

## A Matter of Life and Death

*Kathy Rees works for change from a range of roles: parent, educator and organisational change consultant. The imperative for change can come from many sources such as a passion for social justice or a vision of a better life. In the Buckler family, there was an even more compelling reason.*

When my daughter, Belinda, was nineteen she had a chance meeting with a friend from primary school. That meeting triggered some lifelong changes for Belinda. Hearing from the friend about boyfriends, TAFE classes, nightclubs, and other social activities ultimately led to a hunger strike by Belinda, which lasted for six weeks. The hunger strike was a desperate but clear expression of Belinda's dissatisfaction with her own life. Not eating was the only mechanism that she had for making known her deep dissatisfaction, and it took only two days for me to really start looking at what her message was.

Prior to her hunger strike, Belinda's day ran to a tight schedule, mainly due to my work and the other needs in our family. For example, it was always clear to me that Belinda did not appreciate the need for her to be out of bed early each morning. This was always hard for a person who doesn't *do* mornings. During the early stages of the hunger strike, medical specialists were extremely dubious about my assertions that Belinda was actually controlling her food intake in a purposeful way. I heard them express opinions about people with significant intellectual impairments being unable to make high-level decisions, or of even having the ability to understand the consequences of decisions. However, after a month, these opinions changed to ones where Belinda's intelligence was no longer the issue, and the focus became one of finding solutions that would stop the hunger strike being the sole focus of every day.

The hunger strike ultimately ended when I said to Belinda that I would have to 'let her go': whether to death, through her self-imposed starvation; or by doing everything I could to fast-track arrangements for her to move into a home of her own, where she could begin to develop her own lifestyle. I was in great pain and distress when I said this to her. Nothing prepared me for the shock of later hearing that she had eaten lunch after I left the house. This event, and the six weeks prior to it, reinforced my awe of my daughter's will, and her strong drive to determine her own life. She had even been prepared to die for it.

Within one year, and in time for her twenty-first birthday, Belinda was living in her own home. On her first day there, the full impact of her move didn't seem to register until her father and I said we were leaving to go back home. Apparently, her squeals of happiness lasted for three hours. She appeared to quickly settle into having a team of three people supporting her each day, and this kind of support has continued. Belinda has been supported by people whose ages range from late-teens to fifty-plus, and has been supported by young men as well as young women. She has also been involved in the extended families of some of her supporters and friends, many of whom I do not know.

Belinda has now been in her own home for nine years. She has changed and matured during that time. As Belinda's thirtieth birthday approaches, I know that there have been trials as well as good times in those years, yet Belinda now expresses a serenity and peace that I could never have imagined. This does not mean that I am complacent – far from it. I have learned along the way that whenever things seem to have settled down, an event will occur that will propel all of us to another level of change where we will need to make further improvements in Belinda's life.

Throughout the past nine years, my role and that of Belinda's father has been to strongly support her staff, and to commit to implementing a self-managed team, which includes Belinda in all decision making.

This team has become one that is also self-determining in many ways, with staff members making day-to-day decisions, as well as assisting Belinda with her longer-term goals. They manage Belinda's household

finances, and interact with personnel at Public Trust, who have responsibility for Belinda's funds. During the past year, Belinda and her staff have recruited new support workers and conducted the orientation process without the direct involvement of her father, a Human Resource Consultant, or myself. The staff have been scrupulous about who they want to see supporting Belinda. Belinda's father and I are now seeing our roles, as well as that of the Human Resource Consultant (who is employed for ten hours per month to oversee support staff and rosters), diminishing as time goes on.

All these changes in Belinda's life have also been life altering for me. I know in my heart that Belinda has been, and will no doubt continue to be, a major catalyst in my life. I also know that Belinda has needed my energy, belief, passion and commitment to make the necessary changes. I think it is true that the most important changes that occur in people's lives are the ones that are the hardest won – and that is certainly the case for Belinda. As the anthropologist, Margaret Mead, might have said on Belinda's behalf: *Never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it is the only thing that ever has.* I hope that this will continue to be the case for Belinda and for those people who are at present in Belinda's life, and for those who will continually come into her life in the future.