

The Age: Life or death decision inspired by faith in God

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Despite suffering motor neurone disease, I won't take my own life as Beverley Broadbent did.



Illustration: John Spooner.

I read with great interest, and I hope empathy, the story about Beverley Broadbent ending her life. I think I can appreciate her choice to end her life while still able to enjoy living. But it is not a choice that I intend to make.

It is, nevertheless, a choice that confronts me. I was diagnosed almost two years ago with motor neurone disease, admittedly with a rare variant of the disease that typically progresses more slowly than the more common forms.

Already my legs are virtually useless and I spend about 14 hours a day in an electric wheelchair. I need help to get into and out of bed and to get to the toilet. More recently I have noticed the beginning of weakness in my right arm - a sign of things to come, as all of my voluntary muscles begin to shut down.

At present my determination is to live as fully as possible within these already significant limitations. I am acting dean of the united faculty of theology within the MCD University of Divinity. I am teaching one course within that faculty. As a Catholic priest I celebrate Mass several mornings a week in the church at Richmond where I live, and on Sundays at Werribee. I go to the MCG when Collingwood is playing. I go to concerts in the city, and to exhibitions at the NGV. I frequent cafes that serve good coffee. I do most of the food shopping for my small community.

For some of this I need to use a maxi taxi. But more commonly I travel simply by wheelchair or by train, courtesy of a free myki pass and the help of train drivers who put out a ramp for me. When my arms and upper body become weaker, all this will be more difficult, ultimately impossible, but I have managed thus far to adapt in ways that would a few years ago have seemed improbable to me, and I hope such adaptation can continue.

Why, however, do I choose to press on into the more horrendous parts of this motor neurone journey, rather than seeking to take Beverley Broadbent's path? Ultimately for me this is not a matter of reason, but a matter of faith. I believe in a creator (and creative) God and I believe in the paradoxical power of the cross.

For me, life is a gift from God. So far it has been an extraordinarily generous gift. I have been able to do things, and to experience things, and to go to places (places of the heart as well as geographical places) that I would never have conceived of when I was, say, 20. I have had a wonderful life, and for this I am immensely grateful. I have now entered into much darker places, but even here I find new life: there is a sense of adventure, for example, in finding how to do even simple things from the constraints of an electric wheelchair.

I know that I shall never again go for 40-kilometre walks along Washington's C&O Canal, nor wander around the Parthenon on a misty morning, nor drink a dark lager in Munich's Augustiner Bierhalle, nor go to an outdoor concert at night in the Roman Forum, nor even catch a ferry on Sydney Harbour. There is deep regret in all of that, but it is far outweighed by a sense of gratitude that I

have been able to do these things in the first place.

And then there is the cross. I do not believe that suffering is meaningless, but that, like Christ's suffering, it can be redemptive. Of course, we should do all we reasonably can to prevent suffering, but we will still be confronted with it.

This awful disease puts me in solidarity with others suffering around the world. It has enabled me to enter into the world of the disabled, such as the other wheelchair passengers I meet on the train. With them I see the world with new eyes. And in small ways I have become an advocate for the disabled and for disability access. I have been inspired by the peacefulness of other motor neurone sufferers, some of them much more disabled than I am.

I have also discovered how much people love me. Prayers, good wishes, and material help have come from places expected and quite unexpected. Through my blog (geoffreysj.com), I have met new friends and reconnected with old ones. Having motor neurone disease, then, has enabled me to live life in new ways. I actually see it as a gift, a very challenging and mysterious gift, from a life-giving God.

None of this is to pretend that motor neurone is not an absolutely awful disease, that the later stages in particular are about as nasty as it gets. As a friend remarked, getting motor neurone disease is drawing the shortest of short straws. I just hope that I can maintain my positive attitude as things get a lot tougher. Nor do I want my life to be artificially prolonged, by being kept going on a ventilator, for instance, as my breathing muscles fail. At that point I want to be allowed to die, but for me that is very different from taking positive steps to end my life.

None of this is meant as a direct comment on the politics of euthanasia, nor is it an attempt to rebut the views of Beverley Broadbent. My attitude is based on my Christian faith. I do not want to impose my views on those who do not share that faith. But it is the statement of someone who wants to live life to the full, who has found some of that fullness in the unlikeliest of places, and who trusts the amazing grace that has brought me safe thus far to lead me on.

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