THE DYING CHILD

The Management of the Child or Adolescent Who is Dying

Third Printing

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Death – universal, inevitable, and incomprehensible – can never be fully understood by the human mind, yet the death of a child is especially difficult to comprehend and to manage. The death of a child or adolescent seems to be against the laws of nature and man. These young people are just beginning to live when life is taken from them; they are just starting to be actively productive when their activity is stilled forever. Difficulty may arise when trying to deal meaningfully with a dying child or adolescent without adding further to the burden of this young person.

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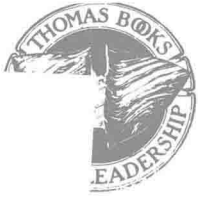

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PREFACE

THIS book is repetitious and incomplete – and it could not be otherwise.

As the growing child learns the meaning of personal death this knowledge stays with him for the rest of his life. He cannot escape what he now understands. What he comprehends as an infant, he has to deal with as a student, a parent and a grandparent. With each stage in his development, he has to adapt to what he has known before and what he now learns. Since this book outlines the preadult phases of human growth, it must show how the knowledge of death is handled at each developmental level and will again have to be coped with at a stage of further growth – repetitious, unavoidable, until death itself gives the final Knowledge.

At this stage of human evolution, the concept of death is still beyond man's total understanding. Poets and preachers, teachers and soldiers, the wise and the foolish – mankind ponders the meaning of death but still does not completely know. This book deals with the practical day-to-day realities of dying and with the management of predictable problems. It cannot answer the unanswerable where even the question is not clear.

The author is especially grateful to Miss Sandra Spillis, who carried the major burden of preparation of this manuscript.

W.M.E.

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Chapter 1

THE CHILD'S UNDERSTANDING OF DEATH

THE child reacts to his own dying with the understanding and the emotional strength of a child. Children respond to their dying with the emotional reactions natural to a child at that age level. They deal with their own approaching death with the childish understanding that they have of the meaning of personal death. The manner in which death is faced, like any other life experience, depends on the emotional capabilities of the person who is living through this happening. The adult grapples with the work of dying with the strength and the capabilities of the mature man or woman. The aged react to death, this final growth task, with the intellectual appreciation and the emotional responses of those who have lived long and experienced much. When a child or adolescent has to live through this unique personal experience of dying, this young person faces a task which he can understand only at the level of childhood or adolescent comprehension and which he can handle only with the personal strengths available to the young child or teenager. The child lives and dies as a child.

The patterns of dying in childhood are changing in response to the advances in medicine and to the changing pace of society. Acute trauma is the most common cause of death in childhood. The young boys, playing with matches, set a fire from which they cannot escape. The adventurous toddler explores his way out the kitchen window and falls to his death. The active, athletic school child runs happily after the ball and into the path of the automobile. The little girl who wants to be like her mommy swallows her mother's pills and poisons herself. In such accidents, a healthy, happy child is abruptly and unexpectedly killed. The child himself has little time to react to the reality of his sudden death. His family is left to face this abrupt, cruel loss without warning or preparation. Happy hopes give way to mourning. The

family needs help and understanding in these unfortunate situations. The child is beyond help.

Extended dying, over months or years, is now much more common in childhood than it was several decades ago. With expert medical and surgical care, sometimes the child may survive the immediate injury of an accident but linger crippled and disfigured to die more gradually over a lengthy period. The congenitally handicapped child, who formerly would have died at birth or in early infancy, now survives with medical care to an older age and succumbs over an extended time. The youngster with a malignant tumor is now kept alive for many more weeks or months by the use of intensive medical palliative procedures and by multiple surgical interventions. The leukemic child continues to live through a lengthy period of transfusions and drug treatments and therefore takes much longer to die. The chronic nephritic adolescent can be kept alive only with the help of repeated renal dialysis procedures. Death is delayed because the teen-ager is attached to this machine at frequent intervals. A kidney transplant may extend the life of this child and thus his process of dying. The child with cystic fibrosis is likely to survive infancy but is still liable to die slowly over months or years after a series of multiple lung infections. Dying in childhood now tends to be more prolonged and much more obvious. With many children, advances in the diagnosis and the treatment of illness have postponed death but at the cost of extending the process of dying (Howard, 1961). When a child dies at home, such a death is liable to be caused by a sudden accident and thus involve only the child and his immediate family. Doctors, nurses, hospitals and treating personnel are much less involved. Children who die more slowly are usually dying in the hospital and frequently are dying painfully. The problem of managing the dying child is most often concerned with the child who is dying slowly, who is in the hospital at least periodically and who is sometimes in pain. Many caring people are involved with such a child who also has a profound effect on those around him, in his family and his community.

As the child is dying the young patient and his family have to face the reality that the medical and surgical procedures carried out on the child frequently map out the manner and the time of

the child's dying (Glaser and Strauss, 1967). The child's death can be programmed and orchestrated by the treatments he receives. That extra transfusion may maintain life just those few hours or days longer so that the leukemic child can whisper a few more sentences – even though the child is exhausted and racked with pain. The additional dialysis procedure may restore fleeting energy to the nephritic child for a few extra days so that he can give that final, feeble smile of recognition. The hypnotic drug may give merciful pain relief to the child dying of a malignancy so that the youngster may sleep longer in the arms of his mother. The same medication may also sedate a child so much that the approach of death is hastened and the final sleep comes sooner.

Though death is one of the more frequent clinical syndromes even in childhood, the management of the dying child is superficially discussed or is completely ignored in most textbooks that deal with children. While there has been a more free discussion of death and dying in recent years, these presentations have been largely focused on the social role of the dying adult in his culture or on the reactions of the bereaved in their family and their society. Frequently the authors are unclear in their presentations as to what exactly they are considering when they write about death. When the limited literature dealing with the dying child and the child's reaction to death is reviewed (see Bibliography), the reader must first clarify to himself what aspect of death is being considered and just how this is being related to children. Thus, certain writers discuss what they state to be the child's reaction to death, when really they are evaluating the child's understanding of death as a general philosophical concept – death as opposed to life, an abstract, impersonal idea, something that happens to other people. Other authors examine the child's response to death but focus only on the reaction of the bereaved child to the death of another person, to the loss of a meaningful relationship. Some writers are really examining the child's management of a fatal illness process when they discuss the child's reaction to death. In the total management of the dying child, all facets – not just one aspect of death and dying – must be considered. The best treatment of the dying youngster can be based only on the knowledge of what his approaching death means

to him and how this young patient can reasonably cope with this very personal reality.

The child's reaction to his own dying and death depends totally on his level of understanding and emotional maturity. He deals with his approaching death as he comprehends this task, and he responds to this challenge with the strength of a child. While the child is growing and maturing, he is developing a changing understanding of the significance of his own death. He deals with this evolving understanding with different intellectual and emotional defenses as he matures. The child's growing level of awareness of the meaning of personal death can be categorized in different growth stages.

TABLE I

DEVELOPMENTAL STAGES IN THE UNDERSTANDING OF PERSONAL DEATH

Aspect of Death to Which Child Responds	*Age When Child Obviously Reacts*
Physiological reaction to dying ("death agony")	Birth
Disease symptoms and treatment procedures	5-6 months
Change in individual Self	4 years
Significance of diagnosis	4-5 years
Significance of prognosis	5-6-7 years
Change in social role and relationships	6-7 years

Physiological Death

With every ounce of strength, the newborn anencephalic child fights for his next breath of life. Even though he lacks a developed brain, this child uses all his energy in his struggle for continued life. The comatose infant, unresponsive to external stimuli, strives with his whole being for still one more inspiration. His inner physiological sensations stimulate his physical organism to fight for survival. Automatically, and without any teaching, the

drowning youngster reaches with every muscle for one more moment of existence. From the beginning of life, each human being has an innate physiological mechanism that reflexly strives to maintain life. This physical reaction is influenced by higher brain centers but appears to be basically a function of more simple reflex processes.

The feelings of inner tension aroused by this primitive but basic physiological struggle for survival seem to be fraught with the very deepest anxiety and appear to provoke the strongest feelings of tension. With good reason, these physically based, nightmarish sensations are often referred to as the "death agony." Each human being intuitively dreads these feelings and strives to avoid, at all costs, these deeply disturbing, physiologically based sensations (Maurer, 1961). The death agony is probably the most unpleasant, intolerable physical sensation to which the human being is subject.

Whenever death is approaching, the death agony grows closer and becomes more intense. As these sensations begin to appear the body reflexly reacts. The individual struggles desperately to avoid these feelings, no matter how old or how young he may be. Often this desperate struggle to escape this death agony and to survive weakens further the dying person and actually hastens his death. The dying child cannot avoid some experience of the death agony. He must live through these very unpleasant sensations whenever he passes from life to death. From his earliest moment of life to as old as he grows, the child is thus faced with this reality of physiological dying.

Disease Symptoms That Result in Death

The child's reaction to his own death and dying is markedly influenced by the actual physical process that produces his death. The child's disease may produce the kind of deformity that frightens other children so that they ridicule or reject the dying child. The youngster may become grotesque because he has a growing tumor of his head or neck. Drugs that maintain the child's life may also cause him to lose his hair or to develop a skin rash. Such disfigurement may bother people so that the child becomes isolated in his own neighborhood and even within his own family.

Parents or teachers may punish the child for symptoms such as vomiting or soiling. Headaches, bleeding, tiredness and irritability may make the child more difficult to tolerate and may also leave him much less able to tolerate the burden of his illness. The child's physical symptoms may thus make him unbearable in his neighborhood, in his school and at home. The child can very sensitively appreciate the effect he is having on other people. He realizes that he is different, deformed or frightening.

Even in early infancy, the young child can sense when he is making people tense or angry. When the deformed child feels that his mother is cringing physically as she holds him, he himself becomes more anxious. He then is more hesitant about reaching out to mother for comfort and consolation. When the little child finds that his cries of pain do not bring relief because people are bothered that he is in pain, he tends to become more hopeless and more withdrawn. His pleas become more plaintive and hopeless and eventually tend to quiet into apathy. The growing child feels good as he feels himself to be appreciated and valued. When the child is sick and dying and appreciates that he disturbs people, he tends to think of himself then as bad. His emotional growth becomes stunted and thus he is less able to deal with the reality of his approaching death. By the time he is only a few months of age, the dying child is responding to the reaction of those around him to his illness. As the child gets older he is increasingly able to respond to himself as he changes with his disease. The little girl may watch with bitterness and disgust as she sees herself slowly wither away in her mirror reflection over the months. The little boy may hate himself for those leukemic purpuric spots he sees. The teen-ager may despise himself for the growing weakness he cannot combat. From the earliest stages of infancy, the child's response to his own dying is influenced greatly by the way the actual disease process affects his self-concept and the way those around him react.

Treatment Procedures

As the child is approaching death he is faced with the reality of unpleasant treatment procedures – the repeated injections, the

bewildering surgical procedures and the excruciating changing of dressings. The very young child cannot understand the therapeutic purpose of these measures. Verbal explanations are beyond his childish comprehension. He knows only the misery he is experiencing, and he responds to this pain. From the early months of life, the young child is conditioned by such frequent, repetitive, painful experiences to respond with fear and anxiety to those people who are supposed to be caring for him but who tend to bring him pain. Treatment personnel – nurses, physicians and aides – are bothered when they find that the child fears them. This reaction may make them so uncomfortable that they tend to keep away from this child, even though he may really need their care and ministrations. Very early the young child is capable of remembering that white coats bring acute pain, and so he may react in panic to all people in white.

These conditioned responses to painful treatment procedures appear in early infancy and will occur in the management of any severely ill child. When the child is dying, these responses may complicate his management.

Change in the Self – Personal Death

Before the developing young child can really understand that his death does mean a change in his own status as an individual, he must first be aware of his personal separateness and his unique indentity. The child has to have a definite, specific concept of himself as an individual being, as a Self, as "I," as "myself" before he can begin to understand that his own death may mean the difference between "me" and "not me."

As soon as the growing infant is responding to people and things around him he is learning that he is a separate being – there is something outside of himself and his Self. When the child begins to reach for a toy, he is starting to learn that he is something separate from other things and other people around him. When he begins to crawl and then to walk on his own, this sense of personal separation and individuation becomes more definite and more specific. The toddler starts to assert his individual opinion and thus to emphasize his difference, his uniqueness and his

separateness. With each surge of negativism, the maturing young child is asserting himself – and showing those around him, and himself also, that he is indeed a Self. He is a person. The child begins to talk to himself and consider himself as "I." With each self-assertion, this "I" in "I want" or "I will" has more solid, definite personal meaning to the youngster. By the time that he is three or four years of age, the child is understanding that he is indeed a separate physical and emotional entity. While he is achieving this definite understanding that he is a "me," he is, at the very same time, beginning to appreciate that somehow there can also be a "not me." When a maturing child grasps, even faintly, the reality of his existence as a unique person, he cannot then avoid the question of where he came from and whence he is going.

This awareness of a possible "not me" is extremely disturbing, not only to the young child, but to every person from that age onward. The appreciation that somehow a time could come when we would cease to be is deeply disturbing to each one of us. This is an unbearable concept and an intolerable idea. The individual really cannot fully grasp the significance that somehow he might cease to exist – this thought is too frightening and too overwhelming. While the physiological death agony is the most unpleasant physical sensation that man has to face, undoubtedly the concept that an individual person might cease to be faces each human being with the most horrible and awe inspiring psychological feelings that a person can have about himself and his existence. This threat of non-being is basically inconceivable and unthinkable to the ordinary, average person. In truth, probably no human being can really face or grasp a full understanding and appreciation of "not being." Normal people do not have adequate emotional defenses to deal with such profoundly threatening self-concepts (Cappon, 1959; Stokes, 1960). All people, no matter what age they may be, automatically deal with these dreaded and dreadful emotions by *denial.* The question and the meaning of a possible "not me" state – the concept that a being may completely cease to be – is automatically covered over and hidden emotionally because such feelings are too painful and disruptive. Though these ideas are kept out of awareness, the anxieties they

arouse are handled by the normal age-appropriate defenses. The young adult blocks out any possibility of personal death and furiously attacks anyone or anything that raises the possibility of dying for anyone. The middle-aged adult shuts out the meaning and the possibility of personal dying and handles the underlying tensions by making the concept of death an interesting intellectual exercise – as in writing a book. As soon as the young child begins to appreciate that he is a separate being, he starts to grasp dimly that this individuality could cease to be separate and individual – and he begins to blot out these understandings and these feelings as soon as they are felt. Undoubtedly the young infant who faintly appreciates that there is something outside of his self and thus he has a self, is also dealing with the unsettling ideal of nonself, even at that very early age. The child handles the primitive anxiety aroused by this fear of not being in the fashion appropriate to his maturation level. He has no option but to suppress these ideas of "not me" because the feelings aroused by these concepts would cause such intense personal anxiety that he could not continue to function if he allowed himself to feel these emotions.

While these concepts of identity and loss of identity are evolving gradually, the child is four, five or six years of age before he has a definite stable concept of himself. It is at about this age that the child obviously begins to deal with his feelings about being and not being. Normally and naturally, these disturbing feelings are covered over and blocked away by denial and repression. Sometimes the preschool child cannot totally repress these emotions. This is the age when nightmares are most commonly seen in normal children. These horrible sensations of some dreadful inability to cope, these feelings of being overwhelmed and annihilated, these realizations that "me" could be swept into "not me," are outward signs that the child has matured to the level where he appreciates that he is a separate individual and that now he is striving to block out his parallel appreciation that he could cease to exist. With the greater emotional strength that comes with growth, the child gradually becomes more able to keep these disturbing feelings and fears well controlled and further from awareness.

The four-year-old child – sometimes a three-year-old and