

Implications of Families'  
Struggles with Childhood Cancer

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IMPLICATIONS OF FAMILIES' STRUGGLES WITH CHILDHOOD CANCER

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This paper is a preprint of the final chapter of a book-length manuscript Chesler & Barbarin have prepared. The entire volume, reporting many aspects of their research with families of children with cancer, will be available in late 1986. Minna Nathanson's editorial assistance is greatly appreciated.

## IMPLICATIONS OF FAMILIES' STRUGGLES WITH CHILDHOOD CANCER

In this chapter we integrate families' reports of stress, coping and social support. The analysis of research results is combined with the wisdom parents have accumulated as a result of their experience with cancer. We also discuss action parents, medical staffs, family members, and friends can take to deal with the psychosocial impact of childhood cancer.

### The Linkages of Stress, Coping, and Social Support

Throughout this book we address the stresses faced by families of children with cancer, the many ways in which parents, youngsters, and other family members cope with the illness and its psychosocial impact, and the varieties of social support family members reach out for and utilize. Figure 12.1 provides an overview of the ways in which different kinds of stress, coping strategies, and sources of social support may be linked.

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Insert Figure 12.1 about here

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Intellectual stresses stem from large amounts of new and technical information, confusion and lack of clear criteria on which to make sound judgements. These stresses are especially severe in the early weeks and months of a child's illness and tend to abate somewhat as parents find effective ways to gather information. Some parents actively read about the illness and its treatments, both from highly technical medical books and articles and from publications oriented to laypersons. Medical staff,

Figure 12.1  
Stresses, Coping Strategies, and Social Support  
For Parents of Children With Cancer

**Categories of Stress  
(Chapters 2, 3, 4)**

Intellectual

Confusion  
Ignorance of medical terms  
Ignorance about where things are  
in the hospital  
Ignorance about who the  
physicians are  
Lack of clarity about how to  
explain the illness to others,

Instrumental

Disorder and chaos at home  
Financial pressures  
Lack of time and transportation  
to the hospital  
Need to monitor treatments

Interpersonal

Needs of other family members  
Friends' needs and reactions  
Relations with the medical staff  
Behaving in public as the parent  
of an ill child

Individual and Family Coping Strategies  
(Chapters 5, 6, 7, 8)

Seek information about illness,  
treatment, prognoses  
Seek information about hospital  
Get help in understanding jargon  
Share confusion with others and  
learn together  
Have open communication with the ill child

Seek information about finances and  
insurance coverage  
Get help at home and at work change  
work schedule  
Divide labor and solve household problems  
cooperatively  
Get information about treatments and symptoms  
Care for the ill child  
Find new financial resources

Get help from spouse, close friend, and  
family  
Be optimistic with others, especially  
medical staff  
Get help from medical staff  
Deny relationship problems  
Make time to be close with spouse and  
siblings  
Find people who care who will listen,  
who will "be there"  
Coordinate coping strategies with  
other family members

Sources of Social Support  
(Chapters 9, 10, 11)

Medical staff  
Social workers  
Scientists and researchers  
Parent group education programs

Social workers  
Family members  
Friends  
Neighbors/co-workers  
Community agencies  
Parent group programs

Family members  
close friends  
Medical and social  
work staff  
Other parents of ill  
children  
Religious congregation

Emotional

Shock

Lack of sleep and nutrition  
Feelings of defeat, anger,  
fear, powerlessness  
Physical or psychosomatic  
reactions

Deny personal problems...deny feelings  
Get physical and psychological  
"checkup"  
Accept the reality of the illness  
Maintain hope, optimism, and emotional  
balance  
Express feelings of fear, anger, joy  
Participate in care of the child  
Live one day at a time  
Get close to the ill child  
Rely on spouse...or distance from spouse  
Eat right, sleep nights, meditate, and  
exercise

Close friends  
Spouse  
Social worker/  
psychologist  
Other parents of ill  
children  
Clergy, fellow congregants

Existential

Confusion about "why this  
happened to me"  
Uncertainty about the future  
Uncertainty about God and fate  
and a "just world"

Trust in God...or re-examine faith  
Seek information about illness cause  
Pray together with family members  
Share the struggle with others

Clergy people  
Fellow Congregants  
Philosophers

especially junior physicians, nurses, and medical social workers are important sources of this kind of support.

Instrumental stresses come from practical challenges and pressures, including the need to monitor medical treatments, balance household and child care tasks, and maintain financial security. Coping with these practical stresses also requires dealing with the intricacies of hospital billing and insurance repayment processes, appealing to public or private charities, rearranging traditional roles and chores in the family, and finding low-cost temporary housing, perhaps at a Ronald McDonald House or its equivalent. Families also must become competent medical care providers for their child, providing treatment, reporting new symptoms, and arranging check-ups. The support of others outside the immediate family, in the form of extra labor for household maintenance, childcare and transportation is often invaluable, as is assistance from staff members and representatives of school or community agencies.

Interpersonal stresses generally stem from the reactions of other persons in the family's social environment. Responding to these others' ongoing needs, as well as to the way the crisis of cancer affects them personally, is a constant pressure. In addition to pressures from previously established relationships, parents must deal with the medical staff; strangers who have life and death power over the ill child. Some parents cope with interpersonal stress by maintaining a positive and optimistic stance on the child's current and future status. In the press of a crisis, denial may be quite effective; however, there also is a potential "pile-up" effect, whereby multiple interpersonal demands accumulate and have to be dealt with later. Just as every close relationship is potentially stressful,

every interpersonal stressor is a potential source of help and support. The most important helpers appear to be spouses, close friends, and medical staff members, although other family members, other parents of ill children, neighbors and members of social or religious organizations may also be important. It is especially important for husbands and wives to make time together to be nurturant, caring, and supportive of one another, and for parents to make time to care for their other children. Some supporters are helpful because they just listen or "are there;" others penetrate deeply into parents' hearts and minds, providing deep affection and affirmation.

Emotional stresses begin with the sense of shock, anxiety and numbing terror, accompanying the initial diagnosis. Over time these feelings fade somewhat, but parents indicate that anxiety, anger, and a sense of powerlessness often stay with them. Emotional stresses may create other stresses, as constant tiredness and irritability lead to new or escalated interpersonal problems with friends, family members, or medical staffs. Some parents cope with these emotional stresses of childhood cancer by not feeling, or by denying strong feelings. Others do their best to be optimistic and hopeful about their child's progress and future. Maintaining emotional balance and avoiding the roller coaster ride of great hope and great depression is achieved by parents who take "one day at a time." By living in the present, focusing on immediate tasks, they avoid extreme fears and fantasies. The experience of "feeling like I am going crazy" is quite common for many parents; friends, other parents, or expert professionals sometimes provide a fresh perspective, or even a formal physical or psychological checkup. Other parents of children with cancer may be in a good position to be sensitive and compassionate helpers, since they

themselves share much of the painful and stressful reality parents experience. Some parents also find it useful to seek help from staff members such as social workers and psychologists.

Existential stresses include threats to parents' basic belief systems and to their established ways of dealing with the world. Coping with such uncertainty and confusion often triggers a re-examination of prior religious beliefs, usually (but not always) resulting in a greater reliance on faith and prayer. Even if religion itself is not a coping aid, an exploration of core questions of identity and social community are typical. The crisis leads some parents to reevaluate the direction and meaning of their lives, and to rethink their work and career goals and priorities, especially those that limit time and energy available for children and family members. Parents also seek factual information about the nature of the illness and its probable consequences to help resolve some of these uncertainties. Social support sources particularly relevant to coping with these existential stresses include members of the clergy.

#### Themes in the Reports of Parents and Children

Throughout parents' discussions of their struggles with stress, coping, and social support, several major themes emerge. These themes constitute the collective wisdom of these families and embody their goals and survival techniques.

Seeking normalcy. The data on stress indicate that the diagnosis and treatment of childhood cancer threatens everyone's ability to continue with a life as it existed prior to the illness. As parents seek to normalize their family life while dealing with the illness, they proceed down one of two



paths: maintaining the family in a pre-illness situation (accepting that prior state as normal), or adjusting their lives to the new context of illness (redefining normalcy to include the illness situation). Few parents are ever able to go back to life as it was before the illness, but most do try to balance these two paths by finding new ways to do old things: sharing intimate feelings with their spouses, nurturing and supporting their other children, rearing the ill child in consistent ways, and encouraging the child to return to an active social and school life.

Youngsters want to be treated like the same person they were before the illness and not solely like a patient or a "person with cancer." However, they also know they now are different in important ways. Thus, for many parents and children seeking a normal life normalization does not necessarily mean a life like everyone else. Rather, it means a life that is not totally focussed on the illness, a life that deals with issues (intimacy, childrearing, schooling) that other families also deal with, and a life that supports positive relationships within the family and between the family and the external environment.

The issue of normalcy, of returning to the past versus growing toward the future, also arises when parents are asked, "How are you doing?" Most parents respond that they are coping quite well; indeed, many parents report that their personal wisdom and skills, as well as family relations, have been strengthened and deepened as a result of their experience with childhood cancer. Many youngsters with cancer, moreover, feel more mature and wiser than their physically healthy peers, and this judgement is echoed by their parents. Thus, many people manage not merely to survive the challenge of childhood cancer, but to grow from it; they alter the threat into a challenge

or growth opportunity. All life is a growth process, of course, and to cease growth leads inevitably to death - death of the spirit if not the body.

Being normal never means being the same as others, nor does it mean being the same as before.

Most parental reports, and most recent research, indicate that these parents and children do live relatively normal, although somewhat different, lives. Most importantly, parents and children dealing with childhood cancer do not necessarily <sup>be</sup> come psychologically abnormal, nor are families necessarily split or destroyed. Most recent research, and certainly the evidence from this study, reveals that although the stresses of childhood cancer are painful and create problems for all involved, neither children surviving this illness, nor their parents or families, are emotionally crippled or candidates for psychological disaster.

Taking one day at a time. Many parents discuss the importance of not planning too far ahead when dealing with the unknown and unknowable situation of childhood cancer. They argue that they have to take one day at a time and stay anchored in the present. Great hopes for the future, and/or great pessimism, both get in the way of the many daily tasks required to take care of the child, maintain the family and go on with employment. Moreover, many parents suggest, there are many joys to be gained from present interactions with their ill child, regardless of the long-term future.

The 50% five-year survival rate for children with cancer also means that 50% of those youngsters diagnosed with cancer will not survive five years after diagnosis. And some of the survivors beyond the fifth year will relapse and die as well. Even those youngsters who are long-term survivors, who have been off all treatment for five years and may be considered cured,

have a significant potential for late effects of treatment, and for contracting a second cancer. Psychological and practical problems also may arise later in life, as an <sup>adult</sup> ~~adult~~ who had cancer <sup>as a child</sup> seeks employment, applies for insurance, marries, wishes to have children, experiences marital stress, contracts an illness reminiscent of the cancer, etc.

The continuing impact of the childhood cancer experience is also discussed by parents of children who have died from cancer. Their child's death is not the end of their struggle. Many issues continue to be dealt with, such as managing and maintaining memories, rebuilding a family that now has one less member, and living in the present rather than the past. As parents think about the future without their loved child, they often can not imagine "going on." As they live this future in the present, most do go on.

Taking one day at a time does not mean ignoring the future, but it does mean focussing upon the feelings and issues at hand, enjoying one's child and one's life at the moment, and creating opportunities for pleasure and growth in the present. Many families of children with cancer take vacations together as soon as their child is healthy enough to travel, instead of waiting until their years of treatment are over; they insist on good behavior from their ill child right now, rather than assuming that after the illness is over they will reinstitute good childrearing practices; and they try to make each day a good day, rather than assuming that good days will only be possible after their child has been cured.

Finding different ways to cope. Some parents deny or avoid discussions of the illness, while others attend to every detail and take every opportunity for conversation. Some reach out to friends and neighbors for help, others manage very privately. Some complain and cry out in pain or

anger, others passively or stoically endure. Every person experiencing or observing families of children with cancer has their own preferences regarding what coping strategies work best, or which do not work at all. There is as yet little sound evidence on this issue, except that different people utilize quite different coping strategies, making it very difficult and perhaps even dangerous to judge different individuals' coping success on the basis of generalized standards and criteria. The majority of parents feel they cope quite well. However, parents' judgements of the effectiveness of their coping are qualified and comparative. Parents do not characterize their situations as rosy -- they are not; rather they contrast their situation with how bad things could be. Whatever strategies they use, most parents feel they are able to keep their heads above water and go on with the tasks of life. While no particular coping strategy is able to neutralize the overwhelming reality of the illness sufficiently to make a big difference, almost any coping strategy can help a little.

Three patterns of coping stand out as especially effective for many parents: the use of active and assertive styles; the creation of open family communication; and the presence of a coherent belief system. While many parents report the positive value of adopting an active coping style in dealing with the varied stresses of childhood cancer, not all parents are active in the same ways. Some become active information seekers; some work actively to care for their child at home, in school and in the hospital; other actively seek emotional or material help from professionals, friends and neighbors, and members of their extended family; some actively organize (or reorganize) family chores, work relationships, and solutions to financial problems; some actively tend to their own health, utilizing meditation,

exercise, prayer and counseling to promote their physical and emotional well-being. Not all parents are active doing all these things at once; most pursue some of these tasks actively and passively let others go by. The typical notion of active versus passive coping styles needs to be reconsidered in light of the many different tasks facing parents of children with cancer.

Many parents emphasize open communication as a cornerstone of effective personal and family coping with childhood cancer. Parents often report their preference for accurate information and two-way communication with the medical staff, and for good communication with spouse, the ill child, the immediate family, friends and the school staff. Youngsters often report a desire for open and honest communication about their illness. Not all parents and children pursue open communication with all these people with equal fervor, however. While open communication is greatly valued, its use varies considerably.

As the existential challenge of childhood cancer threatens one's understanding of the natural order of life and death, of innocence and suffering, it becomes important to have a set of understandings that helps make sense of this chaos. Many parents <sup>rely upon or develop</sup> a strong and consistent belief system, a way of thinking that explains and gives meaning to the world, their place in it, and the illness. For many parents this belief system is rooted in religious faith and a relationship with God which provides a theological interpretation or response to the illness. Being part of a religious congregation or spiritual community helps support such interpretations. Other parents find similar comfort and aid in a more secular tradition, in thinking through anew their notions of a good life and what a good person

does when confronted with unreasonable suffering.

Relying on others. Parents report childhood cancer's great effect on others than the individual child and parents. Siblings, grandparents and other relatives are concerned and upset, and their lives are often traumatized and altered by the demands of the illness and their concern for the ill child; neighbors and friends may mirror parents' reactions in their own stress and anxiety; teachers, medical staff members and others who come into regular contact with the ill child often find themselves in great pain and concern. Figure 12.2 depicts the widespread impact of childhood cancer.

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Insert Figure 12.2 about here

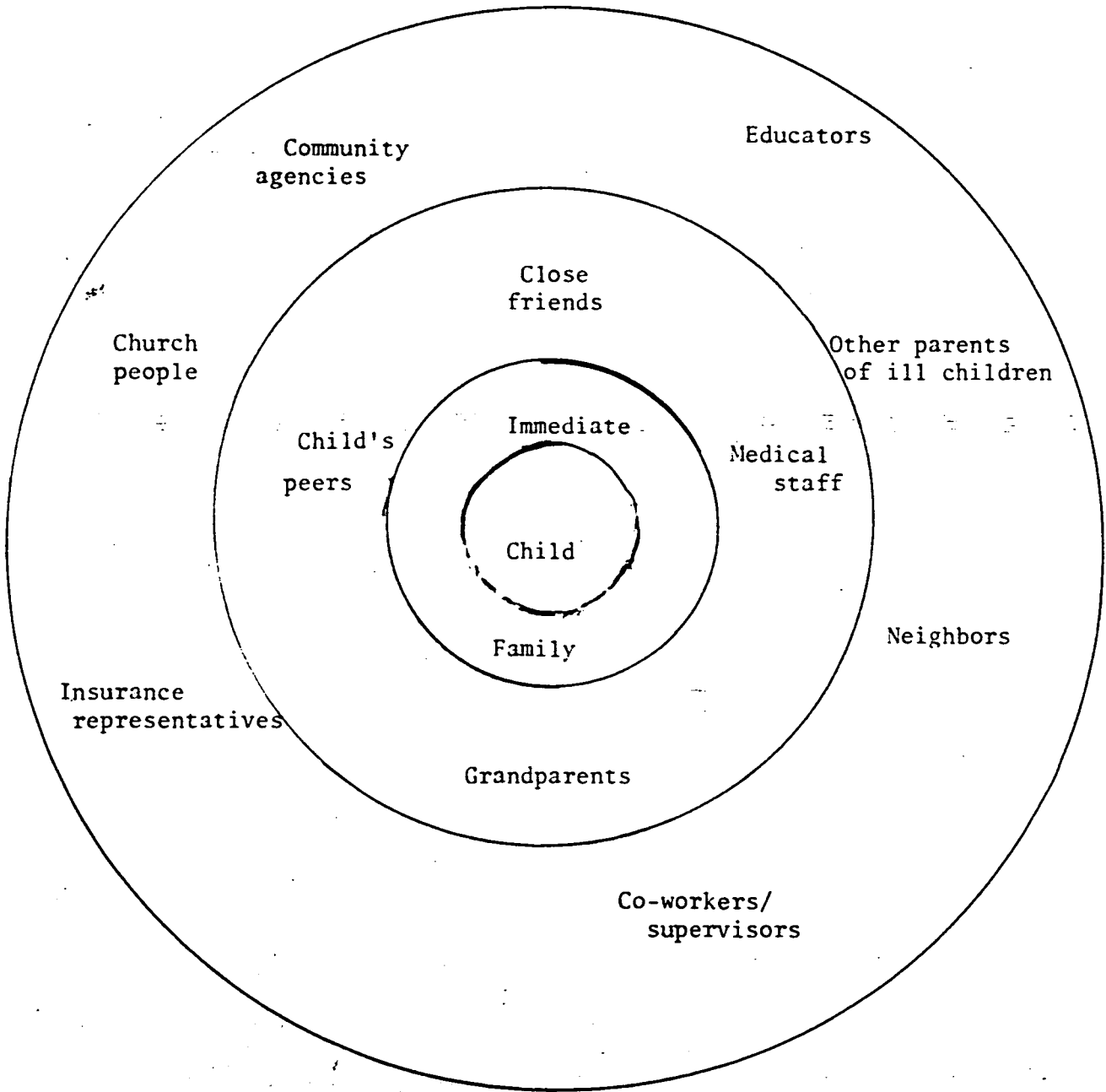
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The reactions of this broader network plays a significant role in shaping the ill child's quality of life, since many of these people and groups are sources of personal and family support. This reality establishes a reciprocal or mutual system of helping, with parents both providing help to others and relying on them for assistance.

No parent manages to deal with this chronic and serious illness alone. Everyone reaches out for help, although the sources of help vary, as do the kinds of help sought. Most parents report that their spouse is a great source of help and support, although it sometimes is difficult for parents to take time and energy from new childcare and household tasks to fully care for one another. Some find their own parents a great comfort, while others find their parents' reactions quite distressing and difficult to deal with. Others parents primarily reach out to their friends, who provide both tangible and intangible support, including helping with childcare and

Figure 12.2

The Widespread Impact of Childhood Cancer



household chores, and providing listening ears and affirmation. In relying on friends and family, however, parents often struggle with concern about others' energy and feelings, their own level of openness and vulnerability, and whether others really can be effective helpers. Professional services, in the person of social workers and psychologists, represent an important source of help for some parents, although a relatively small number overall use these services. Some parents also reach out for help from other parents of children with cancer, either on an individual basis or in mutual support groups. Parents who have the same experiences, some of whom have dealt with issues others are only beginning to encounter, often provide a very special resource. Getting help, and having an opportunity to give help to others, is an especially important aspect of peer support and self-help.

Another important source of help that parents rely upon is the medical staff treating their child. Dealings with the medical staff are complex, and parents often indicate the mix of positive and negative feelings with which they perceive and approach physicians and nurses. While most are grateful and appreciative of the medical and psychosocial aid their child receives, many also are quite uncomfortable with the staff's overall approach and are reluctant to ask for special help. Some parents indicate that they fear the staff's power over their child, and potential retaliation should the staff's authority be threatened. Such dependency is escalated when it is embedded in the larger impersonal bureaucracy of a major hospital. Bureaucratic procedures, which may interfere with their child's particular needs, often fail to make good sense to parents. Parents are most pleased when they can combine their reliance on the staff's help with their own ability to offer valuable help to the staff in the treatment of their child. This is a



specific example of the general phenomenon many observers report: effective help requires a sharing of resources and the establishment of reciprocal helping relationships.

Becoming a partner in health care. Many parents seek to become partners with the professional staff in the provision of medical and psychosocial care. While professionals are acknowledged to be experts in medical problems and treatments, parents feel they are experts in the physical and psychological makeup of their own child. Both forms of expertise are critical for the child's long-term welfare.

In order to create an effective partnership, both parents and professionals need to feel potent and useful as they each try to do their best for the child and for one another. A partnership relationship provides parents assurance that their insights about the needs of the child will influence the treatment plan, and enables them to feel competent in their efforts to cope with the illness. Parental assistance may relieve busy nurses for more essential medical duties, and parent cooperation may make it easier to secure cooperation from a frightened and reluctant child. Thus, new partnerships entail not simply a revision of existing roles, but a new vision of how professionals and the people they care for relate to one another. Such visions of a more egalitarian physician-patient relationship, a more symmetrical conception of expertise and power, already characterizes some staff-parent relations.

Successful implementation of a partnership role requires parental education regarding the nature of childhood cancer, its treatments and side effects, and psychosocial and medical problems. Armed with this information parents can work closely with the treatment team to formulate and select

alternatives, make decisions, and help monitor and implement treatment.

Parents can play an especially crucial role in learning and then teaching the child how to use self-administered pain control techniques such as relaxation and visual imagery.

Some medical care organizations make it easier for parents to become well-informed and active participants -- partners -- in the medical and psychosocial care of their child; some do not. At the Seattle Children's Orthopedic Hospital, a staff team has developed an information program designed for parents of children with cancer.<sup>1</sup> Much more extensive than the annual or biannual lecture by a local oncologist, these materials provide parents with a great deal of information about medical and psychosocial issues. In discussion groups led by experienced parents and/or trained professionals, parents gain the information required for them to take educated and active roles. This information package, and others like it, are beginning to be made available to parents whose children are being treated at medical centers around the nation.<sup>2</sup> Unfortunately, we have a long way to go before such information packages and materials, or effective combinations of parental and professional resources, will be available to support all children with cancer.

A partnership also can operate at a group or organizational level, as when professionals ask experienced parents of children with cancer to meet with parents of newly diagnosed children. Young people with cancer also may meet with newly diagnosed youngsters with cancer or with their parents. It often is tremendously comforting for a parent of a newly diagnosed child to meet someone "who has been there." This is a normal feature of self-help sessions, and illustrates the potent role self-help groups play in assisting

individual parents and the medical staff. When the hospital itself supports or encourages such individual or group activities it takes one step further toward establishing an effective partnership with parents.

Parents with special expertise have joined some medical staffs, in volunteer or semi-professional capacities, to improve the quality of the health care delivery system from within.<sup>3</sup> As advocates of parents' interests, and as links to parents at large, their presence on the staff clearly reflects a new form of partnership. They both keep the staff informed of parental concerns and special needs, and inform parents about the issues faced by the health care staff.

Even when parents and staff agree about the need for new programs to benefit children and their families, local financial resources may not be sufficient to take appropriate action. In some instances, parent groups take an active role by helping to raise funds to support hospital programs or to finance new programs. The development of Ronald McDonald Houses is one splendid example of parent-professional community partnership, but it is not the only example of self-help activities that benefit the hospital, the child and the family. Sometimes parents and parent groups are not only fund-raisers, but partners in the process of deciding how to spend funds to improve hospital services and facilities.

Despite the positive potential of parent-professional partnerships, a number of objections exist. Figure 12.3 presents parents' and medical staffs views of some of the positive and negative aspects of such an approach to health care for children and families.

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Insert Figure 12.3 about here

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On the negative side, partnerships may be viewed as intrusions into staff roles and responsibilities, as unnecessary and dangerous options for untrained persons, and as the expressions of a small and vocal minority of parents, perhaps parents responding inappropriately to the stress of illness. Thus, much of the medical staff's reluctance to embrace active parent involvement may be related to their expectations that the primary consequences of partnerships are negative. Parents also may be hesitant, as they fear their own lack of skills, time and energy overcommitment, and resistance from the staff. On the positive side, some staff members and parents see partnerships as a fruitful way to join hands in multiplying the resources available to ill children. They may also see it as a way to deal with current problems of misinformation, grievance and low energy or burnout. Thus, their interest in active parent involvement is related to expectations of positive consequences of partnership, and perhaps to new and different visions of the medical care system.

The creation of parent and staff as partnerships on the health care team will require exploiting these payoffs and overcoming these barriers. They may include new forms of parental involvement in the provision of care which do not yet commonly exist in health care delivery settings. They require parent and staff acceptance of different forms of expertise, and the establishment of a more egalitarian view of patients' rights and status (Bakker & Karel, 1983).<sup>4</sup> Clear boundaries, as well as meaningful responsibilities, and an agreed-upon division of labor is essential if conflicts are to be avoided. In the end, the value of these collaborative

Figure 12.3

Views of the Positive or Negative Aspects of  
Parent-Professional Partnerships

Positive or supportive views of partnerships	Negative or cautious views of partnerships
Aid to medical system	Challenge to medical system
Learn about often unaddressed issues	Some things parents cannot and do not need to understand
Information leads to helpful action, and improves choices	Unrealistic demands create a fuss Misinformation and simplistic views or fads might be spread
Parents are a unique source of information	Comparisons create anxiety and thwart research protocols
Clarify parent fears and misinformation	Parents are an important source of information but lack objectivity
Positive outlet for staff and parents energy	Intrudes on staff or patient privacy Lack of parent skill in dealing with medical and emotional problems
Channel for dealing with grievances	Sap energy from more important things
Increase funds and support for the medical system	Arguments about who gets the credit and who controls funds
Can cooperate to create a better system	Heighten parent-staff conflict
Useful for most parents	Direction of medical system is a staff prerogative
	Great potential for mobilizing
Represent a constituency often without access	anger and "acting out"
	Active parents are special interest group not necessarily representative

roles will be their own reward, insofar as they harness the resources of parents and professionals to help with the crucial problem of maintaining a high quality of life for the child, family and staff.

Are these themes credible and typical for all parents? The stresses, coping strategies and social support reported by parents in this study reflect typical issues experienced by all parents of children with cancer. However, every family's experience is somewhat different, and various personal and social factors influence people to respond quite differently to the threats and challenges of this illness. In addition, there are some important limits to the sample and inquiry methods on which this research is based, and these limits mandate caution in generalizing about families' experiences, about the above themes, and about the suggestions that follow.

First, this sample of parents is overwhelmingly white/Anglo, and does not reflect the experience of black, hispanic, asian and native American peoples. These groups often have fewer educational and economic resources, and thus more limited access to high quality medical and psychosocial services. In addition, their socioeconomic and cultural status may generate different stresses, different coping strategies and different social support patterns than those common in a white population. In particular, they may affect the roles parents play in relationships with the health care staff and community, and the way in which various institutions (medical and educational) interact with them.

Second, the relatively small size of this sample makes it difficult to compare and contrast effectively the experiences of parents of children who have different types of cancer. This problem is exacerbated by our lack of direct conversation with parents about the difference that different

diagnoses make. Although many of the dynamics of stress, coping and social support appear to be quite similar regardless of the specific diagnosis, this is not true in all circumstances. For instance, since children with brain tumors have a relatively low rate of long-term survival and children with Wilms' tumors a relatively high rate, more extensive comparisons of the experiences of a larger number of these parents might be very instructive. An in-depth comparative analysis also could help us understand potential differences between the experiences of parents of adolescents with bone cancer and those with Hodgkin's disease.

Third, all the parents in this sample sought treatment for their child at a single major medical center. Parents' experiences at other medical centers, or at smaller community hospitals, might be substantially different. This is especially possible with regard to parents' relationships with the members of the medical staff and the medical bureaucracy itself. Although we think that the depth of our analysis of parents' experiences with the medical system identifies and explains issues that occur regardless of particular parent and particular medical setting, we cannot yet be certain.

Obviously there are many more things to learn about the psychosocial aspects of childhood cancer, and about how parents and children (and friends, extended family members, educators, etc.) respond to the stresses associated with this illness. Although the themes generated by this research appear to be typical of a wide variety of parents and families, there are still many unanswered questions.

#### Practical Suggestions for Parents

One way of summarizing the research findings is to address questions

parents raise as they consider how to deal with the stresses of childhood cancer. Below we articulate parents' typical questions, and answers provided by our research, indicating chapters where each issue is discussed. These suggestions or action guides are just that, guides; they are not inflexible rules or guaranteed paths to success.

1. How can the medical staff help me? How can I best manage my relationship with the staff? (Chapters 4 and 5) It is natural for the medical staff to focus their primary attention on the ill child's physical condition. Staffs that have become more sophisticated, and that have added pediatric social workers (and other ancillary staff such as psychologists and child life workers), have developed programs aimed at meeting both the child's and parents' psychological needs as well. There is some evidence that staffs relate best with parents who have relatively passive and optimistic coping strategies, at least parents adopting those strategies report better relations with the staff. But this does not mean that parents who wish to know more about the illness and its treatments, or wish to play an active role in medical care, should not assert themselves by asking questions or making suggestions.

Parents' questions may extend from requests for written information about the illness and treatments to questions about nutrition, feeding, and child rearing practices. Parents who have questions would do well to write them down and bring them to an information session with the staff. In this way important issues will not be forgotten. Active parental participation in care may extend from monitoring drug dosages and watching for returning symptoms to attendance in treatment rooms and holding the child while blood is withdrawn or bone marrow aspirations performed. Parents have much to



offer to the staff and to the treatment process; as experts on their own child, they may help the staff modify or apply standard regimens to fit their unique child's styles or needs.

As parents express their own or their child's needs and desires to the medical staff it is useful for them to remember that the staff, too, is busy and under emotional stress. Not only does the staff see many young patients under trying circumstances, but they also care about their young patients and so suffer many of the emotional stresses common to parents. The staff can best be approached in a gentle but firm manner. Physicians and nurses do not like being attacked or harassed any more than anyone else. On the other hand, care for the staff's feelings should not lead parents to stifle their own questions or desires to play an active role in the treatment process.

Parents' feelings of intimidation and fears of retaliation if they should offend the staff are common. Most staff members would not consciously retaliate against a child for a parent's offense, and most are not deliberately intimidating, but parental worry about this issue often deters effective staff-parent communication and problem-solving.

Parents are the guardians and protectors of their children, and this role does not cease when a child is diagnosed with cancer or when a physician takes on the battle for the child's life. In the best situations, parents and staff members are able to combine their different roles and expertise in a lasting partnership to provide effective physical and psychosocial care. They often care for each other as well as for the ill child.

2. What should I keep in mind regarding my child's adjustment? What does my ill child need from me? (Chapter 7) Parenting continues even when a child is ill. The stress of a serious illness creates considerable confusion

for the child, and this is a time for clear and firm parenting, perhaps even more than when the child was healthy. The basic guidelines by which a positive parent-child relationship existed prior to an illness need not change in the face of cancer. In fact, some observers argue that a dramatic change, such as a relaxation of all expectations, may have negative impact, as it may be a signal to the child that something quite terrible is wrong. A nonhospitalized and nondisabled child -- a child with cancer in remission -- can be expected to perform a reasonable number of typical household and family chores. Moreover, the ill child can be encouraged to re-engage and maintain normal social relations with friends and classmates.

One hallmark of a healthy parent-child relationship is clear and open communication between parent and child. Since many things may be happening to the child that he or she may not understand, open communication is especially critical during the early days of the experience with cancer. At this time the child is especially dependent upon parents to share information about the illness and its meaning. Most observers now agree that children of school age should know the nature of their illness, treatment and prognosis, although many parents and staff members are still reluctant to share such information with young children.

The stress that the child is under is exacerbated when loved ones are not available for the maintenance of a loving and caring relationship. Thus, it is important for parents to be constant and attentive visitors for the ill child, as much as that is possible. Parents also can create loving support by encouraging the child's siblings and friends to visit and/or to send cards and letters. Some parents of children who are terminally ill have elected to have their child die at home, just so the child may be surrounded by a loving

family environment in the last days of life.

Finally, we emphasize that a child with cancer is not necessarily dying, is not likely to be useless, is not likely to be an emotional cripple. With proper medical care and some luck, with firm parenting, with good communication and with love, many children will recover and live long, happy and useful lives. Even those who do not recover are still children and need to be treated as such.

3. What does my child think about all that is happening to him or her?

How can I best talk with my ill child? (Chapters 7 and 8) Youngsters with cancer often want to talk with their parents about their illness. In some families these conversations can be very open and direct. However, sometimes parents find these conversations difficult, and youngsters may sense their parents' discomfort or unwillingness to talk about painful topics. Thus, partly in an effort to protect or shield their parents, older children often do not talk about their concerns openly. Adolescents with cancer may be especially reluctant to talk openly because of their normal concerns about privacy and independence.

Younger children often rely upon denial as a dominant coping strategy. Perhaps not understanding the full implications of the illness, or perhaps understanding it full well, these youngsters may not want to talk. Then, parents who do wish to talk may find it difficult to take their cue from these children, and to permit them their own space and their use of denial. Youngsters who are not able or who do not wish to talk with their parents may find it useful to discuss their concerns with social workers or psychologists, with nurses, with other ill children, or with their friends. Child life workers can provide play situations in which children may easily

express many of their concerns. Parents can be helpful in encouraging their children to make use of these resources.

4. How can I deal with my other children's reactions? What are the needs of siblings of ill children? (Chapter 6) Increasing attention is now being paid to siblings' reactions and needs and to encouraging parents to recognize and deal with these other youngsters' jealousies, fears, and feelings of being left out.

Siblings need to be loved and they need this love in the midst of a family illness just as they needed it prior to an illness. In a family atmosphere of love and open communication, siblings can both meet their needs and play a useful role in helping the ill child, parents, and other family members. If they are informed about the illness, siblings often can be involved in visiting and helping to care for their ill sister or brother, in picking up - temporarily - a larger share of family chores, and in carrying messages to and from extended family members, neighbors, and classmates. If the ill child dies, they <sup>may become</sup> ~~can also be~~ a source of support, and a model of courage for parents.

5. How can I best facilitate my child's progress in school? How can I help schoolpeople work well with my ill child? (Chapter 11) Since school is the normal extra-familial environment for children between the ages of 5 and 18, it is important for the ill child to return to school as soon as he or she is able. It indicates to everyone -- child, classmates, school, family -- that the ill child is going on with the normal business of life. Parents can help their children deal with their fears about their appearance, peer teasing or rejection, and falling behind in work with family conversations, linkage to educators for up to date assignments, and maintenance of peer

contact. In order to avoid loneliness and isolation for a hospitalized child, classmates can be urged to write notes or visit. Parents can urge the medical staff and educators to meet together to plan for the child's re-entry to school. In cases where a re-entering child is visibly changed or disabled, it is worthwhile to prepare the child's classmates as well as the child. Effective preparation can prevent the worst forms of peer teasing and rejection and can help develop a sense of mutual responsibility and caring among an entire class of youngsters.

In addition to supporting the child, parents often must support educators as well. Teachers and administrators unfamiliar with cancer or other chronic and serious illnesses in children may not know how to deal with the ill child. They may overreact by overprotecting the child, or they may underreact by refusing to deal with the child's real limitations and needs. Meetings with educators and the medical staff, with or without the child present, may help create an information flow and a pattern of joint planning that helps the child adapt to the school situation. Be assertive!

6. How can I best deal with this terrible crisis? What do I need?

(Chapter 5) No one knows anyone else's answer to these questions. Almost all parents report that at times they were overwhelmed or thought they wouldn't "make it in one piece." However, to the extent that parents understand their needs and their traditional ways of coping with stress, they may be able to respond more effectively. Most parents cope with the situation quite well, although some plans are delayed or even shelved permanently. Even when a child dies, most parents and families survive the pain and suffering; life continues and most parents' lives return to normal. However, normal does not mean the same as before the illness.

Some people exercise and work off their internal tension. Others seek friends or family members to talk with. Many people try to focus on the present, "take one day at a time," and deny or refuse to deal with longer-term issues and implications -- for themselves, their child, or their family. Others rely on a religious belief system, faith in God, and a community of fellow congregants to provide spiritual and existential relief and support. Still others try to adopt a "happy face" and create an optimistic environment for themselves and others. Some seek professional counseling as a way to learn new ways of coping with stress.

7. What can I do to preserve the best in my relationship with my spouse during this difficult period? What do I need from my spouse? (Chapter 6)

People need the same things from their spouses that have always been at the core of good marital relations: time together, affirmation and mutual regard, a sense of pulling together, commitment to the long haul, and intimate sharing. Given the strain childhood cancer puts on all people and relationships, these issues become even more important. Above all, husbands and wives indicate it is critical to make time for themselves, time when they can share information with one another, buttress and support one another, love one another, and plan joint action. In these intimate times, husbands and wives also can share the feelings -- anger and fear, joy and hope, pain and promise -- that they cannot share easily with others. A couple must also be accepting of each other's different responses and differing timing -- one may be grieving while another is using optimism to sustain her/himself. The time needed for this sharing is so critical it may have to be taken at the expense of extra time with the ill child, with the rest of the family, or with work responsibilities.

Husbands often indicate they are especially threatened or pained when their wives spend a great deal of time with the ill child at the hospital, leaving them out of this information network and requiring them to pick up a great deal of slack at home. Wives on the other hand, indicate that they are most pained when their husbands do not ask about or spend time in the hospital, appearing not to care about the ill child and dumping too much medical responsibility on them. The child is, after all, the product of both their bodies and both their hearts, and parents must be involved both in medical care and in home maintenance. Husbands can make sure they express care and visit their wives and ill child. Wives can make sure they include the husband in their expressions of caring, and take time off from the child's bedside to be with their husband and other family members at home. It is not easy to leave the bed of an ill child. But that child is still only one member of a larger marital and family system, others of whom also have important needs for sharing and a life together.

Single parents carry the same burden, often without the financial and social resources of an adult partner. For them, the help of extended family, friends, and community resources is particularly important. The ability to reach out and negotiate help from one's social network may be the most crucial determinant of long-term adjustment in the single adult household.

8. Can my religious beliefs help me at this time? How can I get comfort from religion? (Chapter 5) Many parents indicate that their religious beliefs and associations are very helpful. Some report an increase in their religious faith and commitment. Not all parents find comfort in religion; some feel that their religious commitments were tested in this experience and failed. Others who had not found religion important to them previously, did

not rely upon it during the illness.

Some parents report that their religion helps them make sense out of their child's experience with cancer, that it provides "reasons" for the illness and so eases their existential stress. Others report that a direct personal relationship with a loving God supports them emotionally; they feel less alone and adrift as a result of constant prayer and communication with God. Still other parents report that the most meaningful aspect of their religion is fellow church members who lend a helping hand, listen, pray with them, and provide a sense of being part of a community of faith. Religious beliefs and concerns take on special importance at the time of a child's death, when questions about life after death or relations with God and the hereafter become even more poignant. These positive functions of religion stay with some parents long after the illness, even after the death of their child, providing new meaning and direction to their lives.

9. Can my friends make a difference? How can I best reach out to my friends for help and support? (Chapter 9) Parents report receiving many different kinds of help from their close friends. Emotional sharing and affirmation, practical aid with family and household chores and transportation, and assistance in the care of the ill child are important resources friends are able to provide. However, not all friends are able to or wish to "be there" for parents of children with cancer, and the withdrawal of some close friends is often a source of disappointment, pain, and added stress.

One of the critical steps in gathering help and support from friends comes early in the experience with childhood cancer - at the time of diagnosis. Parents who quickly share information about the diagnosis often



are able to involve friends in dealing with the emotional trauma of the illness. To the extent parents are able to be clear about their needs, and about who could meet which needs, their friends are more likely to be well-informed and able to provide help.

Four actions parents can take with friends are: (1) telling friends about the diagnosis, perhaps with the aid of medical staff members who can answer a wide variety of questions; (2) discussing openly the level of pain and shock everyone is experiencing; (3) providing clear cues regarding the kinds of help that is needed, and from whom; and (4) providing clear feedback regarding the effectiveness or utility of help that has been provided.

10. What help can I get from other parents of children with cancer? How can I help others? (Chapter 10) Many parents who have been active in self-help or mutual support groups indicate that they both give and get from these groups. In fact, "giving is getting" is a common refrain. Among the benefits parents receive in such formal or informal settings are: affirmation that their feelings of guilt, fear, anger, and powerlessness are normal; information from others who understand <sup>problems in</sup> the medical situation, marital relationships, and childrearing; a listening ear and a helping hand from others who truly know what living with childhood cancer feels like; emotional comfort and comradeship during the hard times of surgery, relapse, or death; an opportunity to help others by making a contribution to the medical care system; a sense that they are coping well if they still have the energy and skill to be helpful to others.

11. How can I help coordinate care for my child and family? (Chapters 11 and 12) Many medical and psychosocial staff members, educators, and community agency staffs will try their best to provide effective care for the

child with cancer and the family. However, these groups seldom are experienced in working together, and their care often is less effective because of a lack of coordination. Parents usually are responsible for connecting all these professionals, and for providing the information, direction, and focus of their efforts. Parents can call a meeting where members of the hospital staff and the school staff share information and plans for the medical and school treatment of the child. Likewise, medical services and community services to families must be coordinated by parents or it is not likely to happen. The day when medical and psychosocial care is delivered in a sophisticated and coordinated manner as a matter of course is not yet here. It is still up to parents to make their own and their child's needs known, to advocate for their own and the child's welfare, and to guarantee the effective delivery of a full range of care. Parents unsure how to take these steps should consult sensitive medical staff members, other parents of ill children who know this "game," the American Cancer Society or the Candlelighters' National Childhood Cancer Foundation.

### Footnotes

1. Pendergrass, et al. (1982); Rudolph, et al. (1981).

2. Staff members at Children's Hospital, Los Angeles, have built on the resources and materials used in Seattle to develop a 6 week, 12 hour educational program for families of children with cancer ("We Can Cope"). An evaluation of this program showed education to be successful in reducing parents' self-reported anxiety, depression, anger, and lack of vigor (Ruccione, 1985).

3. Pitel, et al. (1985) describes and evaluates one example of this strategy, the parent-advocate role, in a major medical setting.

4. In the language of Borman (1979), partnerships require a new definition of the professional as a collaborator instead of a controller of care, a virtual paradigm shift in the conceptualization of human sources.

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