

Give Sorrow Words

WORKING WITH A DYING CHILD

Third Edition



DOROTHY JUDD

ROUTLEDGE


Give Sorrow Words

To my father, Samuel Woolf, who died in 1984;
to the memory of 'Robert' himself;
and to Elinor.

'... ne'er pull your hat upon your brows;
Give sorrow words; the grief that does not speak
Whispers the o'er-fraught heart and bids it break.'

Macbeth

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THIRD EDITION

Dorothy Judd

Foreword by Dora Black
New Foreword by **Jeremy Whelan**

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London, January 1989

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London, February 1995

Acknowledgements for the third edition

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London, April 2013

Foreword

Those of us working in hospitals have the task of helping children and their families cope with the effects of chronic, sometimes life-threatening, illness in children, and with the pain, inconvenience and constrictive effect of the 'high-tech' treatments now available. Multiple injections and venesections, cytotoxic drugs and radiotherapy are now routine in the treatment of leukaemia and solid tumours, but radiotherapy may involve the child being placed alone in a room inside a machine for an hour. He has to remain still and is likely to feel very sick and vomit. He will be a long way from home, especially if he comes to a regional hospital for a bone-marrow transplant. If his parents come in with him and we encourage and even insist on it – they have to cope with separation from other children and home, and live in a strange artificial environment. They have to relate to many different people at a time when anxiety about their child makes it difficult to function optimally.

For the child, according to his stage of development, anxiety is moderated by the presence of his parents, but he cannot help but be aware of the danger he is in, and research has revealed the propensity of the child to protect the parents from pain and depression (BluebondLangner, 1978). This partial reversal of the normal state of things – the parents usually protect the child – is often self-imposed and is rarely sought for or encouraged by the parents, but it constitutes a burden on an already overstressed child. Small wonder that the level of psychological disturbance in child, parents and siblings in life-threatening illness is between 50 and 75 per cent (Koocher *et al.*, 1980). If the price the child has to pay for recovery is a crippled mind, then the price may be too high.

In an effort to alleviate the emotional pain for children and their families, physicians are now working closely with child psychiatrists and their colleagues in some centres to provide a psychological support and treatment service. Dorothy Judd, a child psychotherapist, came to us to help develop this service, which also involves child psychiatrists, psychologists and social workers. Sometimes we are able to work with the whole family together, at other times, individual therapy may be more appropriate. Our aim is to provide time and space for children and families to reflect on

their experiences, understand what is happening, adapt to the reality of the illness and treatment, enable the expression of fear, anger, anxiety and sadness and provide a safe place and person – one who is not involved in the medical treatment, and so can be the container of unwanted and sometimes frightening feelings. In this way it may be possible to bear the unbearable – the uncertainty about the future.

Doctors and nurses who have to do painful and unpleasant procedures to children, who may have to make an apparently well child sick, sometimes also have unbearable emotions. In order to carry on, we may develop defences against this pain which may make us less sensitive to our patients' emotional experiences. Child psychiatric teams can offer to share this pain and allow it to be lived with and therefore not denied – a process which makes us all more human.

In what follows, Dorothy Judd offers us an overview of children's attitudes to death and considers the moral and ethical issues raised by treatments for life-threatening illness in children. She allows us to share her attempt to enter into the world of the dying child, to experience with Robert and his parents the bewilderment, the isolation, the mutual pretence, the pain and anxiety that serious illness brings to families. Using her sensitive personality, honed by training and experience, she is able to make a space for this boy to make some sense of his experience – to 'live until he dies', as Spinetta has put it (Spinetta and Deasy-Spinetta, 1981). At the same time her social worker colleague is helping the parents to bear the unbearable.

Robert did not win his battle with his illness. But an increasing number do, as our haematology colleagues refine and improve their treatments, using the knowledge which they gain from their experience with many children like Robert. It is our task to make sure that they and their families have as high a level of emotional care as they do of physical care. With resources dwindling within the NHS we may not be able in future to offer the help to these families they need and deserve. I hope this moving account of a talented child psychotherapist's work with one very ill boy will help those who have to make funding decisions to understand the nature of our contribution to the care of these suffering families.

Dora Black, Consultant Child and Adolescent Psychiatrist

Foreword to the third edition

While medical advances have transformed the outlook of many previously rapidly fatal illnesses, modern medicine's continued shortcomings are all too evident whether we watch children dying from malaria on television or the still all too frequent experience of our own personal loss from diseases such as cancer. Venomous public campaigns driven through the media – such as that which recently defined the Liverpool Care pathway as 'killing patients' and a 'death pathway' for babies – add to the difficulties that both professionals and families face. Our need to prepare for, to understand, to experience death, remains fundamental. But the profound emotional complexity shared by those experiencing any death presents repeated and predictable challenges. For those whose professional life engages them as participants, effective preparation to meet those challenges is an essential responsibility.

Some twenty years ago I was introduced to Dorothy Judd's excellent text and to Dorothy herself. Before and since, in my work as an oncologist, I have shared over and over again in the experience of the death of patients, especially of young people. Even with this familiarity, in welcoming this new edition of Dorothy's work, I am convinced that I and all professionals whose work encompasses end of life care will be well served by repeatedly reflecting on their understanding of the reactions and responses of patients and families to the threat of loss of life. By so doing, they themselves will be better able to maintain effective care. In seeking that understanding, there will be few better places to start than with this analysis whatever the age group one may work with.

Despite the universality of death and suggestions that nowadays there is greater openness to discussions about dying, pretence continues to be a familiar, often dominant feature of interactions between patients, their families and professionals. So often, we can conspire to sustain an unrealistic but 'hopeful' quest for avoidance of the inevitable. Sustaining that conspiracy is such a temptation, especially for doctors, trained to think in terms of 'saving lives', and parents, desperate not to contemplate the most painful loss of all, that of a child. As so many of the interviews with professionals in this book

indicate, we need never to lose sight of this. Modern multidisciplinary teams have an especially strong role to play here: to detect, confront and support interrelationships that may predict for the needs of a dying child or young person being shifted from the centre stage of care. And of course, ensuring that the support needs of staff themselves are recognized.

I was recently struck to hear 'Am I going to die?' as a question remembered by a cancer survivor 17 years after been diagnosed as an 11 year old. Also recalled was her mother's response 'I am not going to let you'. Whether spoken or unspoken, our fears of dying are powerful. This key question, whether uttered or suppressed, is of course only the opening question. Other questions must follow. How? When? Will it be painful? What will I experience? What do I need to do? Doctors, nurses and other professionals working with patients with cancer should have the skills to acknowledge and support those fears, to elicit them even when hidden by the webs of protection so ably woven by patients and their families and so often condoned by the responses of professionals.

But how should we prepare for this most difficult and exacting role? What language should we use? How will it sound and what will the effect be? The sensation of taking a discussion with a patient or family on to 'thin ice' may be familiar to the most experienced clinician or therapist. The skilful practitioner will also have more to give as a teacher and supporter of others. Here again, the insight and direction threaded through *Give Sorrow Words* is an invaluable aid. I would not hesitate in defining this as an essential text for any professional involved in the care of the dying.

Jeremy Whelan

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London.*

Preface to the first edition

To begin at the beginning. The work which this book describes arose out of a workshop I attended at the Tavistock Clinic in 1985, for child psychotherapists working with physically ill and disabled children. It gave me support and some very early insight into my work as a child psychotherapist with a small number of physically disabled children some of whom had limited prognoses, at a special school. I began to consider basic problems concerning the chronically ill, the disabled, and the dying. When are defences useful and when are they maladaptive? How can the chronically ill child work through the normal developmental phases – particularly adolescence, with its essential bids for independence and autonomy – when his illness or disability makes him dependent on adults for basic care? Beyond which point should life be sustained by medical intervention, and how do we evaluate the quality of the remaining life for a child whose death is prolonged? Arthur Hugh Clough's caveat from *The Latest Decalogue* comes to mind:

Thou shalt not kill; but need'st not strive
Officiously to keep alive.

This interest led me to further work mainly with leukaemic children, in a large teaching hospital, where I was supported by colleagues and a workshop for those of us engaged in working with children facing lifethreatening illness.

When I showed my account of the work with one of these children 'Robert' (in Part Two of this book) – to Ann Scott, at Free Association Books, she expressed interest but called it 'the foothills of a publishing project'. I wasn't sure whether to feel discouraged or encouraged: only the foothills – but at least it could be considered a potential publishing project. With Ann's encouragement I developed it further.

It grew at first into many little offshoots, which somehow, almost organically; became a recognizable shape. The process was not unlike that of knitting a garment: the various parts developed, to be pieced together; details like 'pockets' were added; some mistakes were corrected and 'dropped stitches' picked up, while others remained, perhaps for ever; finally, the 'rough ends'

were tidied up. Through the creative process of making this book, it felt that the painful ordeal of this particular child, and many like him, could at least lead to further thinking about crucial issues around the care of dying children.

At a more personal level, one of the underlying reasons for writing this book is that the impact of working with terminally ill children affected me deeply. Robert appeared in my life as suddenly as he departed from it: a first brief encounter, late September, with a pert little boy with a beguiling Scottish accent, so full of life and spirit that I reeled from the first meeting. I was shocked deep inside myself to think of his diagnosis – leukaemia – and the life-threatening disease in his body, destroying his blood. He occupied a pleasant side-room off the children's ward of a large teaching hospital in the North of England. The bustle of the ward seemed to take this new patient in its stride: it was only his mother's anxious expression and startled eyes that conveyed to me the seriousness of the situation.

The smell of the ward pervaded my nostrils for hours, strangely reminding me of a combination of talcum powder and babies' faeces. Perhaps this was evoked by the atmosphere of nurturing and cleanliness, of the apparent acceptance of bodily products that accompanies the care of the ill, of a powerful maternal presence in the ward, and by the helplessness of most of the patients.

This experience touched on other, earlier, more personal losses. The process of writing, firstly, the detailed account of my contact with one dying child, and then a fuller survey of the subject, was not only a way of sorting out some of my own thoughts and feelings, but also arose out of a sense of my own finiteness. For it is partly through this sense of mortality that our creativity is galvanized; that we seek to repair, create, and recreate, phoenix-like, that which has gone before – in the sense of 'happened' as well as 'lost'.

Nothing can alter the absolute loss of a child, but we need to consider the climate in which a child dies, in an attempt to allow the experience to carry its own truth. Part of this truthfulness, and of the allowing of truthfulness on the part of the child, lies in acknowledging our 'not knowing' about the meaning of death, nor when it will come, to a particular child or his family: to be able to tolerate the uncertainty that a limited prognosis brings.

In *Four Quartets* T.S. Eliot writes:

In order to arrive at what you do not know
You must go by a way which is the way of ignorance ...
And what you do not know is the only thing you know ...

This uncertainty, and the sense of vulnerability it brings, is hard to stay with, without what Keats (1817) calls the 'irritable reaching after fact and reason'. Perhaps Keats's own life-threatening illness contributed to his understanding of this 'negative capability', as he called it, 'when a man is capable of being in uncertainties, mysteries, doubts'.

Much of this book is factually and theoretically based, hopefully not as a way of avoiding some of the uncertainties, but as a way of providing a framework within which to reflect. I hope that alongside the research quoted and the arguments presented there is sufficient quiet and stillness, where the reader can dwell on his or her own thoughts and search for meanings.

The theoretical framework of this book is, generally, a Kleinian one: that is, I have drawn upon the writings of Melanie Klein, who, beginning in the 1920s, pioneered child analysis. Klein's perspective arises out of Freud's discoveries of the child within the adult: she developed Freud's theories further, thus encompassing the possibility of seeing the baby within the child and within the adult. At first, some of her theoretical conclusions seemed surprising even to Klein herself: 'My study of the mind of the small child brought certain facts before me which seemed strange at first sight' (1932). Understandably, some of the ideas put forward in this book may well appear strange to the reader who is new to Klein's ideas.

This perspective arises logically for me out of my training at the Tavistock Clinic, my personal analyses and supervision, as well as a continued appraisal and reappraisal of these ideas through ongoing clinical work. Inevitably, further studies by Anna Freud, Winnicott, Bowlby, Bion, Meltzer and many others have helped me, in common with many other child psychotherapists, to extend the theoretical framework.

However, although theories help to form a useful structure, it is the actual work with a child from which the excitement of discovery springs – the essential 'learning from experience', as Bion (1962) calls it. Alongside this comes the inevitable frustration of not understanding, of waiting, of continuing to look at one's own internal world, and attempting to understand one's own unconscious processes.

Recently much has been written about death, dying, and bereavement, and a great deal about children, but little has been written about the issues involved in bringing these two areas together. Therefore I address children's attitudes to death and how an imminent death affects these attitudes; ways in which adults, both professionals and parents, approach the death of children; and the increasing problems which arise when death is postponed through medical intervention and children are either living with an uncertain prognosis or experiencing a protracted dying. I have not focused fully on bereavement – on the effects of the death of a child on parents and siblings – because that is a full study in itself, but of course the book greatly concerns itself with our attitudes to loss and mourning. As the main focus is on dying children, the book aims to encompass their preoccupations and the climate in which they find themselves.

I have attempted to marry clinical experiences with theoretical concepts, published research on children's attitudes to death, and interviews with other experienced professionals.

My main focus is children with cancer, because, after accidents, cancer accounts for more deaths in children aged between one and 14 years than

any other cause. Yet cancer can be considered rare. One in every 600 children under the age of 15 develops a cancer, and of these leukaemia is the most common.

The experience of working with the child whom I describe in detail in Part Two was a very intimate one, and therefore one that is not easily shared in a public way through writing and publishing the account. However, I felt that it was important to try to convey the story as I perceived it. It raises many questions about approaches to dying children, and about the support needed by the family and by the medical and non-medical professionals involved. Besides considering the appropriate psychological approach, this account raises the question of the medical efficacy of keeping someone alive where the chances of survival are very slim. The extreme physical suffering in many cases of this type has to be borne in mind when the decision to pursue medical treatment is made. It can be argued, of course, that each case can provide new medical knowledge, leading hopefully to further improvements in the future treatment of illness.

Above all, this book raises the question of whether those involved can or should ever shift their focus from one of working towards the day when the patient will be well again to one where death is accepted more openly and the impending loss is shared among all, including the patient. I can never generalize about the approach in such a delicate and painful situation, especially where a *child* is facing death, when 'where there's life, there's hope' is a necessary and understandable dictum for all those involved. In parallel with this, however, I believe there could be a place for thinking about that which perhaps is not unthinkable.

Bion (1984) describes how the infant, as part of normal development, when overwhelmed by a state of extreme helplessness, may project a feeling that it is dying into the mother. This is part of a basic psychic interplay between mother and child; the mother helps to make the infant's unmanageable experiences more tolerable through her 'reverie', her ability to take the infant's projections and anxieties 'on board'. In time, that which is thus 'processed' by the mother can be reintrojected – that is, taken once again into the infant's psyche, to become a part of his inner world.

However, if the projection of a feeling that it is dying 'is not accepted by the mother, the infant feels that its feeling that it is dying is stripped of such meaning as it has. It therefore reintrojects, not a fear of dying made tolerable, but a '*nameless dread*' (Bion, 1984, p. 116, my italics).

If the '*nameless dread*' becomes something that can be acknowledged, perhaps given a form and shape, in words, play, drawings, or in a tacit calm acceptance, then perhaps fear, despair, isolation, and depression can to some extent be alleviated. Although here Bion is writing about an infantile phantasy and not a reality of dying, the feelings aroused in a fatally ill child may well be similar.

Preface to the second edition

I feel privileged to have this opportunity to bring out a new edition of *Give Sorrow Words*. Not only does this give me the opportunity to resurvey the research over the past 8 years, draw on my increasing experience, and refine or clarify some of the text of the first edition, but I have also been able to add a range of new interviews with other professionals, in order to explore more fully some of the issues and debates.

In my work in this field since the first edition, I find that there is an increasingly healthy awareness amongst nurses, doctors, medical students, and other professionals, of the painful issues around truth-telling (Weil *et al.*, 1994); consent (Alderson, 1990, 1993); the need for health workers to have more support; around the difficulties of switching to palliative care; and the need to look into our own psyches as well as attempting to be aware of those of our patients. These developments have occurred alongside pressures and changes in the National Health Service: the financial implications of treatment loom larger than ever. As treatments improve, and cure is possible for more patients, the temptation to try whatever may help is increased, both for parents and for doctors. The ethical implications explored in this book then become increasingly pertinent. Do decisions about *when* to treat have to be influenced by financial constraints? Or do we need to pay more attention to the emotional ‘holding’ that parents, ill children, and health professionals need, so that they can more effectively and appropriately make excruciatingly difficult decisions and keep in mind the quality of life? Indeed, the cost of the salary of a health worker who provides this holding, or thinking space, is infinitely less than many of the medical treatments that carry very slim chances of a successful outcome.

With many years’ increased experience, I am now braver in speaking the unspeakable, in naming fears, when with a dying patient. Although this still takes courage, it is often rewarded by the patient’s relief and increased trust. This leaves me with an awesome sense of responsibility, but in favourable circumstances the parents or other close family members can often then take on some of that intimate sharing.

In this work I find it increasingly striking that many of the normal characteristics of human nature – love, hate, guilt, a wish to repair, sexuality, hope, fear, gratitude, destructiveness, envy, despair, depression, denial – are compressed into an intense, concentrated period of time, where some, or all, of the emotions or states of mind are felt or glimpsed by those involved. This ‘living nightmare’, as it is often called, cannot be thought about, for the victim is subsumed by the catastrophe. Under such pressure, the predictable, meaningful, ordered world falls apart, into intense shards. The mental states that may then ensue include madness, disintegration, repression – all defences against the awful reality – or the immense task of struggling to make sense of it all, to piece together some of the fragments.

I am aware of a profound dichotomy, which, though delineated in the first edition of this book, has become more stark. How can we embrace death as part of life (which it is) and yet accept the death of a child? How can we accept the death of an adolescent girl, who cries that she will never have babies, never see them grow up? Or another, who says, ‘It’s worse for me than for my family, because I lose everyone, while they only lose one person’? How can we accept the death of a 12-year-old, who was his parents’ only surviving child and pride and joy, after 10 miscarriages? How can we accept the death of a 2-year-old who was particularly beautiful, engaging, and zestful, despite extensive surgery and despite her single-parent mother’s rejection of her? Or another 2-year-old who underwent brain surgery, chemotherapy, and radiotherapy, was particularly traumatized by the treatment, lovingly nursed through it all by his parents, and then died?

There is no rationale, so all we can do is register and express outrage, feel or try to understand the resonances in our own inner world: resonances with our own damaged internal figures (see Appendix III), and yet hope that within the bitter constraints of the short life that is left there can be some joy, some love, some hope, some opportunities to repair damaged relationships, and yet express the protest.

... joy shines out only to reveal what the annihilation of joy will
be like.

J.M. Coetzee (1994)

In other words, death is equated with destruction, but it does not mean that our minds and our spirits are totally destroyed too, or that we lose all hope for something creative to emerge within this ‘war-zone’.

The dichotomy, then, is about a struggle between, on the one hand, an acknowledgement of the death of a child as, by definition, anti-life and therefore insane, and yet, on the other hand, the need to make something hopeful out of it, without simply defending against its destructiveness. This book, and the work described therein, is one attempt to make sense of this irreconcilable tension, even though the feelings that shake us to the core do not find an easy outlet in words.

Preface to the third edition

I am very pleased to have the opportunity to bring out this 3rd edition of *Give Sorrow Words*. Although the main events it describes took place nearly twenty years ago, I feel that the book is still as valid and relevant as ever, and continues to express what I wish to say.

The body of text remains the same as in the 1995 edition. The book has a significant new Introduction, by Claudia de Campos. I am very grateful to Claudia for her careful appraisal of changes in the hospital care of children and young adults and advances in paediatric oncology which provide a contemporary context for the book.

I am also grateful to Professor Jeremy Whelan for his new Foreword. I knew Jeremy in the 1990s at the Middlesex Hospital, London, when he worked with Professor Robert Souhami, who I interviewed for this book in 1995. Recently, when I talked with Jeremy in the new University College Hospital Macmillan Cancer Centre, London, I was struck by how, after over twenty years in the field, he still appears to be in touch with the emotional weight and subtleties that this work entails.

I am aware of huge developments in the medical treatment of all cancers since 1995, and new arrangements to help increase the amount of research studies available to all patients including children and young adults. Notable, is the National Cancer Research Institute which has a 'Teenage and young adults clinical studies group'. They have instituted cancer registration; are following a survivor cohort of 15–39 year-olds; are promoting research needs for this age range; and, significantly, use clinical trial accrual as a marker of clinical care. Furthermore, international collaboration nowadays leads to improvements in treatments in just a few years, compared with, say, a twenty year span to bring about improvements in the past.

More recently, *Brightlight*, a study of 13 to 24 year-olds, is exploring if specialist cancer centres improve how well and how quickly young people recover. This research is still in its early stages. However, teenage and young adult cancer care is now considered mainstream, and not marginal.

Not surprisingly, I am aware of the fundamental similarities between the emotional problems faced in bearing the pain of working with the seriously ill, as well as the dying, child, as when I worked in paediatric oncology and

haematology twenty years ago. The healthy on-the-side-of-life cannot bear the loss of this all too precious span. And so, as Ovid wrote, 'Hope prompts the shipwrecked sailor, in the midst of waves with no land in sight, to strike out with his arms.'

Thus, the main points made in this book (1989 and 1995 editions) are still relevant today: attempts to find ways of helping ourselves and others to accompany the dying child; to suffer anticipatory mourning if we can, because it may facilitate the grieving of the eventual loss; to manage our own anxieties as best we can in order to try to contain the child's, and the family's.

Yet, psychological 'work' has been resisted since Freud began to publish his theories, and before: he stated that man is generally only prepared to look outward, not inward, using a telling physiological metaphor:

So if someone tries to turn our attention inward, in effect twisting its neck round, then our whole organization resists – just as, for example, the oesophagus and the urethra resist any attempt to reverse their normal direction of passage (1929).

On the other hand, Rilke (1925) expressed the potential enrichment of encompassing death:

Death is that side of life which is turned away from us, unilluminated by us: we must try to achieve the greatest possible consciousness of our existence, which is at home in both of these unlimited provinces, inexhaustively nourished out of both ...

In our struggle to face resistance, language itself has its limitations. We may attempt to 'give sorrow' – or the unspeakable experience of suffering – 'words', to try to find a common language, consciously and unconsciously, but full communication is not possible. T. S. Eliot (1944) describes this struggle to express emotions that can feel overwhelming as 'a raid on the inarticulate'. In my first analysis, when bemoaning the impossibility of expressing what I felt, my analyst said, 'Yes, but words are all we have.' So, as Eliot writes, 'For us, there is only the trying.'

While acknowledging that language can feel inefficient and frustrating, or evasive, or deceptive, the interlocutor's capacity to hear and understand what we wish to convey is crucial to the whole enterprise. This harks back to the infant's need for a mother (or significant other) to instinctively make sense of, and give thoughts, or words, to something ineffable and at times unbearable.

There is the possibility, then, that the dying child is not suffering alone, if some common language (albeit inadequate at times) is found.

As some examples in this book show, children – if given the opportunity – have an impressive capacity for truthfulness. It is often adults' inhibitions,

fears, and protectiveness, that leave the child alone in his or her awareness of the seriousness of their situation.

In the illustration that follows we see how powerful a child's protective concern can be. Thirteen-year-old, Michael, (Judd, 2001), had undergone an amputation of his leg and hip for bone cancer. It was this quality of truthfulness (for example, he said 'The cancer is more likely to come back to me than to someone else') that made his task more difficult, for he was generally alone in his ability to speak the truth. My task as his psychotherapist was to try to hear and bear the truth and to wonder how best to help a boy who seemed, at the beginning, not to be defended against his own psychic pain, but sensed and respected others' defences. Thus within a few weeks he had successfully 'fooled' doctors, nurses, physiotherapists, and his own family, by appearing brave and coping, but allowed me the onerous responsibility of sharing his catastrophic reactions to the trauma. Understandably, the more extreme the condition, the more defended the family and professionals can be. In an obvious way, emotional work for the bystander begins if the patient is unhappy or protesting, but less clearly if they are aware that the protestations of being 'fine' are false. However, the protective concern which Michael extended to nearly everyone he came into contact with may have been his way of splitting off and projecting the part of him which could not bear the truth. I felt that if I eroded his powerful wish for others not to know, (which I explored with him in many ways at many times,) I would be infringing the confidentiality between us which he adamantly requested, as well as the ways in which he needed to put his 'don't want to know' feelings into others. I hoped that in time his inner desperation would lessen and he would allow his outer expression to be more truthful, or at least that there would be a gradual integration between his hidden grief and his everyday outer appearance.

Several months into the treatment, with his talent for aphorism, and his capacity to find ways of expressing his despair, he said, 'The way out of unhappiness, the way to find happiness, is to understand how you became unhappy in the first place.' He concluded, 'I don't believe in God any more ... it's up to me to find ... to walk the last bit on my own.' In the next session he said, 'I think life mustn't be wasted ... I think you only get one chance.'

In 1996 I chose not to continue to work in a hospital, but to see some adults in my private practice who were facing a terminal prognosis. I sometimes miss the privilege of working so intensively and intimately with the huge life events which this book explores. I don't think I reached 'burn-out', but I could see it on the horizon. I then had the choice to leave, a choice which tragically many of the patients and families do not have.

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Introduction to the third edition: developments since 1995

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Abbreviations:

BME: Black and Minority Ethnic
CAMHS: Child and Adolescent Mental Health Service
CHCR: Calman-Hine Cancer Report
CLIC: Cancer and Leukaemia in Children
CNS: Clinical Nurse Specialist
CP: Cancer Plan
CRS: Cancer Reform Strategy
ENCORE: English National Cancer Online Registration Environment
EOL: End of Life
GOSH: Great Ormond Street Hospital
GP: General Physician
IOG: Improving Outcomes Guidelines
IOSC: Improving Outcomes: a Strategy for Cancer
IOSC/SAR: Improving Outcomes: a Strategy for Cancer. Second Annual Report
MDT: Multi-Disciplinary Team
MHC: Mental Health Commission
NCAT: National Cancer Action Team
NCIN: National Cancer Intelligence Network
NHS: National Health Service
NICE: National Institute for Health and Clinical Excellence
NSF: National Service Framework
ONS: Office of National Statistics
PCT: Primary Care Trust
QoL: Quality of Life

SAIL: Secure Anonymised Information Linkage
UCLH: University College London Hospital

I feel particularly privileged to have been invited to introduce a new edition of Dorothy Judd's ground-breaking book, which has been a good friend in my own work in paediatric oncology.

Any psychotherapist working today with children who are dying will have read Judd's book at some point for its insights. The very juxtaposition of the words *child* and *dying* at once throw up resistances and defences in the most seasoned professionals; and the humanity, courage and rigour of her work will continue to sustain those whose job it is to give words to the most speechless and unbearable sorrow.

However, since this book was first published in 1989, and since the second edition in 1995, there have been some remarkable developments in paediatric oncology, and also some important changes in attitudes to how children are treated and cared for within the NHS. Psycho-social provision has improved markedly, if unevenly. There has also been some interesting research into psycho-social care of children with cancer and their families. Notice must also be taken of the revolution in information available to people today, especially to patients themselves and their families.

In this Introduction I will look at developments in policy and practice in paediatric oncology, including some psychotherapy research and literature in the field. This will be balanced with interviews with experienced professionals and clinicians working on the ground, giving voice to their 'tacit knowledge'.

The people I have interviewed are all from University College London Hospital (UCLH) or Great Ormond Street Hospital (GOSH). This is because my own work gives me ease of access to them. However, I believe that the views expressed will be broadly representative of professionals working with children and young people with life-threatening illness in other major institutions in the UK.

Changes in health services and guidelines

When she was writing *Give Sorrow Words*, Dorothy Judd was one of the few child psychotherapists working in hospitals, as compared with the numbers of psychotherapists working in adult services. In September 2004, in its review of the National Service Framework (NSF) for children, the *British Medical Journal* observed, 'Children have been invisible in the NHS.'

That children did emerge from the shadows at that time was to a considerable extent the result of the Kennedy Report of 2001 into children's heart surgery at the Bristol Royal Infirmary, and of the Laming Report into the Victoria Climbié case. The Laming Report and the government initiative of 2003, *Every Child Matters*, emphasised the importance of joined-up care, of communication between the NHS and educational and social services. The NSF likewise focused on a broad, holistic and child-centred approach

to children's health. In particular it recognised that children and adolescents have different needs from adults, and that services need to be designed specifically for them.

The Children's NSF for hospital services in 2004 emphasised that 'attention to the mental health of the child, young person and their family should be an integral part of any children's service and not an afterthought.' This document states that child psychotherapists need to be part of any Child and Adolescent Mental Health Services (CAMHS) team, to address the emotional well-being of their patients.

The National Institute for Health and Clinical Excellence (NICE) *Improving Outcomes Guidelines* (IOG) for children and young people with cancer of 2005 also specified a structured psychosocial assessment through the care pathway, to include ensuring that the family receives the information and practical support they need. This covered employment and education, as well as coping skills for different members of the family, especially siblings, and encouraged support groups for both patients and families. This document recognised that 'psychological services have an important role to play at all stages of the patient pathway, including after completion of treatment and into adult life,' (Section 2, p. 73,) and directed that services should be 'age-appropriate'.

The IOG 2005 manual recognised that parents/carers and professionals had identified a shortage of psychological services; the NICE needs-assessment of the same date observed that psychology services and counselling services for both patients and staff were identified by Primary Treatment Centres as having significant gaps in their provision. This substantial shortage is noted also by a survey of psychosocial support provided by UK paediatric oncology centres (Mitchell *et al.*, 2005) which declares: 'The poorest staff provision was among psychologists, where patient to staff ratios ranged from 132:1 to 1100:1.' Of 22 centres, 9 did not employ a psychologist at all. (It is probably reasonable to assume that by 'psychologists' the authors are referring to mental health professionals in general.)

Although psychological support for children and their families remains patchy, these major initiatives of the early years of this century signalled a shift in the culture of the NHS towards a more child-aware service. Their momentum has been maintained by the National Cancer Peer Review Programme, which takes an annual critical look at cancer treatment provision across the UK, and which in 2008 focussed on cancer in children and young people.

Cancer reform documents

After accidental injury in children, and circulatory disease in adults under 75, cancer is the leading cause of death in the UK (ONS 2009). A survey by the charity Cancer Research UK found that more than a quarter of people said that cancer was what they feared most, over Alzheimer's, heart attacks

and terrorism. Over three-quarters of the sample said that it should be a national health priority.

The first substantial strategy document to improve cancer care, the Calman Hine Cancer Report (CHCR) of 1995, laid out the main areas of concern that would dominate policy for the following 20 years. It called for a 'patient centred' approach, as initiated by the Welsh Office, with effective local care, preventative measures and early screening, and consistency of care for everyone. It emphasised the importance of communication and joined up care, data collection, measuring 'quality of life', and addressing the psychosocial needs of patients at every stage. Perhaps the most significant recommendation of this paper was for patient care to be managed by the multi-disciplinary team (MDT). In their introduction, Calman and Hine specified the need for 'humanity' in the delivery of care.

The NHS Cancer Plan of 2000 noted that whilst certain areas of treatment, including that of children's cancer, were world class, survival rates for adult cancers were generally poor by comparison with the rest of Europe, partly owing to late diagnosis and treatment. Also the quality of treatment throughout the UK was 'patchy', amounting to a 'postcode lottery'. Out of this document emerged a programme of education and raising awareness, in particular to help prevent cancer by supporting changes in lifestyle, and increased screening. A start was made in improving local cancer services, in building cancer networks through a lead cancer clinician in every Primary Care Trust (PCT), and in providing palliative care training to district nurses. Funds were allocated for more specialised trained staff and for research, including the establishment of a National Cancer Research Network, and in particular research into cancer and genetics.

A second strategy document followed in 2007, the Cancer Reform Strategy. In its wake the National Cancer Intelligence Network (NCIN) was launched in 2008 to gather, collate and analyse information on cancer treatment in the UK, including measuring cancer awareness, speed of diagnosis and equality of treatment with regard to sex, ethnicity, region and deprivation. Following this policy document, there commenced, in 2008, amongst other preventative measures, the vaccination of teenagers at 12–13 to prevent cervical cancer.

In 2011, there appeared *Improving Outcomes: a Strategy for Cancer* (IOSC). It noted that most patients were seen by a specialist within two weeks of referral, compared with 4 weeks in 2000, but it acknowledged that if the UK were to meet average European survival rates, 5000 cancer deaths per year would be avoided.

However, a single national cancer registration system, the English National Cancer Online Registration Environment (ENCORE) is in process of development by the NCIN and is due to become operational in 2013. The equivalent of ENCORE in Wales is called SAIL (Secure Anonymised Information Linkage) which is linked to environmental data, showing any possible links between cancer incidence and pollution. SAIL is also linked to

education and housing databases to provide information on children with cancer.

This database will provide a window on differences in care throughout the UK. It will enable the individual patient to chart their own treatment and test results, and see, for example, which hospital is best for their type of cancer. It will also enable researchers, both in the UK and internationally, to develop models of best practice and to identify the most effective treatments. And it will allow clinicians to track the individual patient's pathway through the shared care system, helping them to provide a holding function and to co-ordinate care more effectively (Querido, 2012).

Shared care provision

I asked Dr Sara Stoneham, clinical lead for paediatric oncology at UCLH, and consultant oncologist specialising in tumours of the central nervous system, if she thought much had changed in the field of paediatric oncology since 1995. She offered a nicely gnomic summary of the situation: 'The house is the same, but the way we live in it is different.'

The Cancer Reform Strategy of 2007 called for care to be delivered locally whenever possible, to make it more convenient for patients. Yet, as services have become more specialised, consolidated and centralised, there are fewer centres and more shared care provision. The aim of this has been greater consistency. Care is shared between principal treatment centres, which provide expert management of the patient's particular cancer, including a multi-disciplinary team (MDT), and local hospitals, known as 'shared care centres', and community services, including home visits by nurses (IOG 2005).

The National Cancer Plan of 2000 acknowledged that co-ordination of care at that time was 'poor'. As a result of the 2005 IOG guidelines and the NSF, there are now clear service specifications and more specialist nurses. So professionals all know what the patient should expect to experience as part of their care. This includes the psychological and spiritual aspects.

The administration for cancer has become much more robust, and also much more demanding as a result of these new requirements. Dr Maria Michaelinogli, consultant specialist for paediatric sarcoma (UCLH), elaborates:

'There are clear pathways to adhere to; data has to be collected, consensus for care to be secured. Things have to be more clearly spelt out, more defined. One result is that the teams are larger, and there is a broader skills mix involved in the care. Of course, this means that there is a larger number of people to be trained and supported in an emotionally demanding area.'

But as Oncology Professor (UCLH), Jeremy Whelan, says wryly:

'Nowadays there is much less informal care; and much more formal assessment of needs. Whether people actually get their needs met is a different matter.'

Dr Yen Ching-Chang, (known as Dr Chang), consultant oncologist (GOSH and UCLH), provides just one example of this kind of unintended consequence:

‘Since the *IOG for children and young people with cancer* of 2005, you have to have two consultants practising Radiotherapy together in order to have a cross-over of views with the obvious benefits that come with a second opinion. However, this guideline can make it very hard for a smaller centre, as it means you have to be able to justify twice the expense.’

Dr Mark Gaze, consultant oncologist (GOSH and UCLH), also flags up the need to be alert to the problems that arise with centralised systems:

‘When talking about shared care, there is also the potential for shared neglect. It is much more difficult to keep patients’ records complete.’

I remarked on the difficulty of transition from one care system to another and keeping communication going through this transition. It seemed to me that this was paralleled by a domestic version of the same phenomenon, as the communication between members of a patient’s family is not always reliable.

Chris Henry, Clinical Nurse Specialist (CNS) from the Royal National Orthopaedic Hospital in Stanmore, Middlesex, (who was interviewed by Dorothy Judd in 1995 for this book) develops this theme of communication:

‘When the parents are separated – and this is much more common nowadays compared with the 1980s and ’90s – the dissemination of information is often fragmented. With children of separated parents, unless one parent tells the other what is going on, the other parent will be looking after the child at some disadvantage. Even more confusing is when the separated parents have different opinions about the care that should be given their child. This in turn fragments the support given. Each parent needs information, which they don’t usually get from each other.’

The area of transitions – especially from one hospital to another – is seen as needing work in every area of hospital treatment, but especially in the treatment of children. A new hospital always brings uncertainty and anxiety. However, Chris Henry puts her finger on the potential bottleneck:

‘There are still delays in GPs referring to specialist services. Perhaps there is less listening from GPs, and a reluctance to get x-rays done. This is the biggest downfall: the delay in starting treatment. The NHS has excellent treatment for cancer, and GPs anywhere in the country can refer directly to specialist services. When this referral is received the patient has to be seen in two weeks.’ A BBC health news item on 24 February 2012 supported this observation. It quoted figures from the *Lancet*, which revealed that people over 65 were twice as likely to be sent to a specialist after three hospital visits as was a 16–24 year old. Another telling statistic revealed that in a survey of 360 teenagers and young people diagnosed with cancer 47% had visited their GP four or more times with their symptoms before being referred to a specialist (CRS 2007).

Dr Gaze sees this problem as one of educating people about cancer in childhood, to see that it is different from cancer in adults:

‘A diagnosis of cancer is always shocking and frightening, and delays in diagnosis often arise from prioritising reassurance. Even a specialist will constantly look for more benign causes. The word ‘cancer’ comes with a lot of uncertainty, and it is still a social stigma: cancer equals death in people’s minds. But with childhood cancer there is generally a much better prognosis.’

It should be noted, however, that on average a GP will see 8 or 9 cases of adult cancer a year (CP 2000), but only one young cancer patient in 20 years. Together with the lack of a clear set of symptoms, ‘this poses a significant diagnostic challenge’ (NCIN 2010).

One area where advances in treatment have the potential to change outcomes radically is in Radiotherapy, though the provision of the most advanced therapy is still very localised. Dr Chang explains where this progress is taking us:

‘Radiotherapy is always about providing a cure with minimal damage to healthy tissue from the radiation, so as to reduce late effects. 3D conformal radiotherapy, specifically intensity modulated radiotherapy, provides much more accurate dosages of radiotherapy and is now widely available. On the other hand, for an even more precise form of treatment, ‘Proton beam therapy’, we are still sending children abroad. However, from 2017 the UK is expected to have two Proton centres in operation.

Recent years have seen many other developments in treatment. A greater proportion of patients per capita in the UK are involved in clinical trials than anywhere else in the world, and an increasing number of trials take place every year (CRS 2007). In the last few years, research has gone into genetic variations linked to specific cancers which may be used in the future for much more effective screening and treatment (Cancer Research UK).

Owing to the centralisation of children’s cancer services and close links with the Children’s Cancer and Leukaemia Group, most children have the opportunity to participate in clinical trials. This is not, however, the case for teenagers and young adults; one reason for this may be that they will often be treated by adult services at generally non-specialist cancer centres (NCIN 2010; CRS 2007). Because children’s cancer is so very rare, collaboration nationally and internationally is essential in order to gather information of statistical significance from which meaningful outcomes for patients may be derived.

Inequalities in cancer care

The most problematic of these inequalities is that of relative deprivation. Cancer mortality is 15% higher amongst the non-professional population than the national average (CRS 2007). This is linked to lifestyle, smoking and poor diet. It is also often a matter of late diagnosis, due to lack of awareness of the symptoms of cancer. The same is likely to apply to the children of