

GUIDE TO CHAPTER CONTENT AND THEMES

CHAPTER 1

AMONG HIS OWN KIND

Diagnosis at six years old | Ignoring conventional wisdom | Living in the community | Being positive | Starting school | The neighbourhood gang

Besides, his own kind are his sister, the kids from next door, the kids he plays with down the street, and kids he goes to school with. (p.7)

CHAPTER 2

WITH A LITTLE HELP FROM MY FRIENDS

‘Uncle’ Bill, my father | Moving house and new school | Importance of help from family and friends at school and play | Ordinary misbehaving | Being different

I would get lots of practice asking for help and telling people how to help, and my friends would become very used to giv-

ing me a hand. I could only have learned those skills by being part of the 'ordinary' world. (p.27)

CHAPTER 3

HIGH SCHOOL AND PIGGY-BACKS

High school | Passion for sport and being involved |
Volunteers and friends vital for survival and independence
| Holidays and hospital | Mobility problems increasing
[The high school] *readily accepted me on the understanding that the school could confront any problems if and when they arose. (p.37)*

CHAPTER 4

THE BIKE

Family changes | Coming to terms with wheelchair and disability | Increasing independence and getting about in the community | Being different | Puberty and sexuality | Prognosis and fear of the future
The spectre of death gave my life a desperate impetus. I had a reason for getting on with things. If I was going to be dead soon then I had all the more reason to get on with life. (p.64)

CHAPTER 5

'YOU HAVEN'T ASKED ME YET!'

Dealing with fear and depression | Facing reality |
Puberty and sexuality | Need to fit in | Acceptance by

a girl | Renewed confidence and ordinary expectations

Pam's acceptance of me forced me to stop blaming everything on the wheelchair and to stop seeing myself as just a cripple. I started to understand that my disability was only a part of who I was. (p.72–3)

CHAPTER 6

ONE OF THE BOYS

Final years at high school | Mates and parties | Typical teenager | Managing personal care | Social and academic benefits of integration | Learning organisational skills and leadership

It is important to retain flexibility and goodwill in the system... It should be possible to proceed with integration even if the optimum conditions don't exist. (p.79–80)

... integration is an essential ingredient in the life of any child with a disability. (p.82)

CHAPTER 7

'ONE DAY YOU'LL CHOOSE YOUR FRIENDS MORE WISELY'

Car accident and hospital | Matriculation success the second time round | Choosing and valuing friends

The most important thing I learned at Brighton [High School] was how to choose and value my friends... They showed me my life was worth living and taught me a lot about how to live it. (p.94)

CHAPTER 8

MY GENERATION

University | Vietnam war and student politics |
 Standing up for your convictions | Falling in love |
 Needing privacy | Dealing with disappointment |
 Coming to terms with fears about death

But being out there was sometimes painful. I did get hurt both physically and emotionally ... Those feelings are part of growing up and if you're lucky enough to have the support you need, they'll make you stronger. (p.109)

I had the same ambitions as my peers. I thought like them, shared their dreams, language and games... Most importantly of all, I wasn't isolated. I had a huge network of friends and acquaintances at home and university. (p.109–10)

CHAPTER 9

WHERE ARE ALL THE OTHERS?

Liberation through motorised wheelchair | Political understanding of disability | Starting work | Parental support to be independent | Leaving home | Volunteer personal care system

I began to feel the need at least to try and understand the processes which kept people like me out of schools, universities and the ordinary community. (p.120)

I often resented how much I had to organise my life. It was a struggle, but the rewards were more than compensation. (p.130)

CHAPTER 10

INDEPENDENCE

Sex, drugs and rock ‘n’ roll | Sexuality and intimacy |
Choosing relationships | Benefits of paid employment |
Political analysis of disability creates an agenda for change
| Health crisis

Sex was fun and it gave me something special. It gave me a reason for being glad that I had a body. A lot of the time my body felt ugly. It was a burdensome and sometimes painful shell that I inhabited. When I made love my body miraculously became a wonderful part of me. (p.133)

Open employment means not only decent pay and conditions but also a chance to meet and mix with ordinary people in the community. With that comes the kinds of enriched opportunities I was enjoying. (p.138)

CHAPTER 11

AN IRON LUNG

Facing death | Medical decisions | Fears and despair
| Prospect of institutionalisation | Encouragement of
family and friends | Support from other people with disabilities
| Moving back to parents’ home

The support of my friends was enormously significant in seeing me through the crisis. They were there when I needed them but they were never maudlin or sentimental. (p.148)

[they] gave me the strength and motivation to keep trying. (p.153)

CHAPTER 12

KEEPING THE FAITH

Regaining independence | Local action and the Disability Rights Movement | Dehumanising effect of hospital | Love and intimacy | Verbalising emotions

For the first time people with disabilities used the media to successfully challenge a myth about people with disabilities and the power of one of the big charitable voluntary agencies. It was a very significant political lesson and the beginning of a power shift. (p.163–4)

She told me to ‘keep the faith’, to believe that mutual love is real and possible and to trust other people to... risk loving me. (p.171)

CHAPTER 13

MELVILLE ROAD

Communal living | Friends and informal support the key to living independently | My first ‘attendant’ | Changing traditional service-providers from the inside | Self-help and social change

... I lived independently, owned a car, was a university graduate, had a lover and a very active social life... None of it seemed amazing, it just seemed to happen because I was living in an environment with friends where everyone expected me to do those things. (p.177–8)

For years our parents, welfare workers and health professionals had been deciding what our disabilities meant and what we needed... We were going to take charge of the processes we

had let others control. We started by ensuring we controlled our own organisations and the language we used. (p.183)

CHAPTER 14

DIRECT ACTION

Exposing myths and destructive images of disability | Demonstrating about access to buildings | Protesting against charity fundraising | Fighting for rights, independence and dignity

We were trapped in a vicious circle of discrimination. There was no access, therefore no people with disabilities could participate, therefore we weren't there to raise awareness of our needs and therefore no access facilities were provided. (p.189)

... 'welfare' was an inappropriate way to provide funds for services for people with disabilities. We believed that we had a right to those services... We believed that disability services should be funded through taxes. (p.193-4)

CHAPTER 15

TWO WOMEN AND A BUST

Needing communal household for survival in the community | Compromising on privacy and choice | Relationship 'ups and downs'

... I felt obliged to be accessible to everyone. I was concerned that if I started closing my door my friends would stop dropping in and being as available as they were. These friends were my means of survival... I was obsessively focused on survival. Inevitably that meant that I had no privacy. (p.201-2)

CHAPTER 16

CATHERINE AND MY FRIEND GARP

New relationship | Planning a future together |
 Another realisation of the tenuousness of life | Building
 a new support system | Judgemental attitudes about
 people with disabilities in relationships

Our biggest challenge was to build in enough support to protect Cath from burn-out and to ensure our relationship could survive the pressures created by my needs. (p.215)

We learned how to compromise, adapt and hold on to what was important and essential to us. (p.218)

CHAPTER 17

ORDINARY AMBITIONS

Marriage and honeymoon | The logistics of holidays |
 International Year of Disabled Persons (IYDP) |
 Self-representation, consumer control, collaborative action
 | Accepting myself and my disability

I was employed, married, had a mortgage and a dog. My suburban existence may have seemed mundane to some but it was wonderful to me. (p.226)

[IYDP] was ‘our year’... We... wanted to promote integration, acceptance and understanding of the ‘ordinary’ aspirations of people with disabilities. (p.227–8)

...major changes started to occur but, most significantly, it was a year when a lot of people co-operated with each other and achieved innumerable breakthroughs. (p.229)

CHAPTER 18

RUNNING OUT OF PUFF

Coping with increasing physical disability | Dilemmas of working for a traditional disability service-provider | Changing power relationships between consumers and service-providers | Community development approach | Work-based personal care support | Equal Opportunity Office

My ability to perform another bodily function had gone... I coped with the change because I simply had no other choice. If I wanted to stay at home with Cath, I just had to deal with it. The people around me were... willing to do what was necessary in order for me to survive. (p.234)

[The Equal Opportunity Office] *created a precedent by providing such assistance. With that work-based personal care they enabled me, a severely disabled worker, to remain productive in the workforce long after it would have seemed possible. (p.239)*

CHAPTER 19

ATTENDANT CARE

Development of attendant support | Personal Care Workers Study – DASl (now DASSI) | Consumer control and worker participation | Changing people's lives | Getting government funding

The aim of attendant care is to enable people with disabilities to live in the community in our own homes without relying on an institution or family for our care. It also gives us the unique

opportunity of controlling our own lives... With attendant care we are no longer... passive and grateful recipients of care or service. (p.245)

CHAPTER 20

NO GUARANTEES

Death of friends | Decision to have a child through donor insemination | Positive and negative attitudes of health professionals | Change in prognosis

The suddenness and unexpectedness of [their deaths] made me realise again that no one has a mortgage on the future, there are no guarantees. (p.256)

I don't wish my disability on any child or family, but my life has been worth living. I believe in what I've done with my life and I like who I am. Who I am includes my disability. It has taken me a long time to accept that. (p.261)

CHAPTER 21

TIMOTHY

Fertility treatment and pregnant at last | Timothy's birth – fulfilment of a dream

During the months that followed his birth I felt fulfilled and complete... I have enjoyed the benefits of integrated education, open employment and a life lived in the community. All that had gone before gave me the opportunity to establish my 'right' to be a parent. (p.272-3)

CHAPTER 22

BACK WHERE I BELONGED

Serious illness and Intensive Care Unit | Medical staff who knew me crucial to survival | Lengthy rehabilitation and adjustment to tracheostomy | Home with family and back to work | Australia Day Award – formal recognition of the work of people with disabilities to secure their rights

After months of being institutionalised in the hospital and at home, I was very timid. For the first time I understood and felt the anxiety of a person who has been kept away from the mainstream of community life. (p.286)

I still live in my own home, with my family. I have many friends, go out when I want to... My life is full of ideas, people and activity. (p.289)