

Book Review

The Ben Book

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Dr Michael Galvin in his introduction was blunt and open with the path that his life had taken in caring for his beloved son Benjamin Bede Galvin. Born with Duchenne Muscular Dystrophy, Ben needed intensive support and care throughout his short but amazing life. He writes:

‘As his father, I coped (or did not cope) as best I could with being his father, and my story is also an idiosyncratic one. Yet on another level, we are both representative of concentration points of our times. Benjamin was a textbook case of a boy, and then a young man, with Duchenne Muscular Dystrophy, and what it means to live and die from this disease, in Australia, in suburban Adelaide, at the end of the 20th century and the beginning of this one’.

This introduction then becomes a page turner for those who do not know or understand significant family hardship and the burdens of caring for a beloved child who you know has a limited lifespan. In this amazing book, descriptions of journeys seem to be an ongoing topic – highways, vans, trips, trucks and running keeps the reader breathlessly waiting to see what appears next in this book. Some journeys over long distances would put Ben into a stressful situation as highways and travel in Australia demands coping with the tyranny of distance. Despite heat or cold or other pressures, Ben would respond by saying he would ‘deal with it’. And deal with it he did!

In his early years, Benjamin appeared to be doing okay, despite occasions when he would try to run but then knock himself out. This often required his Dad to run to a neighbour for help or run into a hospital when things became dire and the moments of crisis appeared suddenly and expectedly.

Throughout his short life, Benjamin was cared for and cared about and this placed a burden on a family split by divorce and the distress that this inevitably causes. During this period, both Michael and his family members did everything they could to make his life a journey worth taking.

According to his father Michael, Benjamin was a determined and inquisitive child and later as he neared adulthood was keen to see and do as much as he could. For example, he asked to be taken to a military history conference shortly before his death. These conferences were held at the University where his dad was a Deputy Head of School. These conferences went for

2 days and papers were delivered on a variety of topics from gravestone histories to the language of war. He attended shortly before he died and seemed to enjoy the engagement and knowledge presented there. For him, it was part of being like everyone else . . . just as he went out for pizza or chips from time to time and allowed some people to interact and feed him to his delight.

There are lessons on every page in this book. Resilience training on the run is particularly apt. For example, resilience was called upon in an early visit to a paediatrician who diagnosed his condition, following an alert from the community health nurse’s advice that Benjamin was a bit ‘slower’ in his milestones. From here, came shock as a ‘whole series of medical wheels had been set in motion’ and an understanding that life would be different from now on. Throughout this book, movement and activity surrounding Ben is a core focus and drives the story’s emotional and relevant response.

After receiving the diagnosis, Ben’s parents learned it was a fatal one for their beloved son. From then on, the path taken would be paved with challenges. These challenges were consistent and numerous: learning how to cope with camping trips as Ben became more difficult to manoeuvre in a tent; learning to find delight in natural things like trees, birds and riverbanks; not being afraid every time, he was thrown by a surf wave or tripped over. The most important challenge was allowing Ben to live his life as fearlessly and with every possible option so that he could enjoy a shortened journey, but one filled with love, light and laughter.

As Ben’s life ended in 2007, his dad, Michael, found himself running again, this time to the emergency department having been summoned by the Senior Specialist on Duty. His description of the care team suggests a moving space between reality of the moment and the fear that all family members feel on entering such a place. But, he takes time to pay tribute to the health care team:

‘The nurses who were there that night were more presences than people, moving quietly in the zone between two worlds, the world of the living, and the world of the dying and the dead . . .’

Significant movement is a feature of this work. Moving from one space to another, from one part of Australia to another, from one type of care to another. This early on from a child who could move and walk in his early years to gradual and expected loss of the ability to walk or do things for himself and to be moved by others in his wheelchair. Thus, in essence, Ben was carried through life by a caring and loving family. In turn, he repaid them in spades: showing courage in catching a train all by himself, including the family in long treks through parks and streets and the environment and finding joy in the most unexpected places. In turn, Ben taught his dad about emotional commitment and knowing when to let go. An amazing young man in a wheelchair who lived and loved. Michael Galvin tells the truth about what he felt and what transpired in his life and that of his beloved son. His poignant admission ‘when we lost him, we grieved’ a final thought but clearly outlined. Such grief and knowledge now inform this journey of love and loss and will be

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a great comfort to those who work in the challenging environment of disability care.

This is a story that shows humanity at its best – a grieving dad and caring community, and the capability of a child with

disability and different ability to be part of life no matter how fragile or short.

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