

# RASAIID



## THE RIGHT OF CHOICE

It is with much regret that I read that Hazel Hawke has been placed in a high care facility because her care needs are now beyond the capacity of her family to provide. I wish to pay tribute to and applaud the years of devotion and care given by her family, particularly her lovely daughter, Sue Pieters-Hawke. I understand the dilemma and the anguish the family must have suffered in reaching their decision.

It must be acknowledged that they and all other Australian families in their circumstances are fortunate in that the facilities that they require at this time in their lives are in place and accessible. We are lucky to live in a rich society that has made provision for the ageing and ailing in our midst. Not only does Australia now have over two hundred thousand aged care beds but it has a system of benchmarking in place so that as the population ages, the number of beds increases proportionally. I am never sure if this good provision is a result of the fact that we all have parents or that we will all one day be old. Regardless of the reason, we have in place a system that permits the Hawke family and others like it the freedom of choice to care and to cease to care when it sees fit.

Compare this now to the system that surrounds the provision of services to people with a disability that is not age related. There is only one bed for every ten and in some areas every twenty people requiring one. I am never sure if the totally inadequate provision in this sector is because comparatively few of us ever has a disabled child and the rest of us refuses to believe it could ever happen to them or theirs. Regardless of the reason, we have in place a system that allows carers of the disabled, usually their parents, no choice at all in when to cease to care. Because no place exists in our rich society for these people, the parents care for as long as they are able, often unto death.

I have a son with a severe intellectual disability. After thirty-two years of caring on a daily basis, I can claim to have cared for many times longer than Sue Pieters-Hawke. I am also quite a lot older than she is. But there all comparison ends, because unlike her I cannot say that my son's care needs are beyond my capacity to deliver. The only way I can access supported accommodation for my son is to relinquish him to a government department that has no place for him. How can I do this to the person to whom I have devoted the greater part of my life? This is how the disability system works in our country: it is dependent on the fact that parents like me love our sons and daughters too much to abandon them. We are locked into a caring role with no choice but to continue, no hope of retirement (even though many of us are way past retirement age) and no peace of mind around our adult children's future after we are gone.

And we are legion. There are tens of thousands of us, so many in fact that we are growing our own jargon. We are starting to be called "ageing carers", our demand for services that do not exist is becoming known as "unmet need". Only last week our minister released funds for research into "ageing carer networks" - isn't that just what we need! Despite our numbers we have no voice, no union, no peak body

and no representation. Without a concerted stance, we have no power and no political clout. When we say this to our elected representatives we are told that we have Carers Australia.

Carers Australia seems to have difficulty distinguishing between the two different groups of carers that it represents. On the one hand, we have carers like Sue Pieters-Hawke. She has done a marvellous job, but has cared for what looks to us like a relatively short time. She has chosen to cease to care and will resume her "normal" life. She will almost certainly outlive her mother, in the normal course of events, and will be able to close the door on that chapter in her life knowing that she has done all that could have been expected of her.

Carers like myself have also done a marvellous job, often for three, four or five decades. Our sons and daughters will, in the normal course of events, outlive us. We will never be able to close the door on them, because we are all desperate about their future care when we cannot provide it. We wish to see them settled in appropriate supported accommodation and we wish to assist with their transition. We have long since forgotten what a "normal" life is, so we will never return to it. After such a long time as carers, we deserve to have a little time to put our feet up and we deserve the peace of mind of knowing our family member is safe and secure in a new environment.

Carers Australia is presiding over the greatest travesty of justice, the greatest denial of human rights and the greatest social inequity in our society, but are they saying so? Make no mistake about it, it is our sons and daughters, the people of this country who have a severe and dependent disability, who are our most vulnerable and under-resourced. I acknowledge that the indigenous people and the refugees have issues, but at least their issues get an airing and some debate. Our needs are under the radar, not even on the agenda, and needless to say nothing, but nothing, is being done to even start to provide the services we so desperately must have.

So next time I listen to Joan Hughes on the radio, I will expect to hear her give voice to our issues. I do not want to hear about how carers need acknowledgement, money or respite. My very large group of carers is way past all that. We need to be carers no longer. We must have places for our beloved sons and daughters and we must have them urgently. We must see them settled like our fellow carers in other developed countries are permitted to do. We must be allowed the freedom of choice that Sue Pieters-Hawke has exercised - the freedom to decide to care no longer.

Are you, the organization funded to prop us up and keep us caring, the right people to be saying this on our behalf? I hope so, because we have no other.

I will expect a reply from you.

Yours Sincerely,

**Estelle Shields**