

Not allowed to die but allowed to suffer

My name is Loredana Alessio-Mulhall and I have advanced, progressive multiple sclerosis. I am totally disabled and can't move anything except my head and my mouth. I have had a catheter for 10 years and a colostomy for 15 years and for me there is no turning back. It is too late for me. Although I can't move, I feel everything and have pain every day and nerve pain is the worst.

I live at home in my unit and I have carers for a total of eight hours per day. This is the maximum number of hours allowed and as my condition continues to deteriorate this makes my life very difficult.

I am a very positive person and I only started to think seriously about voluntary euthanasia in the last few years. People who oppose voluntary euthanasia just have no idea and they don't want to face the reality of my situation, which makes it so much worse for me. I am not allowed to die but I am allowed to suffer.

Whenever I am interviewed, I ask people to please come and speak to me – politicians, church leaders, anyone, just come and speak to me. But no-one ever does. They could call me, that would be easy, but they never do. So that proves to me that they just aren't interested, they just don't care.

Opponents can close their eyes and ears but they don't have my pain and they don't have my fear. All I want is for voluntary euthanasia to be legalised so that people like me have a choice when my suffering becomes unbearable.

There are many people like me but not everyone can speak up. Some are too sick, some too shy or too scared, or some 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 role of doctors as healers, I think, what a quantum leap that is. Doctors should help alleviate suffering when they can't heal. Nurses understand and that is why so many of them support voluntary euthanasia law reform. Doctors don't always see the suffering.

I support palliative care but it doesn't work for everybody and it can't ever work for me. I have been to hospital before but nobody can look after me properly in there. It is always so traumatic because I can't take my carers and the nurses don't know what to do with me. Nurses are just not trained to look after someone like me and there is no time to train them. Life is hard enough for me at home but at least it is not traumatic. Home is the best place for me. It is the only place for me.

“ I can't even suicide because
I can't use my hands ”

With MS everything goes, all the muscles go and, after 40 years, it is now affecting my voice. What terrifies me the most is what will happen to me when I am unable to communicate with my carers. Nobody is going to say what will happen to me... they don't want to. Even now my voice is going and sometimes it is very difficult to communicate. It depends how stressed I am. Stress is my enemy. I have already reached 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. When my

voice goes and I can no longer tell my carers where my pain is, what will I do?

The big problem for me is that I can't even suicide because I can't use my hands. I can't get anyone to help me because it is illegal. So I am left feeling very frightened, very fearful and under a great deal of stress because I wonder what is going to happen to me.

I have already lost so much independence but I don't want to be a vegetable, or treated like a vegetable when I still have a brain. That is what frightens me...not dying. What really frightens me is the pain and the agony of seeing what has become of me.

That is why I need voluntary euthanasia to be legalised so that I take something and just go peacefully, when I am ready, without any concern. Wouldn't that be beautiful? To be with my family and just go to sleep.

It is hard to argue with that and that is why politicians and others just won't come and talk to me. We are fighting 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.

With this issue, I will never give up.

As told to Shayne Higson