I have found this book very difficult to read, because it is so well written. It is the subject of the book that has gripped me by the throat and made breathing difficult. Eve Hillary is a masterful storyteller and this book is a fine tribute to a courageous girl and her family and a powerful condemnation of professional incompetence and negligence, unethical behaviour and bureaucratic excesses.

Sarah died, aged thirteen, on 25 October 2004, the victim of a system which was originally set up to support children like her. It is arguable that the system hastened her death. It is not arguable that the system utterly failed her and her family. Sarah developed an extremely rare and aggressive cancer that is believed to be incurable, yet she was forced by the Department of Community Services (DoCS) in NSW to undergo chemotherapy, against her expressed wishes and those of her family. Eve Hillary, knew Sarah and her family and writes the account of the litany of lies, misrepresentation, incompetence, callousness, self-interest and bloody-mindedness with restrained passion and unrestrained compassion. The book documents a system gone wrong and the fight put up by Sarah and her family to resist its power.

One could expect a government department which has been set up to protect children from harm to fulfil this function where a child truly is at risk of harm, including possibly removing the child from her parents’ control if necessary to prevent further harm. But to force a girl who has a recurring ‘incurable’ cancer to undergo useless (often fatal) chemotherapy is beyond the pale. The DoCS behaviour and actions and the draconian Supreme Court orders they were able to secure, were made possible by misrepresentations and a raft of deliberate lies told by oncologists and other doctors, and these doctors’ refusal to give Sarah’s family any meaningful medical reports, which would have allowed the family to attempt to secure a different outcome.

When a government department is given almost unfettered powers, there needs to be a system in place to ensure that those powers are not used unnecessarily or arbitrarily. There is no imaginable reason in the case of Sarah that DoCS would need to tap phones, break into private houses, steal letters and personal documents and subject the entire family to overt and covert surveillance. That these things happened is an indication of a government department gone feral.

Case workers in DoCS even used the threat of removing Sarah’s five siblings to get the parents to obey their orders; orders which, through decisions in the NSW Supreme Court, had the force of law. This overbearing approach was also adopted by most of the doctors and nurses ‘looking after’ Sarah and by supposedly independent social workers and lawyers.

The family was also badly served by their own barrister, who refused to speak up on father Mark’s requests to put matters to the Supreme Court judge, including the fact that the oncologists had consistently failed to give Sarah’s parents the medical files the Court had ordered them to hand over. In relation to this last failure, the barrister said to Mark that she would not pursue the issue “against such respectable parties”. In later Court hearings, Mark felt compelled to represent Sarah’s interests himself, apart from the fact that this useless barrister was costing him an unaffordable $5000 per day.

In 2003 it was Eve Hillary’s decision to write a journalistic article about what had been going on – especially in relation to the forced chemotherapy, bogus emergency splenectomy and refusal of the
hospital to feed Sarah an adequate diet – that started changing things for Sarah and the family, but only marginally and too late to give Sarah the opportunity to pursue a course of treatment (of her choice) which may have afforded her a longer life. Eve’s decision to make these events public cost her the medical clinic she had set up, where Sarah received the only decent medical attention she had during her illness. The clinic was forced to close through actions of the NSW authorities, because of Eve’s temerity in helping Sarah and her family stand up to DoCS.

If the Australian place names (and people’s names) had been left blank, most readers of this book would assume that this terrible, bleak story, if actually true, had taken place in some foreign country which was under the yoke of a tin-pot dictator. The story is true and took place, recently, in Australia, which we would like to think is a free society that honours and protects individual rights and freedoms and where forcing unwanted medication on an intelligent and lucid girl would be impossible. We would also be horrified to think that medical and other professionals would deliberately lie with apparently no regard for the effects these lies would have on the health of an individual.

There is a sense by the end of the book that Sarah may not have died in vain, as she had a wonderful effect on many people she interacted with and there is some positive change in the attitude of DoCS and it is less likely that another child in NSW will be forced to go through the horrors that Sarah and her family experienced. But the suffering forced on Sarah is inexcusable and cannot be ameliorated in hindsight just because its exposure may bring changes. It should never have happened.

The DoCS bloody-minded pursuit of Sarah amounted to cruel and inhumane treatment, if not actually torture. This is also true of the hospitals’ consistent refusal of adequate pain relief, their failure to discuss palliative care, their refusal of an adequate diet, their psychological and emotional tormenting and their deliberate lying and hiding of facts.

This remarkable account is also about: the love and internal strength of a family subjected to the worst excesses of a State bureaucracy; the tenacity of a father in doing everything he can to try and protect his daughter; a small number of health professionals and others who stuck out their necks at the risk of their own freedom and livelihoods; the relative safety, efficacy and benefits of injectable nutrient therapies, including high-dose intravenous vitamin C, as an adjunct to other common therapies and in palliative care; and the amazing maturity and clarity of a pre-teen girl dealing with a life-threatening illness and at the same time faced with a hostile world she could not understand.

The lunacy of the DoCS attitudes and actions is illustrated by the cost to the taxpayer of pursuing forced medical treatment for one girl. Eve Hillary says in the book:

“In the past 18 months the child protection department had spent over a million dollars and diverted an army of case-workers just to prevent one 11-year-old child from having a cancer treatment personalised to her needs, while over 80 children in NSW, who had been reported to DoCS, had died of genuine abuse and neglect.”

Although reading this book can easily be an ordeal, I suggest everyone should make the effort. It is not just a difficult-to-take account of injustice and heartache – it is a wake-up call to all of us that governments and government departments can easily take away everything we treasure and hold sacred, including our privacy, our freedoms and our rights. Their doing so and their reasons for it must always be questioned and challenged.

I also recommend you read Ken Crispin’s recent book, *The Quest for Justice* (Scribe, 2010), especially his last chapter. When you’ve read *Sarah’s Last Wish*, I recommend you stay informed about the issues raised, by subscribing to up-to-date information through www.sarahs-last-wish.com.