pain and suffering.”

“Sometimes they can imagine themselves and are wise enough to think that they don’t want to be in that situation.”

“Doctors hold people like me, and others; so many of us, in pain.”

“We aren’t able to just go peacefully, with our families.”

“I would like to die with my kids and family around me.”

“The big problem with me is that I can’t even suicide because I can’t use my hands.”

“So what do I do?”

“I can’t get anyone to do it because it is illegal and it is murder.”

“So where does that leave me?”

“Very frightened, very fearful and in a lot of stress because I wonder what is going to happen to me.”

“How difficult is life going to be for me?”

“In other words, how are people going to look after me, that is what is really frightening me and that is what I don’t want.”

“I have lost so much independence but I am still trying to maintain something.”

“But I am worried about getting to the stage where I have no independence and I feel ....oh God, it will be just, just nothing .... to be nothing.”

“I don’t want to be a vegetable, or treated like a vegetable and still have a brain.”

That is what frightens me ... not dying, no, not dying, what really frightens me is pain and the agony of seeing what has become of me and that nobody can take care of me.”

“That really does scare the hell out of me.”

“And that is why I need euthanasia to be legalised so that I take something and just go peacefully when I am ready. When I am ready!”

“If only people could understand that I need to feel useful, I don’t want to be degraded and have no quality of life.”

“At the moment I still have some abilities to keep my self esteem but when all that goes, then I will want to die and I will want to choose how.”

“I would love to die peacefully, without any concern. Wouldn’t that be beautiful? With my family and to just go to sleep.”

“Now at least I can speak and people can hear, those people who are interested.”

“The more people that I can speak to, the more I can reach out, the better it is for me, obviously, and for people like me.”

“It is hard to argue with that and that is why politicians and others just won’t come and talk to me.”

“We are arguing for something that these people, the politicians just don’t want to face.”

“That’s why we can’t get anywhere with them.”

“But we have to find a way. We have to do it.”

“I am going to keep going.”

“I am not giving up, no, I don’t give up easily.”

“With this issue, I will never give up.”

Yours Sincerely

Loredana Alessio-Mulhall

## Conclusion

Loredana would like nothing more than to be given the opportunity to speak to members of your committee. You have all her contact details on this submission and could I suggest that you arrange a time to speak to Loredana in person rather than on the phone. She is a wonderful person who needs to be heard.

(Shayne Higson)