

## Chapter 5

### The Carer's Journey

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*Starting with memories of her own caring experience over 30 years ago, Elizabeth looks at the Australian Government's recent responses to the voices of carers and their organisations.*

#### 5.1 Elizabeth's voice, 1993<sup>12</sup>

Bill was my companion, colleague, lover and husband. For most of our life together, we lived and worked in Africa. Our son John-William, was born when we lived in Kinshasa, Democratic Republic of the Congo. The respect and trust we shared for each other, the fineness of Bill's character and his gregarious personality drew others into our company. Life was rich, challenging and rewarding.

Somewhere, sometime during our relationship, almost certainly time and time again in both South Africa and the United States, Bill was transfused with HIV-contaminated Factor VIII. Life continued, rich, challenging and rewarding, but we were living first with the fear that he might be infected, later with the knowledge. Then the dying began.

His was a terrible, anguishing, drawn-out dying. His body shrank to a brittle gauntness more harrowing than any offensive plea for famine aid. The ravishing of his mind meant that he became more and more silent, more and more withdrawn, and more unable to distinguish the threshold between his dream worlds and reality.

I wrote some weeks before he died:

'My heart breaks for him. I think after he dies, the nightmare of his dying will live on with me for a long, long time. Images of him while he was at home wanting to, trying to play Scrabble. Now his attempts to communicate, reduced to a few glances, a kiss, incomprehensible sentences. His vivid dream worlds in which he lives as he enjoyed living: dealing with people, smiling, moving about, the two of us together. Now the images are of medicine being forced down him, of him lying in his faeces, of growing gauntness, of infantile reflexes, of helplessness. A terrible encroachment on his dignity.'

Yet, somehow throughout this, he remained. The person, wasted and HIV-demented, such a harsh word, was Bill, seeking my hand to hold, turning his staring eyes to greet me as I entered his room. 'We are one,' he said in a period of lucidity, 'one body, one person. Whenever you leave the room, I cease to exist. I cannot think, go to the toilet, do anything because I am not there.'

The journey from knowing that Bill was infected to knowing how to live with that knowledge was one of the hardest that I or he ever made. The sadness and hopelessness was overwhelming. He refused to buy a new pair of shoes. Bill was infected and there was no way to do anything about it. We were left with a sense of deep bewilderment, of absolute powerlessness. We were fearful, a fear not so much of the death but of the dying.

### **5.1.1 How did we make that transition from diagnosis to living?**

Much of it had to do with the sort of person Bill was. Bill had a strong desire to continue living. He believed that life was worth living, that we had much more happiness to find and that we had worthwhile work to do. He realised that not taking his life into his own hands was leading to a death wish, a sense of hopelessness and helplessness.

The living that we found was simple enough: we did those things that we would have been doing anyway. We led full, happy lives. The reality of his infection had been acknowledged but placed in its proper perspective. And life continued. Pity had no place there. It is an emotion from outside looking in. We were involved, absorbed, challenged, laughing, learning, bickering – together.

But as a carer, I had failed my first task. Our journeys to living were journeys made alone, not together. I had not been able to help him through from diagnosis to living. Throughout the time I knew Bill, it was the only period that we shared so little, where we were so little together in spirit and intellect. However, we did reach the living together and then my role as carer changed back to that of lover, of Scrabble opponent, dinner companion and co-worker.

We had come back to living but our lives had essentially changed. I was never again to be without the knowledge that Bill was infected. It was not incapacitating, just constant. Just something heavy inside me as I went about living my daily life, a constant call for courage, a constant challenge to courage. This constant companion was further conjured up by the need to protect ourselves against the omnipresent nose and other bleeds and, later, incontinence.

Our love was strong, yet we had to struggle to be aware of the intangible, imperceptible things that threatened it. I was within the epidemic but he was of it. His perspective on time, on what was important, changed. His shadows were different from mine. His needs changed. We did not know his fatigue was HIV-related. Small frictions suddenly emerged seemingly from nowhere. Communication and solace became even more important.

Our period of living with the knowledge of HIV was short, just six months, before the dying began. But thank heavens we had made that transition to living, for we were to learn that the living could continue through the dying. We had learned the art of living whatever life was possible.

### **5.1.2 Living with dying was not always easy**

The dying of this disease can be so painfully slow. There were times of deep depression, for each of us. Fatalism and despair lurked in the shadows, at least for me, fed by uncertainties about prognosis and treatment. I faltered from time to time. But Bill's desire to live whatever life was possible was strong, his body was still young, unprepared to die.

There was no one, nothing, to help us. No one spoke of these things. The territory most uncharted was how the HIV-related dementia might affect his mind and his emotional states. As he began imperceptibly to withdraw, doubt quickly crept into the vacated space: does he no longer love me? Have I said something wrong? Is this a rebuff? Later, silent and withdrawn, as he lay looking at me, I was overwhelmed by fears. Is that a look of resentment for something done or not done, of dislike, of sadness that I cannot talk to him, as he might want me to, about his feelings, his dying? These fears bore down on me and had to be constantly held at bay.

### **5.1.3 During the dying, the role of the carer changes**

He or she not only remains a partner and loved one of the living, but must also become the midwife for the dying. This role is almost impossible to take on unless the carer also has learned to live with HIV. The carer becomes acutely aware that he or she is not the dying, but only the observer of the dying.

The carer therefore lives in two worlds: one of the dying, the other of the present and future living, the pain for the now and the pain for the future. The distress is immense but for most of the time cannot be expressed, since it gets in the way of the living.

Finally, Bill died. Immediately they double-bagged his warm infected body in thick yellow plastic and sealed it closed.

I do not know what grief is. The word makes me feel inadequate as I go about my life. It so fails to capture the complexity of what I have experienced.

What they say about grief bears little relation to what I experienced as I tried to establish a life without Bill, to help my children live without him, as I struggled, alone, as sole income earner, sole parent and sole putter-outer of the garbage bin. It bears little relation to what I still feel years later. What they say gets in the way of my understanding of how our lives can be lived, with and without him, with laughter and pain, fullness and emptiness.

Bill's grave was to be a haven, a place of remembering, of closeness. I cannot bear to go there. I cannot bear the thought that there will be no cycle of regeneration, that the matter of Bill's body, trapped in non-biodegradable plastic, will not become one with nature, metamorphosed, living on. The disease itself and its social stigma mark the survivors.

## 5.2 Elizabeth's voice, 2013

### 5.2.1 Lost livelihoods, lack of benefits

Bill died on the last day of winter 1986, giving us, our son and myself, the healing warmth of spring. There were few, if any, social support services available to us. When we came to Australia in 1986, HIV support organisations were just being established. The first care and support volunteers were being trained. We were isolated by the social reaction to the HIV epidemic and by the time demands of caring. There were no benefits for carers. Bill had been employed by the US government in Zaire and so, fortunately, we had some health insurance benefits. I had been self-employed and had had to resign from my contracts. We lost our livelihoods. We lived off our savings and the kindness and generosity of family, friends and strangers, throughout the dying and during its aftermath.

Our son had just turned four when Bill died. He too, even though so very young, had been a carer. His memories are of a gaunt, demented figure, incontinent of faeces, shuffling, unbalanced. He watched his father dying and held out his arms to help him. They journeyed together through the dying and Bill's death stripped him of a life companion and mentor. And care giver for him.

### 5.2.2 Carer's voices begin to be heard

In the years between Bill's death and now, the story-telling voices of the carers of people living with HIV, and of all carers, and their organisations, have begun to be heard. In 2008–2009, the Australian Parliament held an enquiry into the experience of carers, into how their contributions could be better recognised by the community, and into how the government could better respond to their needs.

The first principle of the resulting Carer Recognition Act 2010 is that all carers should have the same rights, choices and opportunities as other Australians. This is in line with the UDHR, which recognises the universal right to social security. The 10 core principles enumerated in the Act recognise that whether carers can achieve these rights, choices and opportunities is dependent on their neighbours, friends and communities, on the way others treat them and respond to them, as well as on their employers and governments. Their need for dignity, acceptance and respect is as critical as their own need to be supported and cared for.

In June 2012, Australia adopted its first National Carer Strategy, which envisions carers as valued and respected by society and with rights, choices, opportunities and capabilities to participate in economic, social and community life.

The Strategy recognises that care relationships vary according to the needs of the person(s) being cared for, the carer's own individual needs, and changing life circumstances:

Caring is done by individuals who bring their life experiences, values, beliefs, attitudes, expectations, coping mechanisms, economic resources, culture and gender to caring. Caring is therefore shaped by the environment in which it occurs and by an individual's history. As a result, every caring situation will be unique and every carer will care differently (Submission 121 from nationwide consultations on developing the National Carer Strategy, 2010).

The Strategy recognises the need to support and sustain these care relationships and the health and well-being of each person involved in them. Its six priority areas are: i) recognition and respect; ii) information and access; iii) economic security; iv) services for carers; v) education and training; and vi) health and well-being (Australian Government 2012).

### **5.2.3 Assessing economic value**

The economic value of the work that carers in Australia do has now been documented. The astonishing extent of unpaid care work was calculated at 21.4 billion hours in the financial year 2009–2010 (when the total population of Australia was around 22.3 million). The 11.1 million full time equivalent workers in the unpaid care economy were 1.2 times the total Australian full-time employed work force (Hoenig and Page 2012).

In the financial year 2009/2010, the combined paid and unpaid work done in the care economy was estimated to be worth a total of AU\$762.5 billion. Of that amount, paid care was worth AU\$112.4 billion, 8.8 per cent of GDP and nearly 20 per cent of all paid employment. Unpaid care, the care I provided to Bill, was estimated to be worth AU\$650.1 billion, equivalent to 50.6 per cent of GDP. Women contributed 77 per cent of paid care work and 66 per cent of unpaid care work (Hoenig and Page 2012).

Carers not only provide direct care but they also do what has been called 'quilting work' (Balbo 1992), that is matching the needs of those they care for with the resources available. The resources available to carers include: kinship networks; community resources; local, state and national government provided resources; resources provided by firms and foundations; and goods and services provided in the market. There is rarely an easy fit between what is needed and what is available. As Balbo says, this 'quilting work' involves 'the endless sorting and putting together of available resources, the minute coping strategies, the overall aim of survival, and the imagination, ingenuity and amount of work that [it] requires' (1992: 45).

### **5.2.4 Psychological, emotional, social costs**

As well as determining the economic value of the work that carers in Australia do, there is a need to understand and address the personal impact of caring work. Our

son and I are still scarred by the psychological, emotional and social impact of our caring. Our son has a recurring nightmare, continuing into adult life, of people he cares about dying without his being able to do anything about it. The social isolation of carers, the disruptions and physical demands of caring, the lost opportunities for work and social relationships and, in our case, the stigma of HIV and the nature of the HIV dying, leave their marks on the carer. Our son was unable to talk to other children at school about his father's dying. He was socially silenced. I am still reluctant to visit the plastic bags in Bill's grave. I dream of taking him out of the earth, cremating him and scattering his ashes where we were happy. Caring has psychological, emotional and social costs to the carer as well as a social and economic value to society.

Caring also has economic costs as well as economic worth. It is women who overwhelmingly take on unpaid care work and this has a significant detrimental effect on their economic well-being, particularly on their workforce participation, their savings and on their retirement income (Australian Human Rights Commission 2013).

The Australian Government has a system of payments to carers but the provision of care has an impact on the carer's labour force participation. In the Australian context, women are more likely to manage their caring responsibilities by working part-time, taking casual work, freelancing, becoming self-employed or leaving the workforce. Men in paid employment with caring responsibilities are more likely to remain in paid employment and take advantage of workplace flexibilities in a way that many women do not. They are more likely to use mechanisms such as paid leave, a roster of days off and flexi-time. Data from 2001 show that in one state in Australia an estimated 15 per cent of carers were self-employed. Of these 16 per cent had started their own business or become a contractor, which made it easier for them to do their care work. This was higher for self-employed women (29%) than men (9%).

The data show that many of the mechanisms introduced to provide social protection to carers and to recognise and value unpaid care work, such as leave arrangements, flexible work hours and other workplace initiatives, largely benefit carers who work in or remain in the formal workforce. Measures are required to help carers who are not in or who did not remain in the formal workplace, including re-entry and retraining schemes, workplace flexibility and assistance to re-enter social spaces.

### 5.2.5 Gender income gaps

The 2009 study of the Australian Human Rights Commission, *Accumulating Poverty: Women's experiences of inequality over the life cycle*, found a significant gender gap in retirement incomes. This is primarily the result of three factors:

- i. women moving in and out of the paid workforce because of their caring responsibilities;

- ii. women's lack of understanding of superannuation, especially those who are freelancing or self-employed; and
- iii. gendered inequities in pay and conditions.

Estimates from financial year 2009/10 suggest that the average (mean) superannuation payouts for women are just over half (57%) of those of men; a significant proportion of women have little or no superannuation (Australian Human Rights Commission 2013).

### **5.2.6 Social and economic justice for carers**

This raises the question of how a social protection framework can provide increased social and economic justice for carers. This is complicated by the fact that, as quoted above, 'every caring situation will be unique and every carer will care differently'. However, there are some principles. Most carers are women, both in the paid workforce, where wages are low, and in the unpaid workforce. Predominantly women work as unpaid carers for children and the elderly, and both women and men care for spouses and partners (Australian Human Rights Commission 2013). Most women provide care at some stage in their life cycles, hence caring requires a social protection framework that is women-centred and anticipatory. Such a framework would recognise and enhance women as citizens and enable women to live the lives they choose and fulfil the obligations that they value (Sholkamy 2011).

Relatively little work has been done on the types of employment conditions that can best support caregivers to combine caring with paid employment. Many women in caring work are not in full-time work. Forty-two per cent of women not in the labour force cite family reasons (Hoenig and Page 2012). Many women in caring work engage in informal, occasional or insecure work. Hence a women-centred and anticipatory social protection framework cannot rely just on labour market mechanisms and carer payments to provide social and economic justice for carers.

So the situation of carers, and those they care for – children, the ill, the dying, the disabled, the frail elderly and communities – poses the question of scope of social protection programmes. Are social protection frameworks meant to address the underlying social and economic structures that are at the root of insecurity and inequity for carers, and therefore in that sense, are they meant to be transformational?

### **5.2.7 Feminisation of care, masculinisation of labour**

Two root causes stand out: the feminisation of the care economy and the masculinisation of labour markets.

For as long as men fail to take their rightful place in the care economy, the burden, as well as the joys, of caring will fall mainly on women. The continuing disproportionate

absence of men from unpaid and paid caring work will remain a cause of social inequity and caring work will remain the site of gendered discrimination and deprivation.

But a transformative approach to social protection will require more than men's presence, more than equal participation, in the care economy. If the architecture of labour markets, that is, their structuring values and regulatory principles and practices, remains as it is, men who take on the care of others will also be disadvantaged – in their careers, their earnings and their retirement incomes. The vulnerability of carers to such inequity is a structural problem created by a workforce that reflects and is structured by the way men have lived their lives; by their narratives, their values and their categories (Reid 1995).

Underlying both the feminisation of the care economy and the masculinisation of labour markets is the deeply socially embedded doctrine of the headship of men and its corollary doctrine that a woman's place is in the home. This doctrine gives rise to the concepts of the 'male breadwinner' and the 'male head of the household', to images of women as home-makers, and to gendered differences and inequities in wages and conditions of employment. A women-centred, anticipatory and transformative approach to social protection needs to challenge this doctrine if social protection is to be more than palliative care for carers.