

RASAIID



VALOUR

Valour is extraordinary courage and bravery, especially on the battlefield. It comes from the Latin meaning *strong*. Parents who have raised a disabled child know about battlefields, particularly in a country in which suitable support services are not in place. There is much battlefield imagery in the discourse of caring. Carers have called themselves the *Hidden Army* while our politicians tell us we are *Unsung Heroes*. Speak to any carer and you will hear about the *fight* to obtain services. A fine article to be published on Saturday next speaks of carers who *solider on* and carers as *the last line of defence* before governments become overwhelmed with demand to find places to meet unmet need. Of course, no soldier except a carer would be asked to serve on the frontline for thirty years and no soldier would retire from a lifelong career without recognition, accolades and rewards. While there is a point at which comparisons are no longer valid, the valour remains the same regardless of the nature of the battle.

Unlike military personnel, the carer has no way of honourably retiring except by death or illness. There is no way to effect a discharge of duties while there is capacity to carry on. Without any place available for the disabled family member to go, carers keep on keeping on, their sense of duty and their parental love driving them to endure. Those few who succumb and relinquish their person to the care of the government department are regarded with the same disdain as the soldier who has gone AWOL. Sometimes the league of carers can be the best support a parent can have, but other times we can be our own worst enemies. When fellow-parents relinquish their disabled adult child after decades of caring, or even discuss the possibility of doing so, within the peer group there will be a chorus of *I could never do.....* or *I don't understand how they could ever.....* It is time to examine some of the myths around caring which have engendered such a mindset and brought about these responses.

Myth No 1: **I had him so he's my responsibility.**

This is the subtext in most government documents, as the families are portrayed as the majority player in the caring stakes and the department as a benevolent and supportive assistant, there to prop up the family in its hour of need. It is the subtext in many of the academic papers around family resilience: to endure equals success, to cease to endure means failure. It is implied by Carers Australia when they announce:

It is not uncommon for older families of people with severe disabilities to have expectations that the state will provide ongoing care for their relative when they are no longer able to do so. (p4, Submission to the Inquiry into Special Disability Trusts, June 2008)

This says that not only is it wrong for families to have such an expectation, but it is old-fashioned, as well. Strong families look after their own, provide what is needed and don't complain. After all, it is their responsibility to do so.

We need to ask why the responsibility must fall on the family and for how long this should be so? Earlier generations received supported accommodation for their disabled family members when governments

assumed responsibility for their disabled citizens. Other carers in our country, those caring for someone at the end of life and for a much shorter period, have only to put their hand up to gain admission for their family member to nursing home facilities. Most developed countries boast services that allow their disabled members the right to live out of the parental home with high degrees of independence and autonomy. If other societies can accept collective responsibility for their disabled fellows, why not ours? Most families agree that the primary caring role should be theirs for the first two decades of their son or daughter's life. After this, we enter a grey area where responsibility is unclear. Families must not assume that because no services exist, the responsibility must therefore be their own. They must demand services and if these are not forthcoming, then they must do whatever is necessary to force the government's hand.

Myth No 2: I care best.

It is easy for families to delude themselves with this thought. Of course, they love their disabled family member more than anyone else can do and have cared for decades, so they have more experience than anyone else. But parent carers in their sixties, seventies and even eighties have spent the greater part of their lives doing the hardest job in the world: raising a disabled child to adulthood. They will have done so largely unsupported and they will be exhausted, stressed and depressed with no end in sight to their caring role. They will be anxious about the future of their disabled adult child and probably have health issues themselves. Why do they think that no-one can care as they do? How does an ageing parent compare with a young, fit, enthusiastic care-worker who comes in fresh for an eight-hour shift? Parents can still have significant input and close relationships with their family member in an out-of-home situation. They can monitor new residential settings and help to train workers in the special needs of their person, but they do not need to do everything themselves for the rest of their lives.

Myth No 3: He prefers to be with me.

Change is difficult for us all. We know what we like and we like what we know. Often the disabled family member has passed the optimum age for moving out of home and has become set in his ways. Sometimes he has little experience of an alternative to the family home and the parents have difficulty picturing him in another setting. Often without the cognitive capacity to imagine other residential arrangements, the disabled person must physically be there and experience the life before deciding if it is right for him. Anecdotal evidence says that in many instances, the person enjoys the company of his peers, who are people with a disability similar to his own, and is far happier with the new setting than he was in the parental home. Many of us know how lonely and isolated our person is living with boring, ageing parents. We also know how much our person delights in the company of his peers and how these relationships engender a sense of identity and belonging. We believe that philosophies that place integration with the non-disabled community at a higher value than integration with people with a similar disability to be misguided and incorrect. This belief is born of decades of observation and is widely shared by parents, who have no collective voice and no representative to speak on their behalf.

Those parents who say that their disabled person prefers to be with them may be afraid to let go because their own identity has become so closely tied to caring. They may be concerned for the adaptability of their son or daughter, for the quality of the future care and for the responsiveness of the service provision. They will be worried about their person being moved out of the local area and the compatibility of future housemates. However, one thing that they will all agree upon is that a transition from the family home is best made under their watchful eye, while they are there to ease the way and oversee the move.

Myth No 4: Relinquishing is weakness.

In a country in which no supported accommodation services are available, what does a parent do when he rejects the above myths, when he acknowledges that he is no longer responsible for a grown adult, that he no longer is the person who cares best and that his adult child does not prefer to be with him?

Does he hang on in there because he has been conditioned to think that abandoning his son or daughter to the vagaries of the government department is a sign of weakness, poor character, lack of love or worst of all, insufficient resilience? Does he look askance at his fellow carer who contemplates the unthinkable and say to himself: *I could never do such a thing*. Or does he muster all his courage, his valour, pack the bag and surrender his son or daughter to the door of the department?

I have recently been travelling with a family who has done just this and my eyes have been opened. These parents have made a bold and positive decision in the best interests of their family member. It has been immensely difficult and many tears have been shed, but this courageous couple have put aside the fears and doubts that beset us all and acted with quiet determination. There is not a word to describe what they have done. Words such as *relinquish*, *abandon* and *surrender* scream of negativity, but these parents have bitten the bullet (to use military analogies again) and done the only thing possible to secure a better future for their person. They have made a humane and emphatic decision. After three decades of caring, they could see that the needs of their family member were not being met and that the situation at home was deteriorating. With valour befitting the bravest soldier, they have intervened to arrest that decline and turn around their adult child's life. At the moment, they are in no-man's land, awaiting a transfer from the respite cottage to a permanent home.

The correct response from us, their peer group of fellow carers, is *Congratulations*. We need to acknowledge their three decades of selfless devotion to their disabled child, because no one else will do so. We need to support them in their difficult decision and reiterate that they have made the only decision they could. We must offer commiserations, because what they are suffering now is grief and loss similar to a death in the family. But most of all, we must offer heartfelt congratulations to them that they have been brave enough, not desperate enough, but brave enough to let their beloved child move on.

Myth No 5: Something must happen.

This is a phrase often spoken by caring families. It springs from an expectation that people in developed countries have of their governments. After all, we have children and there are schools for their education. We get sick and there are doctors and hospitals. In every area of our lives, services are available when needed. It is difficult to accept that in the area of disability, and in this sector only, services are totally lacking. Parents prefer to believe that if they wait long enough, something must happen. After all, we all know someone who has received an accommodation placement in the past few years so it must just be a matter of time before we get ours. There will be a case worker telling us that we are a very high priority and this will reinforce the delusion.

The reality is that there is one place for twenty needy people. Always there will be someone older and more desperate than you. There are no new places being created and there are no plans for new places. Our department can fudge the figures and make old appear as new. It can fool the general public but it cannot fool us because we have been around too long. It is unstated government policy that families will be supported to care until they can do so no longer and that siblings will be coerced into the caring role if at all possible. We are always waiting for the shift in policy that will make everything right. At the moment, it is the proposed Disability Insurance Scheme, which, if adopted, will transform the disability industry. However, if it gets up at all, it will be at least ten years away and it will struggle to cope with the enormous backlog of demand. Many of us will not have another ten years and even then, there will be no guarantees.

We have two choices. We can groom another of our children, if we have other children, or an extended family member, to continue in the caring role after our death. If this is not an acceptable option, we can take courage in hand and make the only decision possible. We must at all costs act to avoid that unimaginable catastrophe, wherein our beloved disabled person suffers, at the same moment in his life, the loss of his primary carer and the only home ever known. If we are brave enough, if we have the valour of the family mentioned earlier, we can avert this crisis and help to smooth the transition of our person into a new life. But we must put aside all the myths surrounding care giving. Caring for its disabled citizens is a nation's responsibility and this nation has betrayed and exploited its family carers. We are not acting in

our persons' best interests by keeping them at home indefinitely and it may well be that we are not the best people to care at this stage in our lives. It is possible that our people will be happier living out of home or may come to be happier over a period of time. The chance of our receiving a supported accommodation placement through "normal" channels is about the same as our chance of winning the lottery.

Who among us has the valour to take the next step? The battle has been fought for decades but can never be won except by taking this step. It is so scary that it is easier to look away and do nothing. It is easier to decide to think about it tomorrow. It is the cruellest decision and one that no civilized country should ask its citizens to make. But it is the only way we battle-weary parents have to make a future for our sons and daughters. If our government has decided it can provide for three percent of its disabled population, it is our duty to ensure that our person is included in that number. By forcing the hand that provides the funding, this percentage may necessarily increase. Perhaps we are responsible for the dearth of services because we have been too docile, too accepting of our lot, too afraid to demand what we need and too ready to believe the myths. We who are without representation, union membership or association are too easily taken advantage of. Yet we have power because we have ultimate control over how long we choose to care. We just have to have the courage to cross the line.

Estelle Shields

(This article is free from gender bias. For *he* please read *he/she*. For *him* please read *him/her*. For *his* please read *his/hers*.)