

Sweet Adeline



Adeline—1930

Sweet Adeline
A Journey through Care

Patricia Slack
and
Frank Mulville

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Patricia Slack, *School Nursing*, Baillière Tindall (1978)

Frank Mulville, *Terschelling Sands*, Herbert Jenkins (1968) and
Conway Maritime Press (1987)

Frank Mulville, *In Granma's Wake*, Seafarer Books (1970)

Frank Mulville, *Rustler on the Beach*, Angus and Robertson (1976)

Frank Mulville, *Schooner Integrity*, Seafarer Books (1979)

Frank Mulville, *Single-handed Cruising and Sailing*, Macmillan
(1981)

To everyone who loved Adeline and helped us to care for her

'The clouds you so much dread
are big with mercy, and shall break
In blessings on your head'

William Cowper

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Preface

This story of the last six years of my mother's life began when she was still active and reasonably healthy. She suffered a severe stroke and was not expected to survive—but she did. She rallied to find herself severely disabled, in a wheelchair, unable to read, write or speak except to say “do, da, do” in response to everything.

The event devastated my mother, myself and Frank. We lived through the emotional trauma of her disablement, of poor hospital care and of having to decide on her future long-term care. At first we maintained her in her own home, in the north of England, two hundred miles from London where we lived and worked. Eventually, through many vicissitudes, all three of us survived to live happily in the same house.

We learnt how to manage as we went along. Useful information was difficult to find. I seized on the experiences of other carers for the practical details outside the experience of professionals and missing from the books they write. I found that carers' accounts of the emotions surrounding their experiences helped me to grapple with the cauldron of love, remorse, anger, fear, hatred and violence which boiled inside me. I sat late into the night reading Dervla Murphy's autobiography *Wheels within Wheels*, part of which describes her caring experiences in heart-rending detail, and found it more comforting and refreshing than sleep.

I too wanted to share our experiences but I did not want to hurt or embarrass my mother. I explained to her what I wanted to do and I believe that she supported the idea of this book, feeling that her tortuous experience would have been justified if it could be of use to others. In some strange, inexplicable way I feel she helped to write it.

Severe handicap can tear families apart and destroy relationships. Because the attitudes and response of every member of the family affects a dependant's care, Frank and I have

written this book together from our different points of view. We have tried to combine practical details with the story of our experience and the emotions it produced. I hope it will help other carers and give professionals a glimpse into the problems and feelings of the patients and relatives they meet.

Learning through experience takes time and therefore some of the practical information is spread over several chapters. To help consolidate and include extra points we have added a chapter 'Points for Carers' at the end. It concentrates on the details sparsely covered or missing from other books.

We have left some of the characters nameless or given them fictitious names as we have no wish to hurt any of those involved in the story. We do not believe anyone intended to hurt us but they often did and we have presented events as they seemed to us at the time. The story has been reconstructed from journals and diaries kept throughout the period and from notes my mother's helpers and I wrote to keep us informed. In re-reading these journals we were surprised how much our perceptions of events had altered and how we had forgotten most of 1982—our worst year.

Caring for a severely disabled relative is demanding and exhausting, as so often depicted by the media. We hear little about the rewards. My mother showed Frank and me a new depth and breadth of love for each other. Her tragedy formed the basis for the most enriching emotional experience of our lives. Caring is a challenge, with rewards for those who take heart and shoulder it successfully. We hope this book will help.

August, 1987

P.S.
F.M.

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