

# **Cicely Saunders –** founder of the hospice movement Selected letters 1959–1999

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# Foreword

## Balfour Mount, Montreal, Canada

The life work of Dame Cicely Saunders led to the creation of St. Christopher's Hospice in London, the development of the international Hospice/Palliative Care movement, the birth of Palliative Medicine as a new medical specialty and a decrease in suffering around the world. Sir Isaac Newton wrote, 'If I have seen further it is by standing on the shoulders of giants.' While giants are a rare breed, the twentieth century saw several physicians who qualify based on their contributions to the relief of human suffering. The list includes Alexander Fleming, Frederick Banting, Jonas Salk and Cicely Saunders. Fleming, Banting and Salk are remembered because of their discoveries – penicillin, insulin and the killed-virus vaccine against poliomyelitis, respectively. Dame Cicely's contribution differs in kind. She has been the catalyst for a paradigm shift in global health care.

In 'The Structure of Scientific Revolutions,' Thomas Kuhn argues that scientific research and thought are shaped by 'paradigms', or conceptual world views born out of formal theories, classic experiments and trusted methods. He questions the traditional view that scientific progress represents a gradual, value neutral, cumulative acquisition of knowledge as the result of objective, rationally chosen, experimental strategies. Instead, he argues, the accepted paradigm determines what is seen as being important and relevant, the kind of questions scientists ask, and the experiments they perform. A shift in the paradigm, Kuhn asserts, alters fundamental assumptions concerning the issues under consideration and gives rise to new research directions and strategies, new standards of evidence and a general reframing of priorities so that the new paradigm is incompatible with the old.

During the first decades of the latter half of the twentieth century, deficiencies in the care of the dying were documented to be endemic in Western health care and beyond. On assessing this conundrum John Hinton observed, 'We emerge deserving of little credit: we who are capable of ignoring the conditions which make muted people suffer. The dissatisfied dead cannot noise abroad the negligence they have experienced.' Strained communications between patient, family and professional care givers were shown to lead to isolation and distrust. Symptom control was found to be inadequate and psychosocial and spiritual needs were too often ignored.

There was a clear need to extend the horizons of healthcare beyond the reductionist biomedical model to the more inclusive perspective of whole person care, to move beyond an exclusive focus on disease, pathophysiology, curing and quantity of life to include consideration of experienced illness, suffering, the art of caring and quality of life.

Cicely Saunders was born on June 22, 1918. Though shy and unsure of herself in adolescence, her leadership potential was evident at an early age, leading her headmistress to write prophetically, 'I should be greatly surprised if anything deterred her once she had decided to embark on a piece of work.' Cicely was accepted in the St. Thomas's Nightingale

School of nursing in 1940 at the age of twenty-two. However, chronic disability due to back pain cut short her nursing career, leading to training as a medical social worker or 'lady almoner' as they were then known. In 1947 she was appointed assistant almoner at St. Thomas's. Within a year Cicely had started working evenings as a hospice volunteer at St. Luke's Hospital, originally 'Home for the Dying Poor.' A clear sense of vocation nurtured by that bedside experience, her deepening Christian faith and the advice of a mentor, then precipitated yet another career change. She read Medicine at Thomas's in order to start a 'home' for the dying and frail elderly. Her impressive determination in these studies led one of her tutors to comment 'her industry is overpowering.' She qualified in 1957 at the age of thirty-nine. In 1958, her paper 'Dying of Cancer' was published in the St. Thomas's Hospital Gazette and in 1959, 'Care of the Dying' in *Nursing Times*.

What personal qualities enabled the staggering productivity that was to ensue? In 'Cicely Saunders, Selected Letters, 1959–1999' we are privileged to enter the private world of a dynamic, highly effective leader. A candid picture of her motivations, priorities and actions emerges. Her legendary determination and vision, her warmth and enthusiasm, confident humility, sense of humour, curiosity and attention to detail shout from every page. She repeatedly stresses that her role has been to reshape, not innovate. Always ready to acknowledge her patients as the 'founders of hospice' and the importance of her mentors and team, she observes, 'What have I that I have not received?', and again, 'There are not many original ideas in the world. One only brings together things culled from here and there, shakes the kaleidoscope and finds a new pattern.' To paraphrase Churchill, 'Some kaleidoscope! Some pattern!' St. Christopher's Hospice was her kaleidoscope, Hospice/Palliative Care the pattern she so carefully created.

The letters in this book will be important to a variety of audiences. With their wide ranging topics, clarifying detail and robust candidness, this lively corpus offers rich rewards for both the general reader and those with specialized interests. For those working in Palliative/Hospice Care, Dame Cicely's letters are a touchstone against which one can reflect on subsequent developments from a personal, programmatic, or broader perspective. For scholars concerned with the changing aspects of death in society, those responsible for political and policy decisions and medical historians, these letters are a precious resource, for they provide a window on a healthcare revolution that has touched countless lives. Indeed, these pages provide an intimate picture of an ambassador for change and insight regarding the dynamics of leadership. They also will be of interest to students of the Cartesian dualism / whole-person-care dialectic, team functioning, organizational theory and expressions of religious conviction in the context of a pluralistic society.

The global paradigm shift to the healthcare pattern developed in Dame Cicely's kaleidoscope did not happen as the result of random good fortune. Each reader will glean his or her own list of personal attributes that contributed to Dame Cicely's success. I have been struck by her dogged determination to bring to her mission a sense of balance in body, mind and spirit. That balance has been hard-won. Along the way she has remained open to lead and be led. This is wonderfully captured in her letter of 31 July 1964 to The Most Reverend the Lord Archbishop Anthony Bloom, written a full three years prior to the opening of St. Christopher's. 'We have been looking and praying for the right person to take over as Chairman for a very long time.' 'Looking'; 'praying'; 'for a very long time'! Active searching is coupled with openness to the Way, in an attitude of patience. Attention to process, presence and patience, with tenacity and clarity of purpose as resources for the journey.

During the four decades in which these letters were written, St. Christopher's continued to expand and modify its programs. Currently, it addresses the needs of 1,600 patients and their families each year. The 48 beds complement a home care program following 500 patients on any one day and a day centre for 20 patients, five days a week. In addition, the St. Christopher's team continues an active research program into all aspects of Hospice Care and annually accommodates 2,000 visitors and hosts 80 conferences and workshops. During the same decades the St. Christopher's model of comprehensive patient and family care has spread around the world. Well in excess of 8,000 hospice/palliative care programs in 100 countries have now been established.

As impressive as the statistics are, numbers do not convey the significance of Dame Cicely's work. Compassion cannot be tabulated in columns, nor are we yet able to assign a p value to the significance of diminished suffering. These letters have helped to shape medical history. We are indebted to Dame Cicely and David Clark for this precious gift.

*Spring 2002*

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# Acknowledgements

A great many people, in ways seen and unseen, have assisted in this endeavour. My interest in the life and work of Cicely Saunders forms part of a larger project on the history of hospices, palliative care, and related fields and this has enjoyed considerable support from the Wellcome Trust to which I remain constantly grateful; I particularly want to thank John Malin, who, during his time at the Trust, provided both a steady eye and measured guidance, which were so helpful to me over a number of years.

I am fortunate indeed to be based in the Sheffield Palliative Care Studies Group where colleagues from the clinical disciplines, from the social sciences, and from the humanities make up my day-to-day working world. I am grateful to them all for their constant encouragement and intellectual stimulation. Several within our group over the years have made particular contributions which have made this book possible: Clare Humphreys, Rachael Marples, and Michelle Winslow have each given direct assistance in various ways and I thank them for their help.

At the University of Sheffield I was also fortunate in being able to take advantage during the year 2000 of a period of study leave in order to undertake the core work for this project; I am grateful to two successive Deans in the School of Medicine for supporting me in this way. Above all, however, it has been Margaret Jane at Sheffield who has unflinchingly and with enormous dedication produced and refined the entire manuscript from so many rough drafts and photocopies. Without her involvement, quite simply the project could not have come to fruition. I extend to her my warmest thanks and appreciation, as always.

At Oxford University Press, Catherine Barnes and her colleagues have shown tremendous enthusiasm for this project, and their interest has done much to help me finish off a work which has been several years in the making. I am particularly grateful to Kate Smith for her assiduous help on the proofs.

Much more than others in which I have been involved, this book is also caught up with my family life. Certainly it cluttered up the dining-room table for many months. Also it was being prepared at a time when our home was affected by illness, by death, and by bereavement. So it will always have some very special associations. My daughter Rachel Clark helped me with it throughout this time and did huge amounts of careful photocopying, in the process becoming expert herself in the book's subject matter. I thank her for her kindness and for keeping the whole thing moving, even when the spirit flagged.

At St Christopher's Hospice, Christine Kearney has been a constant source of help, and I am indebted to her for sharing so much of her knowledge as well as for giving practical assistance.

Finally, there is one person without whom truly this book could never have existed. Dr Cicely Saunders wrote all the letters. She worked tirelessly to realize the vision that is contained within them and she inspired so many others to go into the work of hospice and palliative care. From the outset she has been doubtful that her correspondence will be of interest to others. Naturally, I hope that the reaction to this book will prove her wrong. It

has been my privilege to work with her on this project, though she has shown no inclination to influence my choice of correspondence or my interpretations. Her letters, so engagingly written, so full of energy and commitment, so practical and yet so reflective, deserve a wide reading. I hope, therefore, that she will feel satisfied with the products of my labours here and I take this opportunity to thank her for everything she has taught me along the way.

David Clark  
Dalswinton, Dumfriesshire  
February 2002

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# Introduction

The main duty of one who edits another's letters is to intrude as little as possible upon what they have to tell us. I therefore do not propose to offer too many distractions from the fascinations which this correspondence of Cicely Saunders contains. As a researcher, however, I do feel obliged to give some account of my methods and this should in turn help the reader to make sense of what is presented. I harboured the ambition of producing an edited volume of the letters of Cicely Saunders from the point, in the mid-1990s, when I first realized the extent of what she had written, coupled with the discovery that much of it was still extant. Since that time, as part of a wider project on the history of hospices, palliative care, and related fields, based at the University of Sheffield, UK, I have tried in various ways to understand and analyse the particular contribution of Cicely Saunders.

It has become a commonplace to regard her as the founder of the modern hospice movement: a woman of resilience and vision who, having trained as a nurse, social worker, and then physician, dedicated the remainder of her life to the care of the dying; a woman whose reputation has gone well beyond the healthcare field in which she has worked so tirelessly; a woman who has had very special relationships with three Polish men; a woman of deep Christian faith; a woman who has persistently opposed euthanasia. Several have written about her. She herself has spoken and published a great deal. Yet my own view is that much remains to be understood. This volume of letters is one step in that direction.

I have chosen here to allow her letters to tell their own story, but I also recognize the pervasiveness of the editorial hand. So let me explain how I have undertaken this work.

In 1998 I supervised the cataloguing of Cicely Saunders' personal papers. Since that date further materials have been added to the collection, which currently stands at about eighty archive boxes. Her correspondence goes back in the main to the late 1950s and is still growing. This book concentrates on the forty years 1959–99. Covering that period I estimate there are some 7000 of her letters among her papers. This is by no means a complete picture. In some places (though not many) small gaps occur for no apparent reason. Elsewhere, it is clear that material has been at some point discarded. Moreover, to colleagues who became personal friends, many letters have been written by hand, with no copy preserved. The papers from which I have drawn therefore tend to reflect a professional life in which letters are typed by secretaries and copies are filed and retained. That is not to say that they do not contain remarkable personal insights, or that her correspondents do not write to her by hand and in a personal way; several do so. My choice here, however, has been made from Cicely Saunders' own typed (occasionally handwritten) and preserved letters. I have made no attempt to seek out from their recipients other letters which she has written, but copies of which she has not kept. Moreover, I have selected only from letters written by Cicely Saunders herself. No letters are included here written *to* her, so this is a narrative in her voice only. In this way I have made a selection covering about one-tenth of the total.

From within such a corpus, how did selection proceed? I have to say that for this I used no protocol or formula. Rather, I have built on my growing knowledge of Cicely Saunders

and the hospice movement to create a particular kind of narrative. This book should therefore be regarded as one sort of perspective on the life of Cicely Saunders, as seen through a selection of her correspondence. It may serve as a source book for further analysis, but the careful scholar will prefer the original documents for this.

I have chosen to depict a narrative which does several things. It begins by revealing something of the motivation of Cicely Saunders to study the problem of caring for dying people and then to act upon her knowledge. Alongside this it opens up the sense of calling that motivated this purpose. It also shows how a strategy was developed which allowed a rather idiosyncratic and personal vision to be put into operation with help from others. We see the achievements which took place long before St Christopher's Hospice received its first patients, and it becomes clear that the opening in 1967 should be regarded not as the start of the modern hospice movement, but rather as the conclusion to the first stage of its development.

Within this a picture emerges in which St Christopher's is seen as part of a wider network, not just within the United Kingdom, but also around the world. We understand the connectedness and the personal, professional, and institutional links that were developed, and we see the consequences that resulted. We gain insight into the expanding knowledge base of the hospice and the transition to a wider perspective in the form of palliative care. There are letters which deal with the growing professionalization of the work, and with the establishment of national and international palliative care organizations. We learn of working parties and research collaborations, of lecture tours and conference engagements. There are insights into the friendships made along the way.

Over time we read about the changing role which Cicely Saunders had in the hospice she founded, as well as in the wider movement. The letters pay testimony to the numerous honours and prizes that have been bestowed upon her in so many places. We also gain a powerful insight into her inner convictions: the evangelical Christianity which is touched by Catholicism, the gradual broadening of her spiritual path, the importance of prayer and religious reading in daily life. Likewise we learn of the things against which she sets her face: euthanasia, inadequate care, a lack of respect for personhood. There are insights too into three men, all Polish, who in different ways had such a formative influence on her adult life, and one of whom she eventually married. With this marriage came a new domesticity and a pleasure in companionship. In time it also brought direct experience of the informal carer's role. Then, after the death of her husband, she re-emerges from the home once again to travel the world, to write, to lecture, and to enjoy continued plaudits and acclaim.

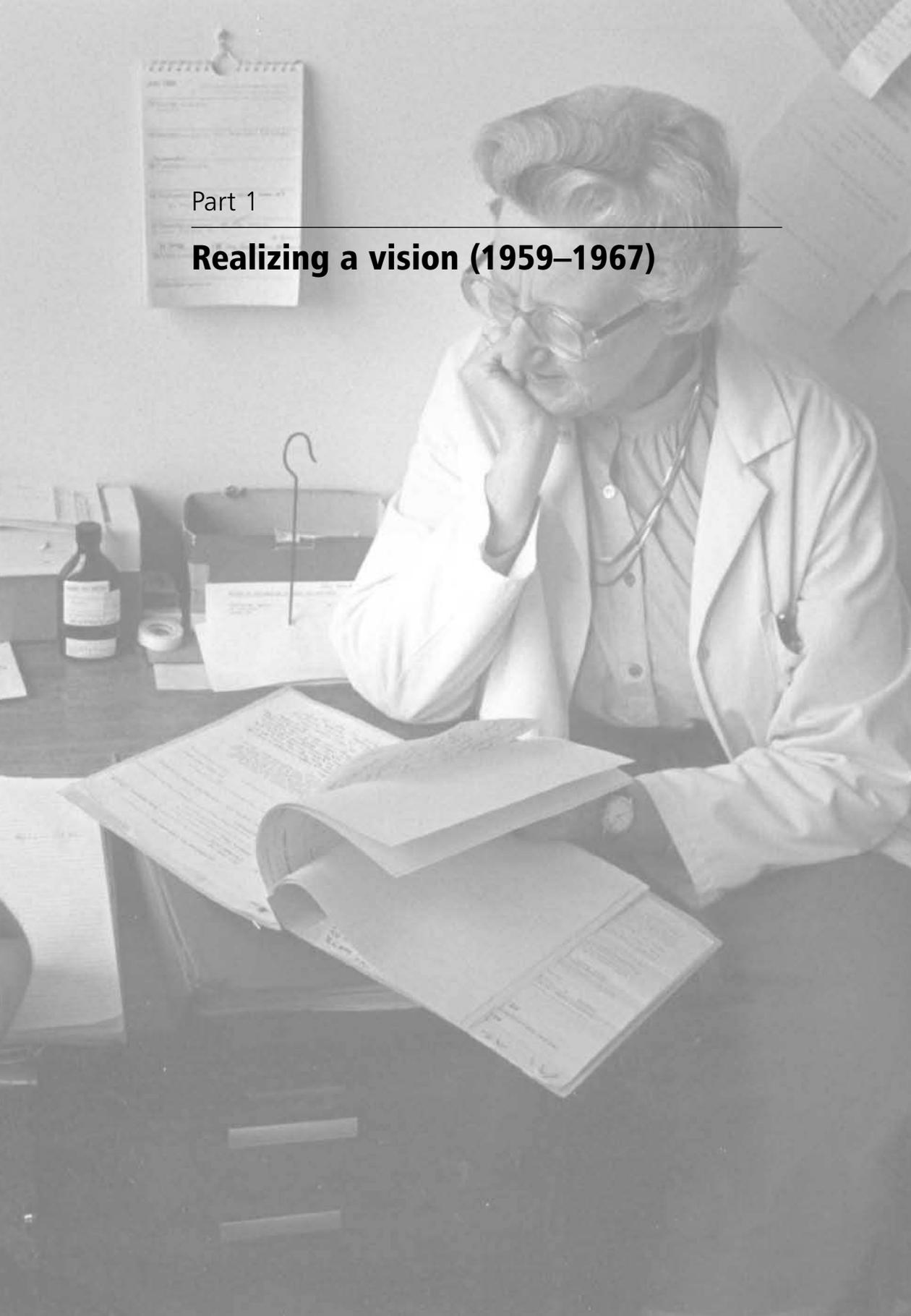
All of these elements I have tried to capture in my choice of letters. Reading them is, I believe, a privilege, for in some ways they serve as a journal or diary. Set out in chronological order, rather than by recipient, they tell a compelling story. They can be read from beginning to end, or a particular time period can be explored in detail. The indices give the names of every person to whom a letter is included and can be searched by those interested in particular individuals and topics. Many well-known names in the history of hospice and palliative care are in evidence. Beyond these are letters to numerous men and women in different parts of the world who have only walk-on parts in hospice history, but with whom Cicely Saunders corresponded and had interesting ideas to exchange. In several cases I do not know who they are.

Apart from leaving out formal salutations and valedictions, I have made a principled decision not to abridge or edit the letters, so occasional irrelevancies and infelicities will

result. Here and there, to preserve privacy, the names of patients, their family members, and some others have been anonymized. The footnotes which I have added are intended to guide the reader through the terrain and, perhaps, to stimulate further reading. Occasionally, in square brackets, I have added to a letter in order to increase intelligibility. The early letters are in the main addressed from St Joseph's Hospice, Hackney; from St Mary's Hospital; or from Cicely Saunders' own home in Connaught Square, London. After 1967 they are mostly from St Christopher's Hospice. A few were typed by Cicely Saunders herself, but mostly she was helped by secretaries, and it is appropriate to acknowledge: Jenny Powley, Harnia Tokarska, and Kitty Cole, all of whom, using a manual typewriter, typed letters from recorded tapes, often on the kitchen table at Connaught Square; subsequently she was assisted at St Christopher's by Freda Saunders, Jenny Jameson (later Chambers), and Monica Steadman, and in particular by Christine Kearney, who became her secretary and personal assistant from 1980.

Finally, I have grouped my choice of letters into three time periods: the years leading up to the opening of St Christopher's Hospice; those in which Cicely Saunders was its Medical Director; and her years as its Chairman, up to 1999. I have prefaced each of these with a short essay intended to give some insight into the main features and preoccupations of the period. I hope that these will serve to orientate the reader, but they are by no means essential to an appreciation of the letters, which need no one but their author to tell their tale.

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Part 1

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**Realizing a vision (1959–1967)**

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