

# ARE THERE SHEEP IN HEAVEN?

## THE SOCIAL WORKER, THE DYING CHILD & HIS FAMILY

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**Evasion and playing a 'let's pretend' game do not serve to protect the child from the truth of his fatal illness but instead leave him in isolation with his fears and anxieties.**

### INTRODUCTION:

There is no more emotionally searing situation for those in the healing and helping professions than a diagnosis of fatal illness in the child, with death the inevitable outcome. Medical and nursing staffs of hospitals are deeply committed to preserving life for the child, and with advances in medical science, every effort is made to ward off the threatening illness, and achieve increased recession, in the continuing hope that some cure may be found. In this battle for life, the emotional needs of the child himself too often have been denied, overlooked or not considered as part of the total caring programme. It is only more recently that the response and adaptation of the child himself to a life threatening illness are being recognised as requiring the same consideration and skill which is given to the management of the disease.

To-day the denial of death and dying is a prominent feature of our society, and can be said to have replaced the taboos that formerly surrounded sex.<sup>1</sup> We all require to face our personal fears and conflicts with regard to the meaning of death if we are to be able to respond with the sensitive understanding that this human experience demands.

Psychiatrists have brought attention to the needs of most dying adults to express their thoughts, feelings and fears and to the deprivation the living can cause by raising psychological barriers which shut them out.<sup>2</sup> What then of children who are facing the threat of death? Do they also have fears and needs which we effectively block? Much has been written on the giving of help to parents of fatally ill children,<sup>3</sup> and more recently, research studies have emerged which focus on the child per se. These have often been carried out retrospectively with a reliance on broad observations rather than on direct intimate in-

teraction with the child. In social work literature the works of Vernick and Karon<sup>4</sup>, Morse<sup>5</sup>, being notable exceptions, there is little material which deals with the giving of direct service to the child and the development of an interventive approach. This leads one to consider to what extent denial and evasion is being perpetrated by social workers in protection of self, and in the form of concern for the child, when in reality the child is not being protected from the truth, but is left alone with it instead.

### Significant role

The social worker in hospital, as a member of the professional team, has a significant role in helping the family of the fatally ill child, but the giving of direct service to the child himself is less well acknowledged or practised. If total caring, in this critical human situation, is to be achieved we must not only reach out to the parents, but also respond to the child. Only by understanding the reactions of both parents and child can one hope to be able to give the type of help which is required and of which use can be made.

### Diagnosis

Once a diagnosis of fatal illness is made, or strongly suspected, the child will require admission or a series of admissions to hospital over time, although every attempt is made to keep the child in his home with his family, whenever possible. At this early stage it is crucial to reach out to the parents and get to know the child. Tangible needs can be identified, but it is the understanding of the coping characteristics of the parents and the tasks related to the special sequential phases of the illness which will determine the ongoing help that is extended throughout and beyond all stages of the illness.

### Telling the Parents

In all the crises which the individual may encounter in his life



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cycle, there is probably no more profound grief experience than the threatened loss of a child. To-day in Western societies malnutrition and the infectious diseases are no longer major threats, so we do not expect children to become seriously ill, far less die. When this does occur parents experience a degree of shock which plunges them into crisis and despair.

Parents have to be told of the diagnosis of a fatal illness and although in retrospect, some admit they had already suspected it, nevertheless, the actual giving of the diagnosis creates the same stunning and shock experienced by parents with no prior suspicions. It is the physician who has the task of telling. There is no good way of giving bad news for the dying will resound in the telling. The manner in which the diagnosis is given can go some way towards ameliorating the acuteness of the parents reactions, and their subsequent adjustment to the catastrophic situation.<sup>6</sup> Truthfulness and honesty are important principles which must be upheld, but not in a manner

which conveys despair and hopelessness. Some parents seem to need to be given all available information at once, gaining some relief from knowing that there can be nothing worse to come, while others may only be able to tolerate a more gradual presentation of the situation. This requires an assessment of the parents which guides the initial approach so that it is understanding to them rather than overwhelming. Whether or not all the facts are given at the initial telling, parents do require to return and hear again. The social worker may facilitate this by first alerting the medical staff, then by listening to and talking with the grief stricken parents. Listening is more important than talking.

#### **The Parents and the Family**

The response to situations of acute grief and the process of anticipatory mourning, described in the seminal work of Lindemann,<sup>7</sup> have been explicated in studies of parents of children with leukaemia and cancer, which to-day constitute the major life threatening illnesses in a child.

The characteristic components of anticipatory grief, denial, anger, guilt, depression, the effective states which emerge, and the common coping mechanisms are now well recognised, but as Friedman<sup>8</sup> observes, each parent of a fatally ill child reacts to the tragedy in a singular manner, in keeping with his personality structure, past experience of loss and "the individual meaning and specific circumstances associated with the loss". It is only when the full implications of the illness for the individual parents are understood, that the Social Worker can enable him to adjust and give to the caring of the child.

On hearing the diagnosis the process of anticipatory mourning inevitably begins. Denial occurs — "No, that's not true! Not my child!" In my experience, denial and the concomitant urge to seek further advice in the hope of a more

acceptable diagnosis, has been a temporary coping mechanism. Binger,<sup>9</sup> in his study of parents of leukaemic children, reported no persistent denial of the diagnosis. Knapp & Hansen<sup>10</sup> observed that denial tended to be more often used and for longer periods by fathers. The fathers who appear to evade the situation by massive denial, which may include aggressive hostility, need to be helped to look at their painful feelings and to recognise that expression of grief and anguish are not only acceptable, but can help other family members to share their grief and to reach effective means of coping with the tragic event.

#### **Anger**

When the diagnosis is assimilated, and no longer denied, feelings of anger and resentment may follow. Irrational anger may be directed at one and all — the hospital staff, God, their spouse, or other family members. Counselling that enables parents to ventilate their feelings is beneficial, and a growing recognition of the displacement of hostility can free them to make use of help and to select a meaningful activity for themselves. Participation in the care of the child in hospital can assuage hostility and the feelings of anxiety which stem from concern that they are not going to be able to cope.

When a child is in jeopardy from illness parents do go through an agonising process of self reproach and guilt. They may express sins of omission, for example, having retorted with anger to the child who complained he was tired, when accused of neglecting his homework. Parents can be reassured that nothing they did, or did not do, attributed to development of the illness.

Deeper feelings of guilt, more difficult to assuage, result from some initial rejection of the child — the mother who tried and failed to procure an abortion, or who was initially extremely disappointed that

the child was not the son or daughter she had desired.

Of the many fears and anxieties which parents suffer there is often the 'silent fear' of how the child will die.<sup>11</sup> Sometimes the fantasy of the parents is greater than the hard reality, and to know what to expect, particularly that pain can be controlled, can be a major relief.

### **Siblings**

In reaching out to the parents other family members must also be included; siblings have their own personal anxieties and fears about death and dying, and the non-overt reaction of younger children can readily be misinterpreted by adults, as that of not understanding. Binger<sup>12</sup> found that in approximately half of the families in his study one or more siblings showed significant behaviour patterns, ranging from severe enuresis to school phobia, which revealed difficulty in coping. Kaplan<sup>13</sup> emphasises that coping with the stress imposed by a severe illness is more than an individual process. The family has a crucial role in the giving of mutual support and, in developing measures of adjustment, which can make the difference between effective and ineffective adaptation. When the family can be brought together in sharing their grief a critical affective experience can be achieved for all.

### **Lack of Support**

A surprising lack of emotional support from the extended family, particularly the maternal grandmother, was observed by Bozman et al.<sup>14</sup> It was suggested that this may reflect a reactivation of earlier conflicts between the mother and grandmother. I fully concur with Friedman's<sup>15</sup> suggestion that an alternative reason may be found in the strong denial which grandmothers tend to present, not only when a fatal illness is first diagnosed, but also during the periods of recession. Mothers who have come to accept the reality of their child's illness,

find that only denial is available at a time when they are struggling to adjust themselves and have need of support. Grandmothers are most often very emotionally involved in the threatening situation, but feel apart and at some distance. An opportunity to be included in the caring programme can have far reaching effects on all family members.

There is no way to eliminate the stress inherent in this period; the help that is afforded seeks to enable parents to integrate the experience without suffering lasting damage or disorganisation.

### **The Child in Hospital**

Admission to hospital is a disruptive experience in a child's life, even in a non-emergency situation when there has been time to prepare him for the event.

The psycho social tasks which are appropriate for the developmental age become deflected as the child struggles to cope with the demands of a new environment and an unknown situation. Many studies have drawn attention to the traumatic effects of separating young children from their mothers since Bowlby's<sup>16</sup> work was first published. Further evidence has been added and refined in support of these propositions, with perhaps the most dramatic evidence being presented by Robertson<sup>17</sup> in his series of films of children in hospital. In the light of this psychological evidence, the welfare of children in hospital became a subject for enquiry, leading to the recommendations of unrestricted visiting and 'mother-in' units.<sup>18</sup> In support of unrestricted visiting, Anna Freud was to write "The child lives from day to day. He depends on the evidence of his senses, and his understanding of the situation is fragmented at best. A mother who remains absent is a figure of whom he is incapable of conceiving".<sup>19</sup>

Separation anxiety is commonly observed in hospitalised children,

but two important questions remain unanswered. Why are some children less seriously disturbed than others by the separation experience? Who are the vulnerable children? In seeking answers to these questions Stacey,<sup>20</sup> et al used a systems approach which related the child's individual development to the social milieu in which he has been reared. Their findings lead one to consider to what extent exposure to minor doses of stressful life experiences can provide some protection against future painful situations.

Hospitalisation when superimposed by a threatening illness with fear provoking treatment procedures can further increase anxiety. The child is also often very perceptive and readily senses the stress and anguish of his parents as well as reading the overt signs in facial expression and tone of voice. However it is expressed, anxiety reveals the lack of adjustment and adaptation to the illness and hospitalisation. The prime sources of the anxiety may be difficult to isolate; many types of anxiety may be operating at one time or another.

Rank regarded separation fear as the primal human problem which he equated with fear of death, while Freud in his analysis of intensive fear revealed castration anxiety as an underlying element. In an attempt to understand the innermost feelings of the child in a hazardous situation the separation experience may be compounded when the child is left in isolation with his fears and fantasies. The medical treatment when it includes painful and fear provoking procedures such as bone marrow aspiration, blood transfusion biopsy, may provoke and reveal castration anxiety. The seven year old who created havoc as he resisted attempts to have a blood sample taken was later seen, at first tentatively and then vigorously, jabbing a hypodermic needle into the arm of a placid house surgeon, who had recognised the source of the child's anxiety.



### **The Child's Perception of Death**

The ways in which children discover and assimilate the concept of death have been empirically investigated by Anthony.<sup>21</sup> Nagy<sup>22</sup> in her studies of children in Budapest found evidence to support the idea that the child's perception of death is dependent on his stage of development. She reports that children between 3 and 5 years of age deny death as final. A beginning acceptance that a person, or a pet, may not return was evident in the five to nine age group, although death was not accepted as a universal event, nor did the child see himself as ultimately dying. Only after the age of nine does the child understand death as final and universal. This was replicated in the study of Childers and Wimmer<sup>23</sup> who also conclude that the cognitive period for understanding death as universal was established after 9 years of age. These studies, however, have been of the child in his normal living environment; neither separated from his home and family, nor suffering the trauma of serious illness.

### **Death Anxiety in the Child**

To what extent does the child hospitalised with a fatal illness have awareness of his situation and comprehend its significance? At what age are children capable of experiencing death anxiety, and how is this anxiety handled and expressed?

In the descriptive and retrospective studies which have been carried out on the child with a life threatening illness there is general agreement that the child through the age of five years knows that something is seriously wrong.<sup>24</sup>

Morrissey,<sup>25</sup> in his descriptive study of leukaemic children found that "a child's verbalisation and behaviour tended to co-relate with the prognosis", and that death anxiety was not uncommon. Of the children studied he quantified that 30% were showing emotional distress related to fears of dying, and this was also observed in one very young child.

A higher incidence of death anxiety was reported by Vernick & Karon<sup>26</sup> who also postulated that all children with a fatal illness experienced such an anxiety. The relatively low rate given by Morrissey may be attributed to the reliance on staff observation and not on direct intimate interaction with the children. Also in contrast to Vernick's study, where the age range of the children was 9-20 years, more than half of the children were under six years of age. It can be questioned whether these findings are conclusive on the grounds that they relate to a research study of children accommodated in a special ward or unit set aside for fatally ill children, which differs from the climate of a children's ward in a general paediatric hospital. Although one can give some credence to this viewpoint I would claim that this does not detract in any way from the need to be aware of the phenomenon, and above all not to retreat into a protective attitude which can leave the child isolated in his fear, and without help and support from those who are caring for him.

### **Opposing viewpoints**

Opposing viewpoints<sup>27</sup> may be held as to whether a child should be told of his life threatening illness, or shielded from the truth as much as possible. Much will depend on the beliefs and attitudes of the hospital staff and of the parents, who often express anxiety as to what to say should the child ask if he is going to die. The older child may be distressingly aware that his expression of anxiety disturbs his parents, and when they respond by telling him not to worry he may resort to protecting his parents and repress the expression of his own fears and anxiety.

The basic issue, however, is not whether to talk to the child about his innermost feelings, or not, but how to talk to him.<sup>28</sup> There is essentially the need to listen, to pick up

cues, interpret what may only be said indirectly and respond in the way which is consistent with the child's age and needs.

"Jamie was nine years old and suffered from leukaemia. He was re-admitted from his island community to a hospital on the mainland. A quiet gentle child, he was responsive to the hospital staff and accepting of his mother's temporary delay in coming to be with him in hospital. His condition, despite further chemotherapy, was deteriorating and signs of depression and withdrawal were observed. His eyes would light up, however, when one spoke of things and places familiar to him, and he enjoyed playing with the picture postcards and photographs of his island home. One day, when talking and playing with him, he told how he helped to look after the sheep, and then asked 'Are there sheep in heaven?' I said that I honestly did not know, but went on to say that just as he cared for his father's sheep at home so we were caring for him now, and that there was always someone to care. We talked further about this, then Jamie drowsily smiled and said 'I am sure there are sheep in heaven', and fell asleep. When his mother arrived, she was told of what had occurred, and was supported in giving Jamie a sense of security and continuation of care. After his death and through her grief she said 'But he was content in his passing over'."

### **In whom does the child confide?**

What determines to whom the child will express his concern about dying? Kikuche<sup>29</sup> suggests that the child may choose the person he knows or likes best, or with whom he is most familiar. She further suggests however, that the most important factor is the person who recognises his indirect questions about dying for what they are, and

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who replies honestly and clearly, thus enabling him to communicate more directly when he is ready.

### **Developing a total care programme**

In order to achieve a total caring situation for the fatally ill child and his family, the social system of the hospital must undergo change. A major change in the social structure occurs when mothers are admitted with their children, participate in their care and when unrestricted visiting is available and encouraged. The nursing staff, for example, undergo role change as some of the routine care of the child is handed over to the mother and in its place a supporting role has to be developed which enables the mother to carry out some of the routine child caring tasks. To meet the emotional needs and problems aroused by the illness of the child the multi-disciplinary team of physician, nurse, social worker, physiotherapist and others, have first to consider the ultimate purpose of medical care, not just as the prolongation of life, but as the enhancement of the quality of life for as long as it may last. Once this goal has been clarified and accepted by all team members the means of achieving it can be developed with the same attention and skill as is given to the physical management of the disease. As the concept of total care is thoughtfully put into practice, the various disciplines learn more surely the contribution that each team member is making and how these are being welded together to achieve the stated goal.

In planning a programme, and the development of an approach, certain important elements can be identified which also bring into focus the various roles of the social worker, and the social work skills which are particularly relevant.

**1) The need for a team approach** where members not only interact in sharing their understanding of the child and his needs, but also share the emotional stress which may be experienced.

**2) The need to develop a**

**warm 'safe environment'** for the child where those who are caring for him can sensitively perceive and deal with his innermost concerns or, as Vernick & Karon<sup>30</sup> put it, "in which the child can feel perfectly safe to ask any question and be confident of getting an honest answer". The younger child tends to express his anxieties indirectly, or through the use of symbolism. Between the ages of five and nine years the child tends to engage in fantasies about death, and may see it as a removal to another physical state, or the personification of death as a "frightening bogymen who takes children away" Burton<sup>31</sup>. These fantasies may be more frightening and overwhelming than anything else the child is experiencing, but they may not be easily communicated as they are perceived as too horrific to talk about. The symptoms of the anxiety become manifest in the depression, apathy or even hostility which can be observed. It is only rarely that the older child has the confidence to free himself from the learned taboo associated with dying, and it is thought that this will only happen when he finds someone with whom he can then talk honestly about his worries and fears.

**3) The provision of services and the development of a therapeutic approach** which enables the child to manage the frightening experiences and feelings associated with his illness. Vernick & Karon<sup>32</sup> describe a programme devised for leukaemic children in hospital which was based on the provision of a 'safe environment' and supported by some adaptation of the 'life space interview' as<sup>33</sup> a method of intervention.

The 'life space interview' first developed by Redl and Wieneman<sup>34</sup> is based on the theory that the problems children experienced in their day to day living have significant therapeutic possibilities when they are dealt with immediately, and particularly when one has been present at the time of

the incident. This method of intervention has twin goals, 'clinical exploitation' and 'emotional first aid', which are particularly appropriate for helping the child with a life threatening illness. The former allows the social worker to utilise an appropriate incident the child has experienced to help him master any problem of adjustment. The latter requires on the spot support being given to enable the child to cope with situations that are causing high anxiety or distress.

**4) The enhancement of the life of the Child and his Family for as long as they may have together.** A feature of many life threatening illnesses in the child are the periods of remission which can be achieved and which allow the child's return home to his family. During these periods children, with their capacity for resurgence, often feel and look well, and are able to engage in the activities which they previously enjoyed. Maintaining the quality of life, and enabling the child and his family to live as fully as possible is the prime goal in the securing of any remission in the illness. Parents, understandably, often express concern about how to care for the child in his home environment, and it is important that advice and help is given and forms part of the programme of total care. The use of groups for parents, whose children are approaching a remission period has been found useful in providing an opportunity for parents to express their fears and anxieties with others who fully understand and share their problem. Knapp<sup>35</sup>. Parents are often questioning about how to deal with the child when he misbehaves, feeling that they could never bring themselves to punish or reprimand the child. An opportunity to think this through brings recognition of the need for children to have limits set and that in the interest of the child and his siblings a normal pattern of living must be established, where mothering does not give way to smothering.

Despite a diagnosis of fatal illness, hope should never be abandoned, for it is only with some hope that the parents can carry on, especially when the illness is a prolonged one interspersed with periods of remission. The validity of maintaining hope has also been dramatically revealed in the recent breakthrough in acute leukaemia, where periods of recession of up to four years have occurred. Not so long ago the expectation of life for the leukaemic child was often a bare six months, but a recent hospital<sup>36</sup> report has shown that through the use of complex chemotherapeutic procedures the survival rate of children has markedly increased. Prior to 1970 out of 47 children treated, 32 were alive and well four years later. As longer periods of recession become available parents require to adapt to this situation of extended hope and some may deny that any threat still exists. If denial is used extensively there may be a failure to bring the child back for medical appointments. The social worker will be able to anticipate the possibility of this happening, and

help the parents to meet these important requirements.

**5) The need to consider what the impending death of a child will mean to the other children in the ward.** When a child dies attention must be given to the other children in the ward. They are unlikely to remain unaware of what has happened, but may or may not ask directly. Evasion and prevarication can provoke anxiety for any sick child who may fear that something terrible is going to happen to him. The staff confronted by a young patient has to be prepared to tell, and to honestly answer questions which are asked, together with helping him to cope with his own feelings and fantasies.

**Conclusion:**

Social workers are committed, not only to helping people with their problems of living, but also with their problems of death and dying. The theme of death is to be considered not only as an abstract and philosophical phenomenon, but in terms of one's own feelings and the meaning it has for the individual who is dying, if one is to engage in

appropriate role behaviour and effectively respond to this human experience.

Eissler<sup>37</sup> refers poignantly to the "stigma of being selected for death, while life continues outside". The social worker may feel acutely the 'stigma' of being in a state of health when a child is dying. Meeting the emotional needs of the child and giving support and help to the parents and family throughout and beyond this pain wracked experience are demanding tasks, but compensation can be gained. Through the provision of comprehensive care the emotional needs of the child are given attention and some level of emotional security found for the child to ward off the anguish of isolation. As the parents are helped to cope with their distress and despair the mastery achieved will bring positive effects not only to the present, but to their future well being. Any programme of total care for the dying child and his family must have goals clearly delineated, and accepted by the professional team, together with a clearly evolved method of achieving them. ●

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