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UNIVERSITY OF ALBERTA

The Lived World Of A Family With A Child With Asthma: Implications For Education

BY

Debra A. Wingrove

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Education

DEPARTMENT OF ELEMENTARY EDUCATION

EDMONTON, ALBERTA

FALL, 1994

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L. Everett Turner, Co-supervisor

R. McKay, Co-supervisor

G. Kysela

October 7, 1999

Date

Dedication

This composition is dedicated to my son Joshua, and to my husband, Frank. They have made this work possible, through the living and telling of their stories. They have shared their stories unselfishly and honestly. They have provided me endless support and encouragement over these past years of research and writing.

Frank and Joshua have been full participants in this study. They have walked along side of me for every mile of this research journey. Most research projects, and especially an investigation of this nature, require a strong commitment from the entire family. We have all sacrificed time and energy to see this study to the place it is today. It belongs to us.

And so, it is with immense gratitude that I dedicate this composition to my family.

Abstract

This narrative inquiry illuminates the lived world of a family with a child with chronic asthma and allergies. It serves to heighten the awareness and enhance the knowledge of school people who work with families living with chronic illness, and to highlight the serious consequences of being unaware of the needs of students who have asthma and allergies. The number of children with asthma and allergies is significant and growing. All teachers will inevitably be faced with meeting the needs of students with asthma and allergies. The needs of these children are unique and urgent.

Acknowledgements

In addition to my family, there are certain people who have encouraged me in this research endeavor, and who have helped me come to know how to " think" about this topic of study. These people are:

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Chapter 1

Introduction

Narrative Beginnings

I am a teacher
I am a mother
I am a wife
And a storyteller
And a researcher
I have a son
He is a storyteller
His story is special
It is a sad story
It is a happy story
A story of hope
And of despair
A story of courage
And of fear
A story of worry
And of ease
A story of strength
And of weakness
A story of gifts
And disabilities
A story of yin
And a story of yang

I sit on both sides of the fence. I am both a mother and a teacher. I see through two sets of eyes. I see my world, my son's world, from within our life-world. I reach out to another family who is on a similar journey. I want to hear their stories. I want to present the bigger story, a united voice, if that is to be. I want others to hear and feel our tales of coping well with chronic illness. I am mindful of being a very small sample of the world of asthma and allergy. I am not trying to paint 'the big picture'. We are only two families--two small families, with all of our differences and similarities. I hope that our stories will provide a glimpse at what it is like to be a student with asthma and allergy, or to be a family member of that child. I hope to strike a familiar chord in the heart and mind of the reader.

This research study has grown out of my personal story and is based on my experience as a parent and as a teacher. As this text unfolds, I will be continually reflecting upon what this research means to me the parent, and to me the teacher. As I explore the educational implications of the student with asthma and allergies, I am mindful of my role as a teacher, and of the sometimes overwhelming responsibility which comes with this role. I also see through the eyes of a parent, how crucial it is for this research story to be shared between families and school people.

I will begin here by stating the purpose of this inquiry and by outlining the key reasons why I have chosen to pursue this investigation.

Purpose

The purpose of this study is to illuminate the lived world of a family with a child who has asthma and allergies. It is hoped that this study will serve to heighten the awareness and enhance the knowledge of educators who work with families living with chronic illness, and to highlight the serious consequences of being unaware of the needs of students who have asthma and allergies. The ultimate aim is to optimize the ways in which families and educators might work together to meet the needs of the child with asthma and allergies. It is hoped that the stories of the people in this study will be in some way helpful to other families who find themselves in similar situations as they experience chronic illness, and as they come to make important decisions about the education of their child. Two questions will guide this investigation:

1. What is the lived world of the family of the child who has asthma and allergies?

2. What are the implications of this family experience for educators?

Significance of Study

We, as citizens of Alberta, have recently experienced a strong attempt to move toward inclusive education. Children with chronic illness are being included in the regular classroom more and more. The number of students with asthma and allergies is significant and growing. All teachers will inevitably be faced with meeting the needs of children with asthma and allergies. The needs of these students are unique and urgent. If there are not informed school personnel to address the needs of these students they are not safe at school, or they will be unable to attend school.

Much has been written in the separate fields of chronicity, family coping, and inclusive education. There is a body of literature on inclusive education and chronic illness. There is a small body of literature that specifically addresses the inclusion of children with asthma. Little has been written, however, from the perspective of the parents themselves (Klein-Walker, Gilbert-Epstein, Boyd-Taylor, Crocker, and Tuttle, 1989). In 1988, Bailey and Simeonsson identified a need for parents of disabled children to have reading material about parents who are in similar situations to themselves. This study will be written from the perspective of participating family members and will be written in the accessible language of story.

Judy O'Halloran (1993), the parent of a child with a disability, suggests that research in the area of families and disability needs to reach the families. She says:

> Families need reliable information. And we need it in ways that are easily accessible to us. ...The information needs to be explained in language that the average parent can understand. ...It is far easier to digest information if it is presented to us through concrete examples and common experiences explained in lay terms. ...Perhaps more parent-researcher collaboration

> would be a vehicle for achieving a good exchange of information. ...But one thing is certain: the information is far too valuable not to reach and be used by the people it is intended to help (p. 28).

Some of the things that she feels would benefit such families is research in the area of:

> -Proven successful coping strategies.
>
> -Extended studies with families who feel they are coping well. Studies that include families' reactions over a long period of time give more realistic strategies than one-time "slice of life" results (p. 28).

In listing the things that would be helpful for the families of children with disabilities, Janet Vohs (1993) addresses the issue of language. She emphasizes the importance of learning to speak differently in order that the words of social change reach the people. She inadvertently supports the use of story as a research method with the following words:

> We are accustomed to encouraging parents to be strong advocates to stand up for their children's rights. Indeed, the conversation to further rights is basic and cannot ever be ignored. However, it does not allow the heart of the tale to be told. Perhaps the next era's unfolding will require parents to be strong poets and storytellers as well, helping to create communities where all belong (p. 63).

There is also a need for longitudinal studies which may shed light upon the process of adaptation over the years of a child's life (Kazak, 1989; Mizen-McCarthy and Gallo, 1992). Shirley Behr and Douglas Murphy (1993) call for longitudinal studies involving parents of children with disabilities who belong to a support group. They feel such work would be "essential to developing an understanding of how individuals learn to use cognitive strategies in the constantly changing processes of adaptation (p. 160).

Pauline Boss (1993) makes the following comments on the direction of research:

> Most caregiver research is done with clinical families. We are missing data from those who are doing so well that health care providers are not hearing from them. ...Furthermore, those families who do well over time may be those from whom we can gain the most useful data simply because they have learned how to remain resilient in spite of caring for a loved one with a long-term disability. While longitudinal studies are expensive and difficult to fund, they may, nevertheless, yield the most valuable information (p. 267).

Suzannne Thompson (1993) wonders about "the effects of being able to tell one's story and the changing themes in stories over time". Of coping with traumatic life events she writes:

> Another promising way to understand how people cope with a stressful life event is to examine the stories or accounts they relate about the experience (p. 171).

For the above reasons, I feel that a narrative study, based on the stories of the participants, and written in the language of story will make a significant contribution to education.

This chapter has helped to set the stage for our research journey. I have outlined the purpose and the significance of this study. Purpose has remained paramount in the writing of this text, and it has been important for me to revisit my research questions often throughout this study. I will now move on to chapter two in which I will lay the ground work for the personal stories which will comprise the main body of the text.

Chapter 2

Literature Review

In this chapter I will review the literature from relevant fields in order to provide a sense of what is already known about the needs of children and families who are dealing with chronic illness. The review of the literature has been divided into three broad areas: asthma and chronic illness, family function and adaptation, and education and schooling. Once I have described what has come before this investigation, I will outline how this study has unfolded. I will begin first by clarifying several key terms to be used throughout this text.

Explanation Of Terms

The following definitions are assumed throughout this text:

Asthma - "a chronic obstructive pulmonary disease characterized by an unusual degree of bronchial reactivity to a wide variety of stimuli" (Hobbs and Perrin, 1985, p. 366)

Asthma/Allergy - because of the strong link between asthma and allergies (Hambley, Brazil, Furrow, and Chua et al., 1989; Kaplan and Mascie-Taylor, 1992; Jurnec, 1988; Gergen, Mullally and Evans, 1988; Walsh and Ryan-Wenger, 1992; Zimmerman, Gold, Lavi, and Feanny, 1991; Infante-Rivard, 1993) I have chosen to use this combined term to refer to asthma. It has been my experience that asthma is seldom ever encountered in the absence of allergies. I have combined the terms because it seems to be the most accurate and efficient way to refer to the condition of asthma (rather than to write 'asthma and allergies' or 'asthma and/or allergies' each time I refer to asthma). This way of referring to asthma is similar to the way in which PACE (Parents of Allergic/Asthmatic Children-Edmonton) has chosen to refer to asthma.

Chronic Illness - "a condition that interferes with daily functioning for more than three months in a year, causes hospitalization for more than one month in a year, or (at time of diagnosis) is likely to do either of these" (Hobbs and Perrin, 1985, p. 2)

Review Of The Literature

Asthma And Chronic Illness

It is estimated that 31% of children with health conditions are affected by chronic illness (Newacheck and Taylor, 1992). These children can be divided according to the severity of their condition: 66% with mild conditions, 29% with moderate conditions, and 5% with severe conditions (Newacheck and Taylor, 1992). An American survey conducted in 1988 showed that 63% of all children with chronic conditions required medication (Newacheck and Taylor, 1992). Children with asthma, respiratory allergies and repeated ear infections constitute 22.3% of children with chronic illness (Newacheck and Taylor, 1992). Recent studies of school children by Pat Hessel (personal communication, February 19, 1993) place the prevalence figure for asthma at approximately 9%. The same study of over 1500 children attending thirteen schools, found that 13% of these children have had asthma at one time. "In every class of thirty students there will be on average four to five with asthma. One or two of these will have obvious signs of asthma for which they may be taking treatment, but the others may not be recognized or treated" (Asthma Society Of Canada, 1994, p. 7). The increase of asthma and of deaths due to asthma are alarming, and "the disease exacts an enormous toll on patients, families, and the health care delivery system" (Clark, Gotsch and Rosenstock, 1993, p. 242).

A student with asthma is generally of average or above average intelligence (Hobbs and Perrin, 1985). Boys, African-American children, and children raised in poverty are more likely to have asthma than girls, white children, or more economically advantaged children (Weitzman et al., 1990). Weitzman and his colleagues (1990) do however cite studies which have produced conflicting results with regard to the connection between socio-economic status and asthma prevalence. They also state that genetic factors may be less important than environmental factors in the clinical expression of asthma (for example, family size, home size, preventive care, and exposure to allergens).

Children with asthma should be considered "normal children with an additional source of stress--a chronic illness" (Walsh and Ryan-Wenger, 1992, p. 461). Such persuasiveness of illness is a significant source of stress for these children. Their condition restricts their activities, exercise, and diet, as well as, academic and social lives (Lynch, Lewis and Murphy, 1992). Many children with asthma experience psycho social problems and a low sense of self-esteem (Hambley, Brazil, Furrow, and Chua, 1989).

Children with asthma do not represent a homogeneous population. Asthma "may be regarded as analogous to 'arthritis', a clinical manifestation with multiple causes" (Bailey, Clark, Gotsch, Lemen, O'Conner and Rosenstock, 1992, p. 218S). Although the exact cause of asthma is not known, it is believed to be due to "inflammation in the lungs which is brought on by allergies, infections ('colds') and irritants, such as cigarette smoke" (Canny and Levison, 1991, p. 1). Asthma is associated with allergy for 60-80% of children with asthma (Zimmerman, Gold, Lavi, and Feanny, 1991; Lee and Osundwa, 1994). The added complication of allergy effects the course of the illness a great deal. In addition, variations in the condition, treatments, medications, and side effects of both asthma and allergy, also vary greatly. "Childhood asthma can range from occasional mild attacks of wheezing, to the more severe chronic problem, when the attacks are frequent and may affect the child's physical and emotional development" (Lamarre and Broadhead, 1988, p. 11). Asthma can and does result in death. The Alberta Asthma Centre reports that in Alberta alone, there were 138 deaths due to asthma between 1984 and 1994 (S. McGhan, personal communication, September 2, 1994). Many people with asthma require frequent hospitalization for their asthma (Newacheck and Taylor, 1992). "Asthma is among the major causes of school days lost and accounts for one-quarter of the health-related absences reported for all students (Shayne, et al., 1987; Klein-Walker et al., 1989).

Family Function And Adaptation

There is an extensive body of literature on family function and coping. Adaptation, as opposed to coping, may be a more appropriate word given the recent focus on positive coping. Much of the early literature focuses heavily on negative coping and family dysfunction. It is encouraging to see a positive focus in the writings of Turnbull and Turnbull (1986), Turnbull et al., (1993), Seligman and Darling (1989), Lipsky (1985) and others. Researchers are asking, "What is right?" (rather than wrong), and "How can we help others to become less vulnerable in the face of life's adversities?" (Werner,1990, p. 97).

The literature clearly shows that families with a child with a chronic illness experience more stress than other families (Leonard, Johnson, and Brust, 1993; Wood, Siegel and Scott, 1991; Klein-Walker et al., 1989; McCubbin, 1988). However, the presence of a child with chronic illness does not necessarily have a negative overall impact on the family. Many parents report the experience as a positive one. Wood et al. (1991) cite studies which show that some families are experiencing fewer child care problems, improved marital relationships, closer family relationships, altered values and priorities, and personal growth. Lipsky (1985) and Shapiro (1983) draw our attention to the ability of stress to mobilize the family unit; create problem-solving energy; promote motivation, creativity and growth; and enhance constructive coping.

Nonetheless, significant stressors to families with a child with chronic illness have been identified in the literature. They are as follows:

-severity of illness (McCubbin, 1988; Leonard et al., 1993; Seligman & Darling, 1989)
-uncertainty (Jessop and Stein, 1985)
-hospitalization (Burke, Kauffmann, Costello and Dillon, 1991; Shapiro, 1983)

-dealing with medical personnel (Muir-Hutchison, 1987; Burke et al., 1991; Sabbeth and Leventhal, 1988; Kroth, 1987; Lipsky, 1985; Mizen-McCarthy and Gallo, 1992; Pizzo, 1990)
- chronic sorrow (explained below) (Berry, 1992; Shapiro, 1983; Turnbull et al., 1993)
-constant worry or fear (Canem, 1987; Wilgosh and Chomicki, 1991; Berry, 1992; Shapiro, 1983)
-visibility/non-visibility of condition (Jessop and Stein, 1985)
-concern for the future (Bailey and Simeonsson, 1988; Muir-Hutchison, 1987)
-being informed of the diagnosis of disability (Wilgosh and Chomicki, 1991; Kroth, 1987; Seligman & Darling, 1989)
-the need for life-long management of the condition (Muir-Hutchison, 1987; Patterson et al., 1990)

Chronic sorrow, or chronic grief, is described as being similar to the stages of grief, however, there is some agreement in the literature (Seligman and Darling, 1989; Meyer, 1986; Mori, 1983) that in the case of a disabled child, the grieving process can be non-sequential and repeated. Chronic sorrow is a natural reaction and does not need to be pathological. Acceptance of the child's condition may exist along with chronic sorrow (Seligman and Darling, 1989). Olshansky (1962) has argued that parents of disabled children "do not ever completely abandon the grief process" (Seligman and Darling, 1989; p. 29).

Much of the research reveals the similarity in the needs of families, regardless of the type of chronic disability with which they are dealing (Jessop and Stein, 1985; Klein-Walker et al., 1989; Patterson et al., 1990; McCubbin, 1988; Wilgosh and Chomicki, 1991; Kroth, 1987; Shapiro, 1983). This literature makes a good case for a non-categorical approach to studying the needs of such families. (See Leonard, et al., 1993, for contradictory evidence). For the purpose of this study, a sample of literature has been reviewed in the areas of cancer (Shapiro, 1983; Jevne, 1994), cystic fibrosis (Patterson et al., 1990), psychiatric disorders (Garmezy, 1987), hearing impairment (Kroth, 1987), mental disabilities (Wilgosh and Chomicki, 1991), AIDS (Kazak, 1989), and Down's syndrome (Klein-Walker et al., 1989). The literature on family adaptation and chronic illness, combined with this sample of literature, has identified the following family needs:

-the need for cohesion and involvement by both mothers and fathers (Bailey and Simeonsson, 1988; Bailey et al., 1992; Kysela, McDonald, Reddon, and Gobeil-Dwyer, 1988; McCubbin, 1988; Patterson et al., 1990)
-the need to be heard and to have a voice (Wilgosh and Chomicki, 1991)
-the need for information and resources (Klein-Walker et al., 1989; Bailey and Simeonsson, 1988)
-the need for support from family (Kysela, 1988; McCubbin, 1988; Turnbull et al., 1993)
-the need to meet other families in similar situations (Klein-Walker et al., 1989; Phillips, 1990; Bailey and Simeonsson, 1988)
-the need to hear other families' stories (Bailey and Simeonsson, 1988)
-the need for hope and reassurance (Jevne, 1994; Patterson et al., 1990; Sabbeth and Leventhal, 1988; Turnbull et al., 1993)
-the need for open communication (Canem, 1987; Bailey and Simeonsson, 1988; Sabbeth and Leventhal, 1988)
-the need to be taught communication skills (Canem, 1987; Kroth, 1987)
-the need for support from medical personnel (Canem, 1987; Klein-Walker et al., 1989; Sabbeth and Leventhal, 1988; Seligman & Darling, 1989)
-the need for trust and cooperation between families and doctors (Wilgosh and Chomicki, 1991; Burke et al., 1991)
-the need for support from school personnel (Leonard et al., 1993; Lehr and McDaid, 1993; Lynch et al., 1992)
-the need for a sense of control and mastery (Shapiro, 1983; Muir-Hutchison, 1987; Burke et al., 1991)
-the need for normalization (Shapiro, 1983; Mizen-McCarthy and Gallo, 1992; Seligman & Darling, 1989; Anderson, Krulik, and Darling, in Knafl and Deatrick, 1987).

Family adaptability, resilience and cohesion have been identified as critical to the demands of raising a child with chronic illness (Turnbull et al., 1993; Seligman and Darling, 1989; Werner, 1990; McCubbin, 1988, Patterson et al., 1990; Knafl and Deatrick, 1987; Shapiro, 1983, Lipsky, 1985, Kazak, 1989, Kroth, 1987). Adaptability, has been defined as "the ability of the family to change in response to external stressor and stimuli" (Kazak 1989, p. 27).

"The concepts of resilience and protective factors are the counterparts to the constructs of vulnerability...and risk factors...". (Werner, 1990, p. 97). Garmezy (1987) and his colleagues have been investigating the concept of 'protective factors' in their extensive work with 'stress-resistant' children. Protective factors are "individual and environmental characteristics that ameliorate or buffer a person's response to constitutional risk factors or stressful life events (Masten and Garmezy, 1984, cited in Werner, 1990). Protective factors identified by Garmezy (1987), and Werner (1990) are as follows:

-personality disposition of the child
-stable adult/child relationship
-supportive and cohesive family climate
-external support system
-nurturing atmosphere for child at school
-faith or spirituality
-socialization practices in the home which foster independence; risk-taking; the absence of overprotection for girls; and structure, rules and positive male role modeling for boys
-required helpfulness (chores and jobs for children)
-friends

(See Kysela et al., 1988, for a discussion of other factors which seem to 'protect' families from the stress of coping with a child with special needs.)

The literature on family adaptation utilizes a family system approach to the conceptualization of the family relationship system (Bronfenbrenner, 1979; Berry, 1992; Kazak, 1989; McCubbin, 1988; Shapiro, 1983; Turnbull et al., 1993; Seligman and Darling, 1989). The family is seen as a dynamic unit capable of actively managing difficult situations (see Knafl and Deatrick, 1987 for a discussion of active and passive approach to research). Any situation which affects an individual member, also affects family functioning. Chronic illness then, not only affects all family members, but the way in which the family manages the illness also affects the health of the child with a chronic disability (Shapiro, 1983; Patterson et al., 1990; McCubbin, 1988; Garmezy, 1987; Mizen-McCarthy and Gallo, 1992). The family must be seen as the basic unit of care by care-givers and educators. Bailey, Blasco and Simeonsson (1992) remind us, however, that all families are individual, and their needs are unique and must not be predicted on the basis of broad categories.

Education

Relevant Aspects Of Inclusive Education

The terms integration, mainstreaming, and inclusion, or inclusive education, are commonly used when describing how "special" students are being educated within the regular classroom. Stainback and Stainback (1990) define an inclusive school as one in which all students are welcome, valued, and offered appropriate programs, within regular classrooms. They emphasize the need for challenging, individualized programs which are backed by all the necessary community supports. They emphasize that this type of schooling is not special, and it is not aimed at meeting the needs of those children who have been identified as disabled. "Instead, the focus is on how to operate supportive classrooms and schools that include and meet the needs of everyone" (p. 4). They refer to inclusive schooling as regular education, and operate on the premise that, once inclusive schools are achieved, there is no need for "special" education, because there will no longer be anyone left outside the mainstream.

Stainback and Stainback (1990) identify several key components as essential to successful inclusion: establishing a school philosophy which embraces egalitarianism; accepting all comers; including everyone involved, in planning and decision making; developing support networks; integrating personnel; adapting the curriculum; and maintaining flexibility. 'Integrating personnel', or similarly, the collaborative team approach, is a concept covered extensively by Morsink, Thomas and Correa (1991) in their book entitled "Interactive Teaming". Collaboration and consultation amongst teachers and other professionals, is essential if teachers are to meet the expectations placed upon them by today's inclusive educational practices (Wilgosh and Chomicki, 1991; Lynch et al., 1992; Palfrey et al., 1992; McDaniel and Di Bella-McCarthy, 1989; Glatthorn, 1987).

Teamwork is of paramount importance when including children with asthma into our classrooms. Each adult who becomes involved in the education of a child with asthma/allergy must be well informed and prepared to deal effectively with this medical condition. "Asthma should never be considered as anything less than a serious condition" (Winzer, 1990, p. 567). Hobbs and Perrin (1985) state, "the importance of emergency procedure training for school personnel who interact with chronically ill children cannot be overemphasized" (p.642). It is important that teachers have the support of a collaborative team when responsible for the education and well being of students with asthma/allergy. The team approach will benefit the child in many ways, not only in times of crisis. Each member of the team can offer his or her own perspective and expertise with regards to all aspects of the child's program.

Palfrey et al. (1992) established Project School Care in 1987, at the Children's Hospital in Boston. The aims of this project centered around the safe provision of care in schools for children dependent on medical technology, and involved the provision of consultative services (both technical and administrative) to school personnel. (It is important to note that some children with asthma/allergy require basic treatments involving the use of a portable air compressor, or the use of oxygen, during the school day.) A key element to their project was the creation of a team. A team, as Palfrey et al. see it, "functions optimally with input from the child's parents, health care providers, special educational or regular educational staff, community providers" (p. 51), and, where practical, the child herself or himself.

Morsink et al. (1991) discuss the roles of team members at length. The role of the classroom teacher is addressed by Myles and Simpson (1989), Sirvis (1988), Johnson, Lubker and Fowler(1988), and McDaniel and Di Bella-McCarthy (1989). It is clearly evident that teachers are willing to work with a team, and are eager to accept the assistance and expertise offered by a team (Johnson et al., 1988; Myles and Simpson, 1989; Palfrey et al., 1992). There is an emphasis on the leadership role, both in the context of an inclusive school, and within the actual collaborative team. The principal may or may not take a leadership role within the team. Any member of the team may serve as a leader (Stainback & Stainback, 1992): someone who embraces the philosophy of teamwork, and someone with the ability to empower others. Palfrey et al. refer to an educational coordinator, as well as, a health coordinator. The health coordinator is responsible to assess health care needs, monitor the care provided, and assure that all training of team members is conducted. A school nurse can play a key role as a primary caregiver and as a consultant. Unfortunately, most Canadian schools do not have full time nursing service available to them on site.

Palfrey et al. summarize the goal of the team by saying "team members work together to create a safe environment that enhances the educational experiences of the child with special health care needs" (p.51). The team works toward establishing "the safest and most appropriate classroom placement and [preparing] for the child's admission with appropriate personnel, training sessions, technical equipment, and supplies" (p.51).

A critical tool used by the Palfrey team is the Health Care Plan (HCP). The HCP is intended to be developed along with the standard Individual Education Plan (IEP), or, as it is referred to by Alberta Education, the Individual Program Plan (IPP). The HCP is devised by the team, and is a much recommended method of documenting the child's needs, as well as, specifying training and emergency procedures. Lehr (1990), and Lynch et al. (1992) advocate for the use of IPP/HCP documents in meeting the educational needs of children with chronic health conditions. It is important to note that, unless a child is identified as "educationally disabled", she will not be provided with an IPP, nor a HCP.

Research Impacting The Inclusion Of Children With Asthma

The rising numbers of children with asthma has been attributed to advances in medical technology, as they pertain to successful intervention with pre-term infants (Gilkerson, Gorski and Panitz, 1990). There is also speculation on the part of leading pulmonary specialists, that our environment is in fact contributing adversely to the prevalence of asthma in children and adults (Dr. F. McDonald, personal communication, September 23, 1992). Students with asthma/allergy will continue to require modifications to their school programs, and parents of children with asthma/allergy will continue to expect that the needs of their children be met within the regular classroom. At this point in time, schools are poorly prepared to deal with the needs of students with asthma/allergy, and other students with special health needs (Johnson et al., 1988; Palfrey et al., 1992; and Sirvis, 1988). Due to the varied and volatile needs of students with asthma/allergy, it is not enough to understand these needs, it is also essential that differing programs and interventions be developed (Hambley et al. 1989). To this end, Jurenec (1988) has investigated the notion that there are certain identifiable subgroups of children with asthma. Jurenec differentiates between children who react to allergens, and children who exhibit "emotional precipitants" (p. 24) as asthma triggers. He studied subgroups as predictors of treatment response, suggesting a very different intervention is called for depending on which subgroup the child falls into. Teachers and other professionals may benefit from such research findings, as they attempt to develop programs for students with asthma/allergy.

Hambley et al. (1989) studied children with moderate to severe asthma, attending a residential treatment program in Canada. Social/medical, and psycho social variables were considered. Their findings have much to offer here. Overall, 41.5% of the children in their sample had been identified as having had allergy-related symptoms (eczema). The incidence rate in the general population is less than 5% (p. 171). No significant differences were found between the family structure of children with asthma and that of "normal" families. Four categories of cohesion and four categories of adaptability were compared to a national survey in the United States, showing that families dealing with asthma are "balanced" as often as "normal" families (p. 171). "All groups of children showed elevated levels of behavior problems in comparison with norms. ...Behavior problems tended to be related to asthma severity" (p. 171). The Hambley et al. data shows "a direct relationship between amount of hospitalization and emotional difficulties in asthmatic children" (p. 173). "Social competency problems were identified for 6-11 year old boys," while "girls at both younger and older ages experienced a lower sense of self-esteem" (p. 173). "These findings suggest that different intervention strategies be employed for boys as opposed to girls. Whereas boys need instruction in how to channel their self-expression more appropriately, the girls need to learn to express and then deal with their concerns and feelings" (p. 174). "Children were rated as having school difficulties...no doubt related to the cumulative effect of large numbers of days absent from school" (p. 174). Hambley et al. conclude that "more global, preventive programs of education geared to education personnel are needed if we are to impact on this problem in any significant way. There is a need to teach children with asthma/allergy methods of coping with school absences as well as providing support to these children when they encounter unreceptive responses from schools" (p. 174).

Parents are generally a reliable source of information regarding the needs of their children with special health needs (Sirvis, 1988; Ysseldyke, Algozzine and Thurlow, 1992; Johnson, 1988). Parents' knowledge and assessment of their child's condition has repeatedly proven to be in agreement with research findings (Wilgosh and Chomicki, 1991; Lynch et al., 1992; Hambley et al. 1989; Stainback and Stainback, 1992). It is still, however, made quite apparent in the literature that parents are not yet seen as key players by all professionals (Lipsky, 1985; Lipsky and Gartner, 1989; Ysseldyke et al., 1992; Morsink et al., 1991). Lipsky and Gartner (1989) address the issue of mandatory parental involvement in the IEP process, stating that parent involvement is limited both in extent and nature. They cite studies which indicate that in 21-70% of the cases, parents provided no input to IEPs. They cite a study by Singer and Butler (1987) which states " '[A] white, married mother who graduated from high school was 5.4 times more likely than a nonwhite, single mother who had not graduated from high school, to have attended the most recent IEP conference held for her child'...(p. 146)" (p. 167). They also cite an American "report to Congress which notes; 'several studies have reported that in the majority of IEP conferences, the IEP was completely prepared prior to the meeting'...(Ninth Annual Report, 1987, p.71)" (p.167).

Critical Issues In The Inclusion Of Children With Chronic Illness

A major issue which is greatly debated is one of a philosophical nature. At what point do we separate education from medical care, where health impaired students are concerned? Should scarce educational dollars be spent to perform health functions in the classroom? What procedures can be expected of a school nurse, and what procedures require the attention of a private nurse? What aspects of "nursing service go beyond a reasonable extension of required related educational services" (Ogg and Elfers, 1988; p. 11)? Who pays for private services? The courts are currently working towards finding the answers to these difficult philosophical and financial questions.

Another consideration seems to be that of health risk. If the risk of being in a regular classroom is considered too great for the child, then school personnel will undoubtedly be reluctant to accept the responsibility for that child's well being. Without access to medical supervision, the risk may indeed be considered to be too high in cases of severe asthma/allergy.

Another issue to be considered when discussing the inclusion of students with special health needs is teacher training. We know that teachers report a willingness to welcome all comers (Myles and Simpson, 1989), and that they have repeatedly expressed the need for extra training with regards to teaching exceptional children (Johnson, 1988; Myles and Simpson, 1989; Palfrey et al., 1992). In a study by Johnson et al. (1988), "teacher knowledge and preparation about the health conditions [of their students with chronic illness], outranked all others as the most important concern in the educational management of these children" (p.234). The Johnson et al. findings "reinforced the concern that teachers often lack both [the] preparation and [the] in-school resources" (p. 234) to meet the needs of these students. Forty-four percent of teachers surveyed by Johnson et al., report that "current requirements for regular classroom certification were not adequate to prepare teachers for students with chronic health conditions in the classroom" (p. 233). "Only 7% responded that their certification requirements were adequate" (p. 233). Given also, that only six percent had parented children with chronic health conditions (p. 233), it is reasonable to assume that teachers are poorly prepared to meet the needs of these children in the classroom. Johnson et al. cite studies wherein "45% of teachers requested more information about the health conditions and management needs of these children"; and "prior to contact by the investigators, almost one in five teachers was unaware a child with a chronic health condition was in their classroom"(p. 232). Four percent of the Johnson et al. respondents who had "taught chronically ill children, reported they had not been informed they would have such a child in their classroom" (p. 233). It is clear that teachers need more course work, more practicum experience, more in-service, more information, and more resources, to assist them in meeting the needs of students with chronic health needs in their classrooms (Johnson et al, 1988; Lehr, 1990; Sirvis, 1988; Lynch et al., 1992; Shayne et al, 1987).

Parents too, are asking that teachers receive more training and information about the needs of their children with special health needs (Lynch et al., 1992). Although a parent's perspective is different than that of school personnel, both groups cite the lack of information, awareness and understanding, as major barriers to "special" education service delivery (Lynch et al., 1992).

The association between asthma and allergy is well documented in the research (Lee and Osundwa, 1994; Hambley et al., 1989; Kaplan and Mascie-Taylor, 1992; Jurenec, 1988; Gergen, Mullally and Evans, 1988: Walsh and Ryan-Wenger, 1992; and Zimmerman et al., 1991). Schools must give careful consideration to providing a "hygienically safe" learning environment (Sirvis, 1988; p. 43), in which students with asthma/allergy may be included, without becoming ill.

Children with asthma/allergy are quite often compromised by simply being in the school building for any extended length of time, or by participating in certain school activities. This, along with high rates of absenteeism, certainly puts them at an educational disadvantage. Parents are faced with medicating their children (more than usual) to help them tolerate the allergens and irritants in the school environment, many of which could easily be eliminated. The other alternative is to have their child's educational needs met elsewhere. In the case of children with severe asthma/allergy, parents feel compelled to choose home schooling. Until parents feel welcomed as full participants in the planning and decision making process, they simply cannot trust that their child will be safe and well at school. Children with mild asthma are most commonly attending a regular school program, however, even in mild cases, the school environment can adversely effect the child's condition.

Most students with asthma/allergy do require some modifications to the school environment (Hobbs and Perrin, 1985; Smith and Luckasson, 1992), however, "safe" (Feingold, 1992) or "barrier-free" schools will benefit all students, not simply students with special needs (Asch in Lipsky and Gartner, 1989, p. 189). The issue of individual versus group rights becomes an important one. When do the needs of the individual interfere with the needs of the group? If meeting the medical needs of certain individuals in the class, interferes with the rights of the class as a whole, whose rights take priority? In the event that the needs of individual students interfere to a small degree, with the rights of the group (e.g., excluding class pets), or with the rights of another individual (e.g., to wear perfume), the right to access to a safe school environment must be carefully considered. If the school environment is safe for students with asthma/allergy, then school personnel can feel confident that the classroom experience presents little risk to the child. An important part of the treatment a child with asthma/allergy receives is the elimination or control of the allergens [or triggers of asthma] in the child's environment. "This may mean that the student will require special precautions concerning the air in the classroom, as well as restrictions on playing outdoors during recess, playing with classroom pets, eating certain foods, and handling certain teaching materials" (Smith and Luckasson, 1992, p. 440). Other hazards in the school environment may be cleaning chemicals; paint fumes; carpeting; roofing materials, such as tar; pest control chemicals; art, science or shop supplies; malfunctioning ventilation systems; perfume; scented stickers and pens; and room deodorizers (Feingold, 1992). Not all children with asthma/allergy will react to all of these triggers, however, all of these triggers will effect most students, to some extent (Feingold, 1992).

Unfortunately, school board officials still consider themselves as having the right to exclude a child with special health needs from the regular classroom, in the event that they deem the child difficult to serve within the school setting. School districts can currently meet their obligation by offering the children home-bound education. As long as this is an easy option for school districts, no further progress will be made toward the successful inclusion of students with asthma/allergy. The big question remains then; how far does a school district have to go to assure that the child with asthma (or any child) has access to an education in the regular classroom?

This chapter has served to build a sense of what has come before the current investigation. I have tried to introduce as many key issues as possible in order that we may all begin the present research journey with an understanding of the contributions of other researchers in the fields of chronic illness, family adaptation, and inclusive education. And now, I return to the current investigation to outline how it has been constructed over time.

Chapter 3

Methodology

Research Design

This chapter will explain how this investigation has been conducted. I will describe each aspect of the research experience in an attempt to bring you, the reader, to the place and point in time where our personal stories begin. Although the research process has been circular and recursive in nature, I have chosen to use separate headings here, and in chapter six, to outline the distinct methods and techniques used throughout this study. The research process has been in no way linear, nor has it, nor could it have been, organized according to these headings.

Method

This is a qualitative study which is naturalistic and descriptive in nature. I have chosen narrative inquiry as the guiding method for this investigation. Connelly and Clandinin (1990) clarify narrative terminology in the following way:

> It is equally correct to say "inquiry into narrative" as it is "narrative inquiry". By this we mean that narrative is both phenomenon and method. Narrative names the structured quality of the experience to be studied, and it names the patterns of inquiry for its study. To preserve this distinction we use the reasonably well-established device of calling the phenomenon "story" and the inquiry "narrative". Thus we say that people by nature lead storied lives and tell stories of those lives, whereas narrative researchers describe such lives, collect and tell stories of them, and write narratives of experience (p. 2).

From the very beginning of my research journey this study has presented itself as a story, the story of a family dealing with asthma. Long before our story became a research study, it was being lived, told, relived and retold. The story grew and changed as our lives unfolded. As I worked with my family and a second family, my intention was to "foster reflection and restorying on the part of the participants" (Clandinin and Connelly, 1991, p. 15).

This study is based on the lived experience of the participants. I hope that, through a process of interpretation, the lived world of each participant has been illuminated through the stories (narrative accounts) which have been mutually constructed (Clandinin and Connelly, 1991). By writing the stories of the families in this study in a compelling and persuasive manner, I hope that readers will be enticed to enter the world of the child with a chronic illness and see in a way which they have not seen before. Barone (1992) believes that " great stories enable readers to gaze in fresh astonishment upon a part of their world they thought they had already seen. They also allow readers to get better acquainted with people they thought they had already known" (p. 20).

By creating stories of our experiences I have tried to "impose order and coherence on the stream of experience and work out the meaning of incidents and events in the real world" (Carter, 1993, p. 7). I do not believe that the rich and complex experience of the participants can be reduced to a set of rules or factual descriptors. Therefore, I believe it is best understood through the structure of narrative inquiry. "Narrative structures provide a format into which experienced events can be cast in the attempt to make them comprehensible, memorable and shareable" (Olsen in Carter, 1993, p. 7).

My family has been living this experience since the day our son was born. As I began to form the seminal ideas for my Masters research, I wondered if there was a 'study' in our lived experience. The idea of using a narrative style to tell my research story began to form inside of me during my journal research course in the spring of 1993. Through this course, I was guided toward a course which investigates narrative as a research method. My work in this class helped satisfy the itch I had about 'storying' my study. As I read and wrote in this class, I grew convinced that it was not only possible to use a narrative method, but advisable and quite exciting!

Thomas Barone (1992) has laid out a set of criteria by which he judges the quality of a story. He and others (Clandinin and Connelly, 1990; Carter, 1993; Schon, 1991) help us think of rigor in terms of a non-scientific language. Words such as compelling, trustworthy, persuasive, and accessible, become the meter stick by which rigor is measured in narrative inquiry. Barone lists accessibility as an important criterion. He makes a strong point of his belief that people in general speak simple language and therefore, research texts should be written in common language, with meaning which is readily grasped and easily shared. He also lists compellingness as a key criterion, saying that a story must be compelling so that people will desire to read it. Moral persuasiveness is the third criterion outlined by Barone. "A persuasive story is one that results in a reconstruction of a portion of the reader's value system. When a persuasive story is moral, the result is a reader who has grown to understand and deplore the cruel social forces that impinge on the lives of individual characters" (p. 20).

Participants

This study, being the story of a family living with chronic illness, features the story of my family: myself, my son Joshua, and my husband Frank. My stories, as mother and researcher, play key roles in this study. My experience as the mother of a child with chronic asthma will be nested in the stories of the other participants.

I have chosen to include the stories of a second family whose members are also dealing with chronic asthma. The "Underwood" family has agreed to assist us in the task of highlighting the lived world of such a family. The participants from the Underwood family are the child with asthma, "Cameron"; the mother, "Pat"; the father, "Al"; and the sibling, "Emile". The Underwoods have been given pseudonyms with the intention of protecting their privacy as much as possible. Contact with the Underwood family was made through a local asthma support group to which both families belong. The family was asked to participate in this study for several reasons. First, after having the study explained to them, they were all willing to participate. Second, one child in the family had asthma. Third, the family is a two parent family, as is our family. I was intent on telling the stories of both fathers and mothers. Fourth, the family had two children which meant that I could include the story of a sibling, something which is missing in our own family story. One other family was chosen, as opposed to several or many, because of the nature of the study itself (being qualitative and descriptive). My aim was to include fewer in-depth stories to illustrate the complexity of the lived worlds of these families, rather than to present broad statistical, survey-type information. The stories of one other family serve the purpose of this study well, and I felt that the stories of seven individuals was a manageable task for the scope of this study.

The issues of conducting research within one's own family were discussed at length prior to the outset of this investigation. The benefits and difficulties of doing so have been closely considered throughout the study, and will be addressed specifically in chapter six.

Limitations

The findings of this study are limited to the families involved. As personal and compelling stories are by nature subjective, the findings of this study are not generalizable in the traditional sense of the word. I anticipate that the experiences shared in the research text will in some way touch other families who may be in similar situations, and readers who may in some way relate to these stories. In this way then, the findings may be generalizable in some sense.

Delimitations

Seven participants have been chosen, all of whom are members of a family where one child has asthma. Both families live in the same urban area, and are members of the same support group.

Family Stories

My story is represented by a series of stories written by me, based on my lived experience, as portrayed by my journals and in my memory. This series of stories is entitled My Perfect Baby, and it stands in place of the interview/narrative account which I have done for all other participants. Joshua has also written a short series of personal stories entitled, All About Asthma.

Journal Writing

> The writer who is a mother should, I think, record everything she can: make notes, keep journals, take photographs, use a tape recorder, and remind herself that there is a subject of incalculably vast significance to humanity, about which virtually nothing is known because writers have not been mothers.

Although dated, the above quote, which Joanne Cooper (1991) borrowed from Alicia Ostriker's (1983) Writing Like A Woman (p. 131), speaks to me about what I have done with my journals over the past eight years. Ostriker's words help me to express how important I feel this writing form can be in capturing the essence of what is important about lived experience.

I have collected eight years of journalized data in my journals, and in daily logs for Joshua. I was especially tired and worn out during the early years, but I managed to write faithfully. Maybe I wrote to turn toward my own needs for a brief moment, in order to protect myself from total burn-out. Cooper (in Witherell and Noddings, 1991), in discussing Nel Noddings' ethic of caring, points out that the person who is doing the caring, must also, at all costs, care for herself. She adds,

> Many caregivers continue to give to the point of depletion. Writing our own stories works to combat this depletion by reminding us of who we are, while it focuses on and attends to our needs. ...Writing in a journal is thus a way to attend to the self, to care for and to feed oneself. It can be a place to dump anger, guilt, or fear instead of dumping it on those we love. It can be a place to clarify what it is we feel angry or guilty about. It can be a place to encourage ourselves, to support ourselves, in working through that anger or guilt, and it can be a place to transform silence into language and action (p. 105).

These words make sense to me as I reflect on the value of my journal writing. The following passages of self-support, fear, and love appear in my journal:

> I touched a cluster of two or three small cyste-like lumps on the left side of [Joshua's] neck, towards the rear. I just (sic) instantly had the worst fear. Then I noticed another site on the front right of his neck. God! Please protect my darling son. As I tucked him in tonight I thought of tests and pain and hospitals and hope and love and sadness and cheering Josh up in bad times. Please let the lumps be NOTHING. Please let Josh live a LONG HEALTHY LIFE. He's so good--he's so perfect. He deserves the best life has to offer! I love him so very much. (July 22, 1992)
>
> Am I over-reacting to the joys and fears of parenting? Is my mind making more out of this than it should? Am I a normal mother? This much love? This much fear and anxiety? (May 23, 1987)
>
> Back in May, I wrote of my intense feelings of love and anxiety over parenting. While in Winnipeg, I had good talks with K., P., and C. about this. Parenting is so stressful and more intense for people like us, because our expectations are so high. ...I am not a weak person. My ability to cope is no less than most parents. I just care so much! Ugh! Its hard. (Feb. 6, 1988)

In looking back at my personal experience, I see how writing our stories in my journals helped me to organize the jumbled events of my life, as the mother of a child who is ill. Although I had no intention of sharing these journal stories with anyone except my immediate family, I still tried to make them understandable and shareable. Joanne Cooper (1991), paraphrasing Madeleine Grumet, agrees that "telling our own stories is a way to impose form upon our often chaotic experiences" (p. 97). Cooper continues, "journals allow us to examine our own experiences, to gain a fresh perspective, and by that means begin to transform the experiences themselves" (p. 99).

I spent the last weary minutes of every day recording our stories in my journal and in Joshua's log. I was driven to record our story and to try to make sense of it all through writing. I was moved to keep Joshua's log for reasons which were unclear to me at the time. It all started with an innocent "Baby's First Year" Calendar which I had received as a shower gift. I recorded the typical things, his first smile, sleep patterns, medical check-ups, etc.. I also entered any illness, rashes, or discomfort experienced by Joshua. Soon there was medication to keep track of and patterns of illness to discern. The doctors would ask, "When did this cough begin?", "When did he finish his antibiotics?". I was so tired, stressed and worried that it was very difficult to keep it all straight. So Joshua's logs became my 'bible', as I diligently entered everything I could think of. I cherished all of the positive anecdotes, the entrees of milestones reached, and the recorded feelings of love and bonding. I counted on the medical records, reminders of appointments, and notations of signs and symptoms of illness and wellness. My feelings of joy and sadness, my concerns, and my worries are entangled in the pages of these logs. When 'baby's first year' was over, I purchased another calendar with large squares to write in, and carried on with this valuable writing tool. Every year, until Joshua's eighth birthday, I kept his log faithfully. Now that he is eight, and now that his health, and our lives, are less volatile, I have left the daily logs, and begun writing letters to Joshua in a separate journal, which I will give to him when he is grown up. I also keep a small calendar for him, in which I record medical information, illnesses, medications and appointments. This calendar is not like his earlier logs. It does not contain the feelings, the reflection, or the story that the logs do. The following are excerpts from Joshua's logs:

> Joshua didn't sleep well last night. ...Mommy knows something is wrong. (June 2, 1987)
>
> A <u>very</u> traumatic week! Mom and Dad worried sick! Mommy cried and cried. She was so upset about

> Joshua. Dad didn't rest well for days thinking about the horrible seizure. Everyone prayed for Joshua to be all right, and thank God he is okay. This was the worst thing Mom and Dad have ever been through. Please may it never happen again! (June 3, 1987)
>
> [Visit to] Dr. [A.], A Healthy Boy! Yeah! First time since mid-May--8 weeks! (July 13, 1987)
>
> 1990 begins with us all healthy and happy. We feel blessed and charmed to have such a wonderful life and family. (Jan. 1, 1990)
>
> Josh's asthma is not being controlled by Intal and Ventolin. Its getting worse. Josh now has to take Pulmicort Turbuhaler. Its a <u>steroid</u> to reduce inflammation in the lungs. (Dec. 3, 1990)

I began keeping my personal journal in January of 1988. The first volume was actually a "Mother's Journal", which I had bought myself on a weekend retreat in Jasper. My journals contain rich description of family incidents, and personal reactions and reflections regarding the experience of being the mother of a child with a chronic illness (among other things). In August of 1992, I discovered Ira Progoff's (1993) Intensive Journal techniques and my personal journal took on a new look. Regardless of form, my journal, which is now comprised of several volumes, tells the story of me--me the person, me the mother, me the wife, friend, sister, daughter, etc.. The following quotation is taken from my personal journal:

> Joshua was a good boy in the hospital. ...Frank and I were there when they brought him back from surgery [bronchoscopy]. God! It was awful. One hour of <u>screaming</u> with such a sore throat yet, and banging his arm to get the IV out. It bled. He couldn't have anything to drink [no bottle to comfort him]. We were <u>so</u> upset. ...The whole experience was so awful. ...Dr. [D.] came to talk to us right after Joshua arrived back in

> his room. He gave us the good news about the windpipe [not quite so constricted], then the bad news about the cyste [found in the windpipe]. I was so terribly upset. He said, "These things are usually nothing, but there is a slight chance it could be cancer"! I could have died. I could not stand hearing this about my baby, even if it was a remote chance. I was just sick until I found out on Wed. Dec. 23/87 that it was just mucous and fiber, caused by irritation ([from] previous bronchoscopies, etc.). (Feb. 6, 1988)

I have always used writing as a tool to help me understand myself and the issues of life. I was unaware that I was writing to think (Murray, 1985; Yinger, 1985), but I was in fact writing to know, and to work things out. The journal writing research course that I took helped me identify the value of writing to know, and to link journal writing, something which I have done for years, to research. This course, pioneered by Sister Therese Craig, proved endlessly valuable in my research journey. A requirement of the course was to keep an academic journal throughout the spring term. In doing so I came to know that I was capable of analyzing and synthesizing the course content and making sense of what I was learning by journal writing. As I worked through the course content, I realized that writing is a key thinking tool for me, and that I can heighten my awareness of what I am coming to know by journalizing on the topic. I wrote in my academic journal, "I will utilize my journal writing tools to actually create knowledge. ...As my research journey unfolds, I will use what I know of journalizing to discover how and what I know" (June 3, 1993).

Throughout this entire research journey, I have kept a research journal. I have used this tool to make sense of my research findings and to assist me in analyzing and synthesizing data. With the guidance of journal writing techniques which I have learned through The Intensive Journal Workshop (Progoff, 1992), I have visited and re-visited, searched and re-searched the data in an attempt to construct meaning for myself.

Data Collection

I have interviewed participants from my family and from one other family in an attempt to discover commonalties and differences between families. In this way, I have attempted to triangulate (McFee, 1992) my findings by placing them in the literature and in the stories of participants other than those in my own family. Seidman (1991), Spradley (1979), and Patton (1987) were my guides in the interview process.

I conducted one or two unstructured formal interviews with each of the participants, as well as numerous informal conversations. All interviews were conducted on an individual basis and were recorded on audio tape. Pat Underwood was nearby during the interviews with her children. Transcripts were made immediately following the interviews and were offered to participants for confirmation. Field notes were recorded during all interviews and conversations.

Field texts were generated from field notes, journal entries, family stories, interview transcripts and conversations. From the field texts, narrative accounts were constructed. Narrative accounts were shared with participants and the opportunity for mutual construction was provided. Narrative accounts were mutually interpreted, and reconstructed using the recursive process of narrative inquiry (Clandinin, 1992). This process involves ongoing data collection, as field text is gathered at every stage of the recursive cycle. All narrative accounts were confirmed with participants to ensure credibility. Pat and Al Underwood confirmed the narrative accounts of their children, who do not yet read.

Data Analysis

Data analysis has been conducted from a qualitative perspective according to criteria and methods outlined by Michael Connelly and Jean Clandinin. Clandinin and Connelly (1990, 1991, 1993), van Manen (1990), and Tesch (1987) offer advise on discovering themes and making meaning from data. Van Manen states "Making something of a text or of a lived experience by interpreting its meaning is...a process of insightful invention, discovery or disclosure--grasping and formulating a thematic understanding is not a rule-bound process but a free act of 'seeing' meaning" (p. 79). Interpretation plays an important role in narrative inquiry. The process of interpretation begins with the field notes and continues throughout the data analysis.

Tesch (1987) argues that intuitive analysis may actually begin before the study is born. She points out that few qualitative researchers choose topics of which they know nothing and in which they are not interested. Therefore, being deeply involved in the phenomenon, the researcher may be capable of producing an adequate account of what his or her findings will actually look like, prior to conducting the study. Because I am so personally involved with this topic of study, I had many preconceived ideas of what this study may disclose. Prior to beginning the study, in an attempt to heighten my awareness of these assumptions, I listed what it was that I expected to confirm by this study. The effectiveness of this exercise will be discussed in chapter six.

All field texts were analyzed and compared in search of recurring ideas, common meaning, patterns and emerging narrative themes. Clandinin and Connelly (1993) describe the importance of reflection and of asking repeated questions as a means of discovering meaning in the field texts. The process is recursive and circular in nature (see Tesch, 1987 for a discussion on the non-linear flow of the process of searching for themes).

My research journal has played a key role in data analysis. Ira Progoff's journal techniques have been used to assist me in making meaning throughout my search.

This chapter has served to clarify how this research investigation has been designed and conducted. We are now ready to enter the world of the people who have participated in this research adventure. Let us then embark on the next leg of our journey which will illuminate the lived experience of its participants--the actual day to day existence, trials, and tribulations of seven people living with asthma.

Chapter 4

Narrative Accounts

The following chapter contains the stories of all the participants in this study. With the exception of Joshua's Asthma Story (or where otherwise noted), these stories have been written by me. My own stories have been written based on the years of journalized data which I have kept since the birth of Joshua, and on reflections and memories. Because they have been written at different times and on different subjects, I have chosen to include the date that each of my stories were written. This is not the case with the other stories. The stories of Joshua, Frank, Cameron, Emile, Al, Pat, and of the Underwood Family have been constructed from conversations and interviews which I have had the privilege to engage in with these very special people.

My Story

The journey represented by my personal stories began in May of 1985 when my husband, Frank, and I conceived (what we thought to be) our first child. Our hearts and minds were full of wonder and anticipation as we prepared to enter a very new stage of our lives. We would soon be parents! Wow, us parents! It was special to imagine! We imagined having one darling baby, and then, possibly...the parents of two! Could this all be real? Was this what destiny had in store for us?

We naturally hoped that our dear baby would have ten fingers and ten toes, and be the picture of health. After all, the pregnancy was going along according to plan, with the exception of the question of size! Was this one baby growing inside of me, or two? With the aid of modern technology we confirmed, that we were in fact expecting one very substantial child! Oh well, we could surely deal with that! We reminded ourselves on a regular basis, that most babies are born perfectly healthy; and this baby was certainly thriving, that was clear!

Today, in 1994, we have a much clearer picture of what fate had planned for us. It was not at all clear in 1986, when our beautiful son Joshua entered this big bright world! Our story, as it unfolds on these pages, tells the tale of our journey, from that day to this. Please join me as I revisit the milestones along the way, and recount the joys and the sorrows of parenthood, and of our life as a family.

"My Perfect Little Baby"

Part 1

Joy, Worry And Confusion

(September 26, 1993)

Ah! The day my son was finally born! What joy I felt; what relief; what emotion; what intense bonding! Wham! In love just like that! Such a darling little fellow. Little?! Did I say little? Twelve pounds does not qualify as little! Ah, but he was little to me, and so sweet, and so precious.

But what was this?! They were taking him away! "Grunty" they said, and off they took him to the Neonatal Intensive Care Unit (NICU)! Why? What could have been wrong with my perfect little baby? What was going on? All of this through the noise of the operating room, the chatter of my bones as I shivered uncontrollably, the tears of joy running off my face, my arm tied down, the screen between me and them at my belly, and the epidural "meds.". They mumbled in doctor lingo about my baby's breathing, then whisked him away! I was there and awake, but it all happened so quickly.

Then, out like a light. Morphine! I knew nothing. I was aware of nothing else until well after midnight when the nurse brought Joshua to me for a few very special moments together. That first wonderful cuddle! He seemed so perfect. He was back from NICU. "He must be okay! He has to be okay!"

Then out again until 5:30 when the nurse brought him for a feeding. What a pro.! He sure knew what that was all about!

On day five, they were doing a chest x-ray; not the first, but the second x-ray! What was going on? No one said anything! "Is he okay?"

Then it all began happening. He became ill, then fussy; "colic" they said. Then "croup", then ear infections. Then another doctor and more tests! Then more illness, and chronic throat and voice problems; "hoarse and raspy" they said. On and on it went, through weeks of recurring illness, more tests and, of course, very little sleep. Sure, I was beginning to have some serious concerns (not that I was able to make a whole lot of sense out of their lingo and the double talk, especially considering I had had so little sleep).

Then, four and a half months after that beautiful delivery, they said he would have to be admitted to hospital. I fell apart. I trembled and sobbed as I carried him from the doctor's office, across the street for immediate admission! "Oh my god! Oh my god!", was all I could say.

From that day till this, it has been an emotional roller coaster for me, and a long haul for my 'perfect' little baby.

Part 2

What's Going On?

(October 17, 1993)

Gradually it all started to make some sense. In February, 1986, my son was born with a respiratory disorder; this we knew. He was ill far more often than other babies; the reason here was not clear. His voice was unusually hoarse and his breathing was raspy. Exploratory surgery (bronchoscopy), at four and a half months of age, determined that Joshua had soft cartilage in his larynx, and that there was an artery pressing on the windpipe, causing a narrowing of the windpipe. The doctors told us that this happens sometimes, but almost always improves by eighteen months of age. Joshua would be prone to chest infection and pneumonia. "Okay, so we can handle this", we thought.

As time went on Joshua experienced more and more health problems. He had frequent bad colds and chest infections. He was often run down from long colds and actually became so ill at sixteen months of age, developing a blood infection, that he had a febrile seizure and was in the hospital again. He had recurring ear infections, and the ear, nose and throat doctor put him back in the hospital again at age twenty two months to insert tubes in his ears and to perform his second bronchoscopy. This procedure confirmed that the narrowing was still a problem. A fibrous cyst was also removed from his windpipe at this time.

A second health issue slowly became a serious concern. Joshua's pediatrician gradually began to use the terms "asthmatic symptoms" and "asthmatic tendencies" to describe his condition. I repeatedly questioned the use of such terms and how they differed from the term "asthma", but straight answers were difficult to get. Then in March, 1988, the dreaded day came that Joshua was actually labeled "asthmatic". We had lots of time to accept the inevitability that he may develop asthma, and the doctor had prepared us in his own way to hear this news. In fact, Joshua may have been born with asthma and it was simply undiagnosed until this point in time. Nevertheless, I was upset that now he had this lifelong condition to deal with. What next?

Shortly before Joshua turned three he was hospitalized again to replace the tubes in his ears and to re-do the bronchoscopy for the third time. The bad news this time was that the narrowing had resulted in a permanent 50% blockage in the windpipe. One doctor did the surgery and another doctor shared the results with us. I still do not know if it was what we were told or how we were told, but we were devastated! The doctor told us of the blockage, which was caused by a misplaced artery, and then went on to describe open-chest surgery as the only possible "cure". He made it clear that neither he, nor the surgeon, were recommending that this surgery be done. There was no guarantee that Joshua would be well following the procedure. There would be serious risk involved. Because of the asthma and chronic chest infection, Josh might remain chronically ill even following such major surgery. Until we had a chance to speak to the surgeon himself, we were extremely distraught about this permanent blockage, the misplaced artery and its effect on the heart, the possibility of such a tiny child having to undergo major surgery, the limitations under which Joshua would live as a child and as an adult, and, of course, the actual seriousness of the condition, which was not as yet clear to us. This was indeed a new low on our emotional roller coaster!

The emotional ride carried on and on. There were so many ups and downs, so much unknown territory, and never-ending disappointment. There were endless decisions with regards to medication. We were now at the stage when the asthma medications were experimental and prescribed in multiples. There were treatments, devices and equipment that went along with it all. We disliked Joshua being on constant "meds.", but we were especially upset when he was prescribed inhaled steroids at the age of four years, ten months. We reluctantly gave it a try. We tried everything the doctors recommended, providing they could convince us it was worth trying and free of significant risk. I wondered on several occasions whether the doctors were using Joshua as a "guinea pig" or a test case. They seemed so excited and intrigued with the unusual details of Joshua's condition. Once a specialist telephoned a fellow doctor, specializing in some other area of medicine, and shared the challenge and intrigue of Joshua's case with this doctor as we sat in the treatment room next to him. It was disheartening to hear that Joshua's case was such a mystery to them both. It left me with more fear that something awful was wrong and that even the "experts" didn't know what to do. It seemed that these "specialists" were putting a lot of energy into making educated guesses about my little boy. Of course, I realize now that medicine is not an exact science, and doctor's do study the "clues" and use the process of elimination when diagnosing illness. It just wasn't very comforting to me at the time!

Then there were the "surprises" and contradictions; he has croup, he doesn't have croup; he needs this certain device, there's no evidence such a device makes any difference; he needs antibiotics, he shouldn't be on antibiotics! The biggest "surprise" was in January 1991, when one specialist "clinically proved" that Joshua did not have asthma, and could go off the steroids! Hooray! We were all for that diagnosis! Unfortunately, another doctor proceeded to "prove" that Joshua did indeed have asthma and was actually ill far more often when not on steroids! So, back on steroids! What's going on?!

Part 3
Chronic Worry
October 17, 1993.

I count my blessings on a regular basis. I am endlessly thankful that Joshua is a happy, capable, thriving child. I know there are much worse conditions, and I know families who no longer have their perfect little baby here to hold. I know my family is fortunate in many ways, and this good fortune has carried us through some difficult times. However, at those times when my heart is breaking for my child, or when I feel that I cannot possibly cope with my child being ill one more time, it is hard to remember how lucky I am. On three occasions, I have watched the O.R. staff wheel my darling son through the doors of the operating room. I have sat outside a treatment room listening to my baby scream while the doctor performed yet another unpleasant procedure. I have entered my house to find four large firefighters leaning over my baby, attending to him following a febrile convulsion. I have waited in despair for test results to come back telling us that there was no cancer or Cystic Fibrosis. I have watched my son cough three times a minute, while semi-conscious, following an adult dose of Codeine. I have driven home from the doctor's office, in tears, trying to process the news of the latest test results.

I constantly monitor, and even celebrate, my son's days of wellness, all the while dreading the next round of illness or tests. When will he be ill again? How ill? What "meds." will he need? What tests will they do? What will they find? Do they really know what's wrong? As time passes, or after extended periods of good health, these fears subside and I become less aware of them for a while, but at the first sign of illness the fear and anxiety clutches my heart again. I think this constant worry has been referred to as chronic grieving or chronic sorrow. Boy, can I relate! I read about chronic sorrow in an article somewhere. I sure didn't need it explained to me. I recognized right away that I have been living with chronic sorrow since the birth of my "Perfect Little Baby". I used to think I was over-reacting or over-sensitive. I thought I was coping poorly and that all other parents handled things like this way better than I did. But as friends and family share their impressions of what we, as a family, have been through, and as I place it all in perspective, I see that I am not over-sensitive, and that my coping skills have served me just fine.

People's reactions are confusing at times. Some people take one look at Josh and wonder what all the fuss is about. (He really does look strong and healthy most of the time). But those who are close to the situation usually worry about Joshua too. My sister has expressed her surprise at how much we have been through, and has reminded me that this is not "normally" what parenthood is like. People with whom I confide know how tough it has been for us, and often say how fortunate they feel to have healthy children.

As I read back in my Mother's Journal I find numerous entries about good fortune, as well as, fear. There are repeated passages pronouncing my enormous love for Joshua and my gratitude that he has come into my life. In the same passages I find expressed the paralyzing fear that something tragic may happen to him, leaving me empty and shattered. I assume that most parents feel as I do, but I am left wondering how Joshua's health condition leaves me vulnerable to this intense fear of losing him. I tell myself he's okay, and I go into his room to check his breathing and temperature. "He's fine!" He is mostly fine now. For this I am eternally grateful. It's still hard to shake the chronic worry; the worry that the next illness or heartache is just around the corner.

Part 4
Off To School
(November 3, 1993)

Having Joshua attend school has been a different sort of challenge for our family. Joshua is fortunate in that he is able to attend a regular school program. The most serious symptom of Joshua's condition is frequent illness. He is so susceptible to chest infection and serious coughs, and there has been no such thing as a "common cold" for Joshua. His doctor has always advised against group childcare because of the increased exposure to illness and "bugs". There are always so many illnesses going around school. This places Joshua at a far greater risk of serious illness, and of needing heavy doses of medication. He has missed a lot of school due to illness.

I recall trying hard not to be annoyed at the little girl who sat directly facing Joshua in school the year he contracted "whooping cough". It seemed like she coughed in his face for weeks with an unattended cough. I'm sure she had parapertusis (a form of whooping cough), although she managed to fight it off without missing school or being hospitalized. Joshua caught her "cold" and was desperately ill with parapertusis, and on dreadful amounts of medication for an entire month. I felt like phoning the little girl's mother and telling her how upset I was that her daughter had attended school with such a contagious "cough". I would have said, "Don't you know how susceptible Joshua is? Don't you care?" But, of course, the mother couldn't have known, and I'm sure she was just as concerned about her daughter as I was about my son. But for a while, I imagined how I could "blame" this terrible illness on that woman or that child. I know now that there was nothing anyone could have done to prevent Joshua from becoming so ill, and it certainly wasn't the little girl's fault, or her mother's. I also know that school is not a germ-free place and that Joshua will probably always be at risk in group settings through no fault of any person. That's just the way it is!

There are several issues for Joshua around illness and school absenteeism. He falls behind in his school work, and although he is bright and can easily catch up, he is quite anxious about falling behind, and he hates missing school. He also falls out of "synch" with his peers socially. He has had some difficulty with peer relations, partly because he is so young, so he doesn't need the added disadvantage of absenteeism. When Joshua is well enough to return to school he always has some concerns about re-entry. He feels he won't know the work, and he worries about fitting in at recess. It is very important to Joshua that his teachers welcome him back after an illness, and he is upset when they do not do so.

There are times when Joshua requires medication during the school day. At the times when Joshua needed numerous or frequent doses of medication we have kept him at home, thus avoiding situations where school staff would have had to be asked to administer treatments or "meds.". At times he has had to administer his own "meds." at lunch hour, but only his inhalers or a pre-measured dose of antibiotic. Any time that he has required a treatment via air compressor and mask during the school day, we have kept him at home. Joshua could very well require such treatment at school in the future. In anticipation of such a time, I approached the principal of our school to ask whether or not such a service would be an option, should we ever require it. After flipping through several school board documents, the principal told me that the school would be willing to act as a "reasonable parent figure" and perform any basic function that a parent may be required to perform. He indicated that the staff would discuss it, consider the request on an individual basis, and attempt to do the "reasonable" thing to help Joshua administer his own treatment, which is all that would be involved.

Joshua is learning to monitor his own condition and to advocate on his own behalf. He is still only seven and doesn't always know what to do or say. As he gets older he is less willing to discuss his condition or do his "meds." in front of his peers. He also talks more about being unlucky and how he hates having asthma. It is bothering him more and more that he cannot run as much or as fast as the other children. For these reasons, I wonder whether or not he would speak up and let someone know if he were to become compromised (experiencing respiratory distress) at school.

There have been many common everyday concerns that we have asked the school staff to assist us with. Upon our doctor's recommendation we have arranged that Joshua remain indoors when the temperature is lower than minus eighteen degrees Celsius. We have asked that we be notified if there will be pets in the classroom, or if the class is going to a farm or a zoo. We have advised the teachers that Joshua may, on occasion, miss school when he is not ill. Joshua does not have the stamina or resistance of other children. We keep him home as a preventative measure when he is fatigued or when he seems especially susceptible to illness. We have asked that the teachers monitor Joshua's breathing in gym, and that they call either Frank or me at the first sign of any illness or distress. We have asked that all teachers, as well as substitute teachers, receive the medical information which we have provided to his homeroom teacher and to the office.

The fear of a medical emergency at school has been a strong motivating factor in assuring that all school personnel have the information they require. We have provided the school with as much information as possible, including a medical data sheet with Joshua's photo, a description of his condition, a list of symptoms, and an emergency plan. We, as a family, have accepted full responsibility for managing Joshua's condition and for informing school personnel of his current situation and his special needs at any given time.

I have tried very hard to have Joshua's teachers understand how this medical condition affects him physically, emotionally, socially and intellectually. I have tried to show teachers that asthma affects our whole family, and that we are doing our very best to manage Joshua's health and to assure that he is happy and well adjusted in school. It is important to me that the school staff know who Joshua is, and that they try to understand him as an individual child, a "normal" child who is carrying an extra burden--chronic illness.

For as much as we try to look at Joshua as a "normal" child, he has never really been "average" in any way. He was born unusually large, and has always been extremely big for his age. He is usually the tallest child in the class, the youngest child in the class, and usually one of the less mature. He was also born with crooked feet and cannot keep up to his peers because of his feet and because of his asthma. Joshua is not an average student academically either. He is very bright and articulate, and in fact, has been labeled "gifted" by the school system. This is yet another thing that has set him apart from his peers through the grades. I feel that the interplay of all of these factors makes Joshua a child of very special needs.

We have had some encouraging success in having Joshua's needs met at school. His case is not severe, and to this point, most things that we have needed assistance with have been handled with care and cooperation. One thing that complicates the consistency of his care is the number of teachers who regularly work with Joshua. He has five teachers on a regular basis, as well as frequent contact with the principal, three support staff, two club leaders, all teachers on the playground, and various rotating lunch supervisors. At the present time there are also student teachers throughout the entire school. This list does not include any substitute teachers which he may have in place of his five regular teachers, or filling in any of these many positions. Our school also enjoys a high level of volunteerism so there are quite often parents and guests with Joshua's group. It soon becomes clear just how difficult it is to have all attending adults informed of Joshua's health needs and of emergency procedures. And of course, other students have special needs of which all adults at school should be aware!

Joshua's grade three teacher, Mrs. "B.", is a wonderful, dedicated individual. I know it must be hard for her at times to understand our needs, because Joshua appears to be quite healthy. We must hope that she trusts us to know what Joshua needs, and that she respects our opinions and requests. We have, on occasion, had difficulty relating to adults who have worked with Joshua. One person seemed to assume that they knew what asthma was all about, and did not listen actively to our explanations and requests. We wanted the opportunity to explain to this person that asthma is not one specific thing, but a manifestation of varied symptoms with multiple causes. I tried to help this person understand that asthma is a kind of umbrella term for many very different individual conditions. When this person said to me, "Oh, my son had asthma so I know all about it.", I became concerned that this person would generalize, or not hear me when I described Joshua's specific problems. I needed to know that this person understood about the blockage in my son's windpipe, and would take it seriously should Joshua become compromised at school. People like this do not leave me feeling confident that Joshua will be safe in their care. I am sometimes left screaming inside, "Please listen to me! It could be a matter of life or death!"

I have always tried to be careful not to come across as an over-protective or unreasonable parent. I feel like teachers will stop listening to me if I rock the boat, or if they don't like me. It is very important to me to keep the lines of communication open so Joshua's situation will be effectively monitored between home and school. I am a classroom teacher, so I sit on both sides of the fence. I hear other parents of children with asthma say that they have been called over-protective. I believe that Frank and I know Joshua better than his teachers or his doctors. I also welcome their professional opinion about 'Joshua-the-student' or 'Joshua-the-patient'. I guess I hope that they are interested in my opinion of 'Joshua-the-child'.

There may be times when I seem over-emotional to others. If so, I hope they will try to understand what I am going through. Maybe I haven't slept well in days; maybe I've laid by Joshua all night listening for him to catch his next breath; maybe I've been anxious about the results of more frightening tests; maybe Joshua is in pain; or maybe we've just had another emergency hospital visit. Sometimes it may seem to others like Joshua just has a cold--"What's the big deal?" But 'just another cold' can be so worrisome to me. Why so many colds? What can I do for him? How long this time? When will the next illness hit? Where will it all end? Although, for the most part, I handle all of this okay, sometimes it can get to be too much.

Part 5
The Vigil
(December 1, 1993)

It's at home where we expend most of our energy in managing Joshua's condition. When he was little he was sick so often--every month for sure--and the nights were the worst. Even before we were aware of the chronic illness I would lie awake listening to him breathe. "Would he catch his next breath?" His breathing was so noisy! He was so congested and couldn't rest well. I heard every little breath right from the start! In fact, Frank had asked, when Joshua was a newborn, if Josh and I were still connected by an invisible umbilical cord. He wondered why he seldom heard what I heard during the night. Joshua woke up crying a lot! Sometimes he woke twelve times a night! I don't think he was simply a poor sleeper, he was just ill so often. We would just have "celebrated" him sleeping through the night and he would be ill again, and so much for sleep! Little did we know that sleeping through the night was a milestone Joshua could not achieve as a baby! And of course, it goes without saying, I didn't sleep much either! I didn't sleep well during the weeks prior to his birth, but looking back, those sleeps seemed heavenly! I rarely had a normal sleep for two years ! I was a basket case! I know now that I had developed a sleep disorder, and I often wonder how I maintained any mental health! I would periodically go to Frank's mom's to sleep (only when Josh was well), but I couldn't get to sleep 'till late and would always wake up early. I just couldn't catch up on my sleep. Grace was my boss at the time. She and I still look back in amazement at how well I managed at work!

When Joshua is very ill we lay with him in our bed worrying and wondering if, and when, we need to take him to the hospital. We lay together, sometimes all three of us; Frank and I watching, listening, counting, timing, recording, sponging and comforting. We monitor his color, breathing sound, breathing rate, temperature, and the movement of his chest. We also assess our level of anxiety, another important indicator that its "time". One such night, at midnight, a very good intern guided us through this "decision" over the phone. She was so calm, so understanding and so helpful. She helped us learn how to make the "decision" of when to take him to the hospital. Once, on one of these hospital nights, my sister and her family were here from Winnipeg. I think this was the first time they had experienced a "decision" episode, and I think it frightened them almost as much as it frightened us.

I am very happy to say that this is not a common occurrence in our household. Since his birth, Joshua has had about six emergency hospital visits (related to illness) and four extended hospital admissions. We are very fortunate compared to other families who deal with asthma. Some children with asthma are in the hospital every month! Our hospital experiences are a drop in the bucket in comparison. Nonetheless, hospital visits are upsetting, scary, and difficult for all of us. My heart breaks every time a doctor mentions the word hospital. If we end up in the hospital in crisis, I am nearly sick with fear. Part of it, of course, is the immediate health concerns, but part of it relates to the chronic worry that I have been living with. Do the doctors really know? What could possibly be found this time? I was most afraid when Joshua had a seizure at home and was transported to hospital by ambulance. The doctor seriously suspected spinal meningitis, and had ordered a spinal tap for our one year old baby. I could barely hold myself together, and only managed to do so if I was at Joshua's side. In the end it was all due to a blood infection which developed as a result of prolonged illness, and fortunately Joshua started to show signs of recovery from the seizure before the spinal tap was actually performed. Thank goodness! It took what seemed like ages for me to recover from the scare. I was overwhelmed with the fear that something awful would happen and Joshua would be snatched away from us. I discussed the impact of the incident with my doctor. She helped me realize that it was natural to be worried, since at the time, Joshua wasn't even well yet. It hadn't been long at all since we had experienced the trauma of the seizure. We had thought Joshua was dying right before our eyes. We knew he had been ill with a cold, and we had just stepped in the door from the doctor's office when the seizure hit. We had told the doctor that we were very worried, but she just sent us home with a prescription! She didn't even check his temperature, which was the reason we had taken him in! We counted on her to help us. It made me think that even the doctors didn't know how to help our little fellow and keep him safe! The combination of events, feelings and concerns was what caused me to be so fearful. In time the fear subsided again, until the next upset.

Until Joshua's condition was stabilized with inhaled steroids, I was constantly on the lookout for signs of the next illness, or indications that his "meds." or treatments needed adjusting. There are usually slight behavioral changes before there are any physical signs. With practice (which we've had plenty of) we have learned to anticipate illness. This is not always the case, but I can usually tell when something is up. Joshua will become fatigued or more sensitive than usual. Sometimes he is too willing to lay around and do passive things. Quite often his eyes will be glazed or slightly different in some way. His ears act as beacons and warn us of changes in his health. They still get red when something isn't right, especially with an allergic reaction. At the first sign of anything we start monitoring closely, adjusting activities, and we may begin treatments, humidity at night, or medication regimes. We are always monitoring the effects of his "meds.", between visits to the doctor. His medications used to change so often, sometimes according to the severity of the illness, but sometimes it was just done on an experimental basis. It is usually my responsibility to monitor the "meds." and to keep a supply of drugs on hand at all times, so we are never caught without. It is usually night time when he becomes compromised, so it is important to stay on top of the "meds." situation. Sometimes I am so tired or stressed out myself that I have to record everything. I used his log books (calendars) to help me keep it all straight

There were times when he was ill for up to two months and we would wait for a chance to celebrate his wellness. It became such a worry when the colds and infections hung on. Joshua has visited his doctors more than any children we know, with the exception of our new friends at PACE (Parents Of Allergic/Asthmatic Children-Edmonton). Joshua has had many doctors; a GP; a pediatrician; an ear, nose and throat specialist; an asthma specialist; a lung function specialist; an orthopedic specialist; and the many doctors and residents who have treated him in clinics and hospitals in Alberta and Ontario. He has made 141 trips to doctors to date, and he's not quite eight years old! The good news is, that rather than his usual 20 visits a year, he only visited the doctor 15 times in 1991, 14 times in 1992, and 11 times in 1993! Now that's progress! The doctors attribute the improvement to the daily use of topical (inhaled) steroids.

We are very happy to see this trend, and to have him on far less antibiotics, however, we are extremely apprehensive about the reliance on steroids, and worried about the effect of the extreme amounts of medication that he has consumed to this point in his life. I am afraid that the medications (especially antibiotics) will fail to be effective, or that Joshua's system will become more and more weakened by such heavy use of medication. I am very concerned about how Joshua will be able to manage future illnesses and more serious health problems (such as pnemonia) if we carry on in the same manner that we have for eight years. Because of these pressing concerns, we have decided to consult a homeopathic doctor with regard to building up Joshua's resisistance to illness, and decreasing his dependency on drugs. Dr. "R." will help us approach Joshua's health from a wholistic perspective, and to explore the use of homeopathic remedies to rebuild his natural ability to fight illness. We look forward to a day in the near future when we can reduce the amount of steroids he needs, and to a day in the not-too-distant future when he can thrive without the use of steroids, or any regularly prescribed medication.

We have always been cautious about medication. We have always made a point of asking the doctors about side-effects, as well as, telling the doctors about side-effects, and they have minimized our concerns, or have blatantly denied that we could be noticing such side-effects! This makes me so angry! Ventolin does make him "hyper"! Cholodryll does keep him awake all night! Damn it! We are the ones who live with this day in and day out! I am beginning to feel that some doctors are extremely desensitized to the concerns about the effects of drugs. I have been told several times, "I have lots of patients who are on much higher doses than Joshua.", or, "This is such a trace amount it can't possibly do any harm." Some doctors seem to almost ignore the written warnings from the drug companies. I know that sometimes the noted complications have been extremely rare, but when we ask a direct question about them, in relation to our child, we expect to receive a satisfactory explanation, not to be brushed off. I ask over and over how a drug works. At times, my questions have been ignored. Sometimes, I get oversimplified answers that do not address my question at all. I think that if I understood how a drug worked, I would be less suspicious of the drug and more optimistic about the effect. Some of the time doctors treat me like I couldn't possibly understand. Then at other times, they tell me to trust my judgment about Joshua's treatments and "meds."! It is difficult for me to get a sense of whether or not a doctor thinks I'm competent! There always seems to be a lengthy 'testing' period when we see another new medical person.

It can be so frustrating and confusing. I have been treated so poorly by doctors. I have also been treated so fairly by doctors--sometimes the same doctors! Once Joshua's school was asking for a doctor's note concerning Joshua's medical school needs, so I approached Joshua's doctor and he almost hit the roof! When pushed as to why he was refusing to provide such a note, he said, "You [as the parents] are the experts on the needs of your child! The school should be taking its direction from you! It is you who should be called first in an emergency!" I could hardly believe I was hearing this! So..., I took this doctor's advice and wrote the letter for the school myself. I explained Joshua's condition, his needs, and the emergency procedures. I stated that Frank and I had been managing Joshua's condition successfully for years, and that we were to be called first in the event of any issues or concerns. I assume the letter was acceptable to the school, although I received no feedback, other than the acknowledgment of its receipt. They did not, however, pursue the doctor's note any further. On this point I strongly agree with the doctor. In many cases, parents are the "experts" on their child's needs, and the school need not bypass the parents to get the "word" from the doctors. I have no problem with the school requiring official prescriptions from doctors, but the day to day "survival" stuff is best provided by the parents.

Part 6
We All Cope
(December 3, 1993)

Joshua handles all of this so well. He actually enjoys being in the hospital! There was a time when the mere sight of anyone in a white coat would have him screaming with fear. He hadn't been afraid of doctors as an infant, but after the seizure episode and all the dreadful tests they made him endure, he was really frightened. As time passed however, he regained his trust and his cooperative nature. He is really good during tests, examinations and treatments. He is also extremely compliant with medication, which has served him well. He doesn't complain unless something is actually wrong, and has always been articulate and honest about how he feels. Sometimes he doesn't let us know right away that he is feeling ill, because he isn't the type to complain, and because he is so used to just coping with it. He is one tough little fellow when it comes to pain and injury. If he cries, we know he's hurting.

I guess that illness is such a common part of Joshua's life that it seems normal to him. In fact, for the longest time he didn't know he was any different than any other child. Illness is a fact of life. Until he was five or six he was very open and comfortable with his medications and treatments. Gradually he began to request privacy for treatments, saying that people would laugh at him. By grade one and two, he was becoming more secretive, and I started to notice that his self-image was changing a bit. He said one day, "I'm just a stupid sick kid! I'll probably be on this medicine for a million years!" It just about broke my heart to hear him say that. Once, last year, when he was recovering from a serious illness (near the end of October), he said, "I hope I can stay healthy 'till the beginning of November, or the end; or maybe the beginning of December!" On October 27th, the day he finished the antibiotics, we celebrated with a family wellness party. He remained healthy for two months, until he caught chicken pox. He didn't have another cold or infection for three months! I guess his wish came true! I think the poor little guy deserved a break.

We try to have as normal a life as possible. We try not to focus on the illness. We try to rejoice and celebrate good health. The times of illness are spent together as a family whenever possible. Joshua loves the special time we can have together when he is away from school or in the hospital. For short hospital visits Frank and I are always by his side. For overnight stays, one of us is with him at all times, while the other tries to catch up at work or get some sleep. When Joshua is ill at home we do our "tag team parenting" thing: I go into work early while Frank stays with Josh, then I fly in the door at noon, while Frank flies out the door to get in half a day of work! I cannot imagine how I would have coped as a single parent, or in an inflexible employment situation!

Our places of employment have been stable and consistent. Through the worst years, we were both in childcare management positions, as members of understanding and supportive teams. We were always able to adjust our schedules when Joshua was ill. I was always free to leave work to stay with Joshua in the hospital. I had the option of pursuing much higher paying jobs, but I had to consider Joshua's needs first. There were many occasions on which Frank and I discussed the infinite value of having such flexibility in our positions.

Because Frank and I both worked full-time outside the home, we needed daily childcare arrangements when I returned to my position after a six month maternity leave. We were fortunate to have a wonderful long-term childcare provider for Joshua. Her name was Rashida. He was cared for in Rashida's home for five years. She took excellent care of him when he was recovering from illness, she monitored his health closely, she honored our requests and respected our needs as a family. She communicated freely with us, and was very quick to call us if she was at all concerned about Joshua. Rashida was an experienced family day home provider and had valuable first aid training. She adhered strictly to medication schedules and was open to learning how to administer treatments in her home. Wow! Looking back, she was a real find! We always appreciated her dedicated care, but we didn't realize at the time how unusual it would be to find a care-giver who was so willing (and not frightened) to take part in medical care!!

There were times when we needed people to help us care for Joshua at home. We didn't know many baby-sitters who could care for him when he was ill or recovering. We are very fortunate to have family and friends who are nurses and therapists. Our friend Lauren, is a respiratory therapist. She has been such a strong support to us. She is not only well trained to care for children with respiratory conditions, she is also someone who knows what we are talking about when we discuss his medical situation. She has been a great emotional support to our family. We have had many long talks about treatments, "meds.", fears and frustrations. We have all become extremely close to her and feel very lucky to have her as a friend.

Having top quality childcare and flexible jobs has been of utmost importance to us. The kind of support we have had from Rashida, our employers, family members and friends is so critical, and has been so appreciated. I only hope that all families in similar situations have, to some extent, the kind of support we have had.

Part 7
Our Support Group
(December 4, 1993)

In 1991, we were fortunate to be part of the beginning of a support group for parents of children with asthma/allergy. I had been wanting to talk to other parents about Joshua's condition, and especially about the chronic worry which I was experiencing. I felt I needed the support of other parents who understood what I was going through. I was looking for information! I was also exploring any possible contacts and resources which may assist me in my university study of families dealing with asthma/allergy. PACE (Parents Of Allergic/Asthmatic Children-Edmonton) has provided me with these things and with much more. I have had the opportunity to further educate myself in the area of asthma/allergy, and have met many people who are living with similar stressors to those faced by my family. Joshua has met other children with asthma/allergy and has enjoyed social events organized by PACE. He seems to like the fact that these events are planned solely for children with asthma/allergy and their families.

When I think of the people in our support group I see very well informed, caring parents. I see families who have been through very difficult times, and children who have been so brave! I cannot help comparing our situation with those of other PACE families. I constantly find myself empathizing with others and feeling thankful for the health we do enjoy in our family. Some of these families have more than one member who has asthma/allergy. Most PACE families deal with far more allergies than we do, and many of the children have severe, life-threatening allergies. Some PACE children have been hospitalized on a monthly basis, and are on almost constant oral steroids. Some parents have watched their children die and be revived by emergency medical teams! Some of the children are unable to attend regular school programs because of severe allergies, frequent illness, low stamina and resistance, and high medication and/or treatment needs during the school day.

As a community, families living with asthma/allergy have endured many hardships. Most of us have managed to adapt and cope just fine. Most of the time we can deal with these stressors within the family. In my experience, families living with chronic illness cope remarkably well, considering what our lives can be like. You might think that we would all be "losing it", or that we would all be depressed, or that our home lives would all be in chaos! Somehow that doesn't seem to be the case. Somehow we manage to draw upon inner strength and family support, and we do pretty well! There is of course some negative impact on these families, but there seems to be so much adaptation and effective coping too.

I have heard some upsetting stories from my PACE friends about the difficulty they have had with schools and with the medical profession. Within our group, there seems to be so many stories of disastrous school experiences. Sometimes, in fact, it is the requirements of one special needs student, which result in distress for another child with special needs. For example, a child with asthma/allergy would almost certainly become extremely ill if a carpet were installed to benefit a hearing impaired student. Another school situation which could in fact be dangerous for a child with asthma/allergy is when a parent requests that his or her child remain indoors due to the weather or the outdoor environment (cold, humidity, pollen, mold). The child may be inadvertently subjected to additional risk by being placed in an unsupervised area for recess. Even when a child with asthma/allergy arrives at school well, he or she could develop a serious health problem in a matter of minutes Because of the seasonal difficulty already being experienced by a child with asthma/allergy, he or she may develop respiratory distress while sitting in a classroom, in the "nurse's" room, or on a hallway bench, where there may not be an adult available to assist in an emergency.

I have heard of similar unfortunate situations involving the medical profession. PACE parents tell me that they have often had to be quite forceful in hospital emergency rooms, in order to have the medical personnel listen to them. In cases where the doctor is encountering the child for the first time, it makes sense to me that they would want to hear what has and has not worked for this child in the past. Many PACE parents have been through such emergencies time and time again, and they have a lot to offer. PACE parents often tell of times when they have not been treated with respect by the medical personnel, and even of times when they have actually been blamed for their child's "attack", with doctors asking, "What did you do wrong this time?" I know that many people have had to deal with medical personnel on an ongoing basis. I'm sure there are probably lots of parents, who can appreciate how much added stress such situations can cause for people like me.

We, as parents of children with asthma/allergy, spend a lot of time working with medical and school personnel. I think that from time to time, we need to be told we are doing okay. We need reassurance from doctors and teachers that we are doing the right thing and that we are not to blame for our child's condition. Of course we rely on professionals to guide us when we are not on the right path, but we also want to be part of the decisions made regarding our children. We need to be treated as the important players we are in our children's lives. We need to be heard and listened to. We do not need to be accused of over-reacting or being over-protective. After all, most families who are coping with chronic conditions develop some very effective strategies and learn to work together to overcome obstacles that some families have never even imagined!

Part 8

What Lies Ahead?

(December 5, 1993)

We always thought of Joshua as our first child. We wanted him to have a sibling. We wanted another child. It seems this was not in the cards. Our lives do not seem suited to meeting the needs of another child. I suspect that we were all coping with all we could have during the difficult times. A second child would not have received enough time and attention. Where would we have found the time and energy to give another child? Who would meet the needs of a second child when we were in hospital or living the midnight vigil? Oh, I know other parents, even single parents, do split their time between two or more children, and in far more critical situations, but it didn't seem like an option we would choose at the time. I feel we coped fairly well and we have always managed to meet Joshua's needs and remain closely connected to him, while maintaining our own health. I seriously wonder how well things would have turned out if we had a second baby to care for. And what if that child were ill? I hate to think of it! I consider Joshua's need for care, love, time, understanding, and security to be so important. I would be very sad if we had not been there for him in some way. I would want the same for a second child. And if that child were ill, I can only imagine how difficult it would have been to give all of this in duplicate! Maybe that child would have been well. Either way, I do not see how it could have been done well; maybe today (because Joshua's condition is stable), but not then. I guess I can honestly say that I am glad we didn't need to find out, as much as I would like to have another child.

Our experience has changed our lives in many ways, as would any parenting experience. We do not know what lies ahead, nor does anyone. But I hope it will be easier now. Things are fairly stable for Joshua at the present time. Part of me still worries, "What next?" I am almost afraid to be optimistic, and I am ashamed of this. I wonder if I make mountains out of mole hills, and I do try hard to focus on the times of good health and on continued improvement. But I catch myself worrying; asking myself, "Will he need the open chest surgery?"; "Will his allergies get worse?"; "Should we try to find a place to live where the air will be cleaner?"; "Will he lead a normal adult life?"; "Will asthma research bring forth some miraculous cure?"; "Will the people of the world come to value and mandate clean air?" I know these are questions we cannot answer, but I ask them from time to time anyway. I do recognize our good fortune and I tell myself on a regular basis that "Everything is good. He'll be okay!"

Part 9
His Ever-Changing Story
(June 21, 1994)

Joshua is now eight years old. We have lived many stories as a family living with asthma/allergy. As our experience and our life world changes, so too do our individual and collective stories. Joshua's story is continually changing. Every time I sit down to record his story it is different. Today was a perfect example of how his story changes. As is evident in his own written stories, he usually thinks of himself as someone who is barely touched by asthma/allergy. However, from time to time, there are sad moments, such as the one we shared in our kitchen tonight.

The zoo trip is coming up at school this week. Joshua has not been well for seven weeks, and his resistance is understandably low. Neither Frank nor I are able to accompany him on this field trip, so we are left with two choices. Joshua could remain at home on

Thursday, or the teacher or a parent helper could take on the responsibility of monitoring Joshua's condition at the zoo. Of course, if Joshua were at serious risk we would not hesitate to keep him at home. In our estimation, however, he is well enough to attend, and until today, he had said he really wanted to take part. So, I wrote a note to Mrs. "H.", Joshua's long-term substitute teacher, explaining the situation. She knows, of course, that he has been unwell for some time now, and she is aware of his special health needs. She kindly called me on her break to say that she would have Joshua in her group for the field trip, and would try to arrange a very small group for herself. We discussed his current health needs and reviewed our emergency plan (including calling 911 if necessary), just in case he should become compromised at the zoo. Mrs. H. took note of the procedures to be followed in the event of an allergic reaction or an asthma attack, and I assured her of the unlikelyhood of the situation requiring an ambulance. She offered to give him special attention, and said, "Okay, well, I'll take good care of him" I sensed that she was nervous. I went on to explain that I really felt it would all go well, but I wanted her to be clear on the emergency information just in case. It is difficult for me to know how his system will react to the zoo environment, given that he has been ill for almost two months. What I am doing is trying to anticipate the unexpected, something that my story as Joshua's mother has taught me to do.

Tonight, after these plans were made, I sat with Joshua to explain the arrangements (he knew that I was going to discuss it with his teacher). To my surprise, he said he was not going to the zoo, and he would not go in an ambulance (on the slight chance that it would be necessary). (He asks me to include here that "[he was] scared, and [he was] scared to go in an ambulance".)

Then came the sad part. Although he immediately acknowledged this statement to be false, he said, "Today I asked God to kill me...'cause I deserve it...not just that [not just because of his asthma]--[because of] everything! I'm just not satisfied with myself!" As he quickly stated, he didn't really ask God to kill him, but I was nonetheless secretly quite upset by the message he was trying to share with me. I was also trying to interpret the message he may be sending. After a brief discussion, I chose to downplay his comments and wait until tomorrow to continue making plans for the zoo. A while later, at bedtime, Joshua prayed, "Dear God, please send a guardian angel to take care of me at the zoo, 'cause I'm really scared. And please take my cold away before [we leave for] Trout Lake."

The message he was trying to give to me is now clear. He is afraid. I reflect on how the zoo situation was presented to him. Did I scare him? Did I scare the teacher? How scared am I? I can only go on my experience, my instincts, and my best judgment. He is well enough to go to the zoo. The day will probably unfold without incident. Joshua must be aware of the emergency plan, and he must be prepared to speak up and tell the teacher if he is having a reaction. The teacher needs information in order to care for Joshua at the zoo. An ambulance must be called in the event of an emergency. Joshua must be prepared to have the ambulance attendants care for him, and transport him to hospital if necessary. I assured Joshua that Frank and I would meet him at the hospital if he ever had to go in an ambulance. We have talked at length about the rare probability of him having such urgent medical needs. I think I have done the right thing in trying to prepare him for an emergency. He is the type of child who wants information, and needs time to think about things and to prepare himself. He also needs permission to speak up to teachers and other authority figures, because he tries to be very obedient. He is also extremely sensitive and fragile in some ways. He is a very young boy to have had to live such stories already.

Most of the time Joshua is very relaxed about his health and very tolerant of all the treatments, missed engagements, etc.. At times, however, he 'blows me away' with his ever-changing story of being a boy with asthma/allergy. His story is shaped by many things, including who he is in the stories of others. Part of his reaction to the zoo situation was based on anticipated peer reaction. He associates embarrassment with having asthma/allergy, and with being taken away in an ambulance. I guess some adults do too.

This investigation has opened many discussions between Joshua and me. I have discovered misconceptions that he has held about asthma/allergy. I have worked at dispelling such mistaken notions, and at allaying his fears. I have also discovered that Joshua has a very clear understanding of certain things.

My story is shaped by his ever-changing story. It is comforting for me to read his light-hearted stories of a boy who is seldom bothered by asthma/allergy. It is also very disconcerting for me to hear his stories of fear or discouragement. Joshua has shared other such sad moments with me over the years. He has told me several times that he likes to keep his asthma private ("sometimes, but not regularly" he adds). Recently, he has expressed fleeting regret that he has agreed to take part in this study, because privacy has become far more of an issue for him of late. We talk. I reassure him that nothing will be used without his informed consent. He is once again agreeable to continue our study together. I realize more than I ever could have in the past, how Joshua's stories belong to him. He is giving me a gift in sharing any story with me. I respect and honor that. I cherish his stories. His stories become part of who I am, and part of my story.

Post Script To Part 9
(also June 21, 1994)

After writing this piece I read it to Joshua, explaining everything carefully. He added, deleted and confirmed it all so conscientiously. He and I reviewed the purpose of this study, engaging in a lengthy discussion about how we hope to reach out and grab the attention of readers who could some day be his teachers. We hope that our story will help them relate to our family situation and to understand students with asthma/allergy. After the discussion I asked Joshua if he understood, and he said, "Ya! I love it!

Upon hearing the compelling piece about his prayer in the zoo story, Joshua called our story "heart touching". From his response, I have concluded that the story must have some compelling qualities, if only to him and me. When Joshua heard his words about not wanting to go in the ambulance, he thought he would like to delete them. He felt he may be "sort of embarrassed" if people should read them. But when the story had been completely retold he said, "Now I feel okay about that. But if you could add that I was scared, and I'm scared to go in an ambulance". I am happy that he feels good about my retelling of his story thus far.

Part 10
In Closing
(June 21, 1994)

As the account of our journey comes to an end, I find myself thankful of the good health that we have experienced along the way, and for the intense love that has grown and flourished day by day. I am also thankful for, and delighted by, the cheerful attitude conveyed by Joshua's own story. I do, however, find myself tired...and all cried out, for although this has been a very welcome and insightful writing opportunity, it has also been painful to relive the worry and the fear. I am now beginning to see why a classmate, with whom I shared a portion of my story, may have used the word 'brave' when referring to my telling of this tale. I had pushed much of the hardship out of my mind and out of my heart, and shoved it deep down into my soul, until, by revisiting the development of our happy little family, the details of the journey began to flow up from their deep hiding place and through my fingers, onto the page. I have always come to know by writing. I should not have been surprised by the depth of thought and emotion that emerged from this task. Through this shared writing experience, I have come to know in a new and rich way, what it has meant to follow this path together over the past eight years. Thank you for joining us. As I leave you, I am full of wonders once again, of what the future has in store.

Joshua's Asthma Story

(These stories were created by Joshua between October 13, 1993 and June 23, 1994. He was seven years and eight months of age when he began to write, and eight years and four months old when he was done. As noted, he has either entered his own words, or dictated his words for me to enter into the computer.)

All About Asthma
Part 1
(scribed by mom)

"Hi, my name is Joshua. I am an asthmatic child. If you are asthmatic you probably know that asthmatic children are usually allergic to dog fur and cat fur. I really wanted a dog, but now that I found out that I was allergic to dog and cat fur, I'm planning on getting either some fish, a reptile or a bird. One of my friends' mom said that there are fish with see-through skin, and I hear they are really neat."

"One day when I was a baby, we found out that I had something called tracheo malaisia which is when you have a blockage in your windpipe. So when I was a toddler and a young child I had lots of colds involving coughing because of my narrow windpipe. It really bothered me then, but I am seven now and it doesn't really bother me any more. And I have much more fun."

"My Mom is in charge of the parties for a company [organization] called PACE [Parents Of Allergic/Asthmatic Children-Edmonton]. It's a group that only asthmatic children can go in. And once a year we have an Easter party and a Christmas party. And my mom usually tells me to bring some of my big Lego blocks called Duplo, for the little kids to play with while the party is on. So far PACE has only been running for one year and for Easter we had Ron Pearson come to do magic tricks for us. And at Christmas my mom bought lots of little books and wrapped them, and a fake Santa Claus came in the room and pretended his elves made them. And some people, like me, traded some books for other books that they didn't have. And I got one that I didn't have. It was really fun! But this year (1993) there is not going to be a Christmas party and the reason why is that PACE arranged to have 30 kids at the party and only 7 kids registered. I'm really sad about that because I really enjoy the Christmas parties and I'm sure that you would too!"

"You can not catch asthma; either you are born with it, or your body develops it. When I was a baby I had really bad asthma, but now that I take a medicine called Pulmicort Turbuhaler, I don't have many colds involving my asthma anymore."

Part 2
(scribed by mom)

"I don't know many people who have asthma and they don't live close to me. If they lived close to me, we could discuss how it feels to have asthma. It feels very frustrating because you can't do things or have things that people that don't have asthma can do and have. And sometimes I feel a little bit left out when other people can have dogs or cats and I can't. Sometimes in gym at school we do a lot of running and it really gets me breathing hard because I'm using up so much energy. When the teacher says 'stop' I'm the only one who's breathing very loud. I also feel blocked up and sometimes I think I am going to get a breathing problem. And if I had a breathing problem in gym, I would have to miss out on some very interesting games."

Part 3
(entered by Joshua)

I have been in the hospital so much that I actually like being in the hospital. Lots of people tease me about that but I ignore them every time because its not their job to tell me what to do, where to do it, and who to do it to. There are lots of people at [my school] who tease me that I have asthma, but there are some people who are really good friends of mine that don't tease me about my asthma!

Isn't that good? At least they don't tease me about how much money I have. I have over $200.00 dollars, cool huh?

When I went to have my allergy tests (very late) [recently] I found out that I was allergic to house dust which means I can't sleep with ANY stuffed animals. But I had some very special stuffed animals and I couldn't possibly sleep without them. So me and my immediate family kind of cheated and let me sleep with the stuffed animals that were very special to me. Their names are Barnaby Bunny, Dina the Dinosaur, Happy the Whale, Jenna the Whale, Gabby the Whale, my Joshua blanket, and my Rudy the Reindeer.

Part 4

(Partially entered by Joshua)

I predict that in the future I will have lots of money to spend on medicine for my asthma and probably by then there will be medicine that will help me fight my asthma and maybe by then I might turn out to have no asthma at all?

Also by the time I'm older I predict I won't have as much allergies to house dust so I will be able to sleep with more stuffed animals. If my asthma gets better in the future I hope to own a dog or a cat.

The real problem with my asthma is all the medicines I have to take. It really bothers me when my mom say's Joshua go do your Pulmicort Turbuhaler, and I always say 'NO! ', and her immediate reaction is always "do it now or you'll miss some of your TV time". So I'm kind of being forced to do it.

I bet that you won't believe this but I've been to the doctor 134 times and I'm only 7 [at the time of writing]. A message to all the little kids with asthma out there: if you're afraid to have a shot or something like that, concentrate on something else, and take it from a guy who's been to the doctor 134 times, I think you'll be surprised of how little it hurts.

(scribed by mom from this point on)

"You see, when you concentrate on something else, your body isn't aware of the shot. So when you get the shot, your blood vessels have to rush to where the needle has been stuck in your body and by the time your blood vessels get to where the needle was stuck in, there isn't much time until the doctor pulls the needle out. And the only way that things hurt is when your blood vessels are around the spot that hurts. A message to all the parents out there who are really worried when their children have surgery or an operation: be sure that the doctors that are doing the surgery or operation are very well trained. And when your child gets out of the surgery or the operation, remember that certain surgery or operations make some parts of your child's body hurt. For example, if your child has to have their tonsils taken out, their throat will hurt very badly. A good thing for your child to eat after he or she has their tonsils taken out is ice-cream, a cold drink, or something cold. When I'm in the hospital, something that makes me feel better is a little treat from the gift shop. My parents job when I'm in the hospital is if one of them needs to go get something in another part of the hospital or city, one parent always stays with me to watch me and make me feel better. Sometimes when I have to go to the hospital its midnight, so I sleep in the car all the way to the hospital. I get scared if I have to get a shot. I'm afraid it'll really hurt. And sometimes it really hurts me even when I concentrate. Sometimes I'm doing something fun and I have to get interrupted to go to the hospital."

"This is just a prediction, but I think my Mom and Dad feel pretty good that I don't have very bad asthma, but they still feel bad that I still have asthma."

Part 5

(partially scribed by mom)

"Since the beginning of May, I have had a very bad cold and today its June 23rd and its still not gone. My Mom and Dad have been very concerned for a long time and they are wondering what is causing it. I wish that it will go away by the time we leave for our trip to Ontario."

(The following section has been entered by Joshua)

This year my asthma has been bothering me more than it has for the past two or three years. I don't feel very fortunate that my asthma is bothering me so much more than it has been. I'm very unsure what is making it do that, but it just does it. Maybe its because we have a new doctor. We call him Doctor "R.". Mom and Dad are so concerned that they wanted another doctor who specializes in something other than antibiotics.

THE END

BY JOSHUA P. WINGROVE

PS Hope you have enjoyed my story.

Part 5
(continued)

(The remainder of this story has been written by mom [also on June 23, 1994], and confirmed by Joshua [on the same day], as he is frustrated and not feeling up to telling his story today.)

Josh is all tired and worn out today. I think he's tired of being sick. It has been a long time. He gets so run down and doesn't like to get extra sleep like the doctors say he should. He does like to drink a lot of fluids (also doctors' orders) because he gets to go on a drink shopping spree!! Maybe he's not aware of how run down he is. I have had to train him to really listen to his body, and to tell us when something doesn't feel right. We still encourage a high level of self-awareness and self-advocacy in Joshua. Sometimes though, he doesn't know what he needs or wants. It is upsetting to see him in such a state. At times like this, I know he is not simply complaining for the sake of complaining, and yet we can't get to the bottom of his problem.

When Joshua is well, he seldom mentions his asthma/allergy. It seems as though he forgets about all the illness, medication, and hospitalization (although he assures me that he does think of his illness, even when he is well). Then, the next time he is ill, he reflects upon his medical past, and will quite often forecast a gloomy picture of his future health. It is this cycle which leads to his ever-changing asthma story.

The rhythms and cycles of the school year are extremely evident in Joshua's story. The natural flow of school days is often interrupted by illness, absenteeism, and fluctuations in strength and stamina. I can't count the number of times, for example, that he has missed the day the class pictures were taken, or the day the Father's Day gifts were taken home. On many occasions I have taken him to school just long enough to write a test, or take part in a dress rehearsal. The teachers notice that he's been away of course, but now his classmates actually acknowledge his return, which means a lot to all of us. As we arrive to join the class on their way to practice their performance for the spring concert, the children bring him up to date in the line up. "Robert is now your partner!", or " You get to wear a hat too!" Joshua feels good because he hates to be ill-prepared or uninformed. Frank and I feel great because the children have noticed he was away, and are welcoming him back into the classroom community. I see this as one of the advantages of being in a small school, and of having the same core group of peers year after year. The children now accept that he will be away, and have naturally taken it upon themselves to 'bring him up to speed' when he returns to school. For the first few years I worried that he was not fully accepted as a member of the classroom community. I think that now he is. This makes me feel much better.

The following is the script of a very recent conversation I had with Joshua. I feel that it illustrates the ever-changing status of his condition, especially when compared to his "Asthma Story", which was mostly written in times of wellness.

D: Can we talk about how you feel now about your asthma? How has it changed?
J: I rushed to the hospital. [June 15,1994]
D: How did you feel?
J: Horrible! I felt like I had a 95% blockage in my windpipe. I was kinda worried that I was gonna faint or something.
D: Were you scared?
J: I was kinda scared.
D: What did you think?
J: Am I gonna faint? Am I gonna live? What will have to be done?
D: Do you think your friends ever wake up and can't breathe?
J: Not unless they have tracheo malaisia.
(discussion about tracheo malaisia--to clarify that it is not a disease, but refers to the shape of the windpipe)
D: You have been away from school a lot again.
J: I took some days off to catch my temper again.
D: You missed some days because you were frustrated, but you had Strepp throat and lots of colds. What do you think the kids think when you are away so much?
J: I'm a dim-wit. I skip school for fun.
D: Why would they think that?
J: 'Cause I skip a lot.
D: Do you think they would like to be like you?
J: What do you mean?
D: Skipping?
J: Well [Jimmy] would.
D: Why [Jimmy] ?
J: Well because people tease him lots.
D: Why?
J: Because he has a learning disability. He doesn't learn fast.
(discussion about teasing)

> D: Now that you'll have a new teacher, what should we tell her about your asthma?
> J: Like who?
> D: Let's just say Miss "T.".
> J: I have a 50% blockage and you better know that. If I cough bad, its okay. Well, kinda half and half. If I get swollen glands, its okay 'cause its usual'.
> D: Why is bad coughing half and half? What could happen?
> J: That might have to--Be aware that I might wanna rush home or rush to the hospital or something like that.
> D: What about if you are absent a lot?
> J: That my tracheo malaisia makes it worse so I might have a higher percentage of staying home. (June 17, 1994)

These words tell a story which is more in keeping with the feelings Joshua shares on a 'down' day. Even though most of his days are bright, I feel it is important to include his words from both perspectives, one of wellness and one of illness.

Joshua's Interview Story

Joshua tells me that until recently he hadn't been sick in a long time, but he remembers when he was little and his asthma was "very bad". He says that he was in Kindergarten when he "started not being sick so much". Joshua describes his health problems as "kinda bad" and says he's "kinda worried" about them. Joshua worries about getting "really bad" and "missing lots of school", to which he adds, "I do not like at all. I repeat, I do NOT like at all!" He also worries about "ending up in the hospital" when he is ill. Joshua used to worry about "dying" or "fainting" or "getting paralyzed" because he knew "asthma can be very harmful sometimes and people could have heart attacks and die [from asthma], but they usually don't". We talked about how, in severe cases, a small number of people do die, and since Joshua describes his asthma as "mild" he doesn't really worry about that any more. Joshua tells me that when he gets ill now he thinks, "I hope I get better soon", because some of his illnesses have been so long.

At times, Joshua has to go to the hospital. He trusts the hospital staff, and says "they are nice and they operate [work] with extreme caution" and they let him "rest between operations [procedures]". At the hospital "they do a lot of tests and x-rays, and take [his] temperature and give [him] medicine".

Joshua can tell me that the things that cause his asthma are illness, allergies, running, and tracheo malaisia. When asked about having allergies and asthma, Joshua said, "Its very severe to get them, and sometimes it can harm you, so if you have asthma [and allergies]--WATCH OUT! "

Joshua says that when he is sick he "coughs and wheezes" and "gets stuffed up". Wheezing is not actually one of his asthma symptoms, so I assume he is referring to "noisy breathing", possibly raspy or croupy breathing. He says because he has tracheo malaisia he doesn't "have as much room in [his] windpipe as other people do", so when he gets a cold he has "breathing problems". Joshua says, "Its really just hard for me". He says it is very easy for him to know he is having "breathing problems" because "lots of [his] windpipe is blocked up so [he'll] start having to kinda push the air through, which makes [him] feel something". If this happens he "starts coughing and not being able to breathe", so he stops running, sits down, and relaxes. He estimates that it takes "30 to 50 seconds" for his breathing to become normal again.

Joshua talks a lot about running, saying that he is "running very fast now!" He tells me that he likes running and that his teacher makes them do lots of running in gym. He proudly tells of winning games of "Tails", "Red Rover", and "Doctor Doctor" in gym class. This is very important and special to Joshua because he used to feel bad that he could not win running games. Running fast at recess is also very important to Joshua because he likes to be the first one out to his fort, "especially if [he is] the boss". He reports that there isn't much time to get lined up when the bell rings to go inside, so he has to "run fast and [he] can get a breathing problem, especially if it is cold outside". Joshua says that his classmates used to tease him a lot saying, "You can't run! Ha! Ha! Ha, ha, ha!" But he says that was when he was a little younger and not now, because he can run faster now (even though he says, "I'm still the slowest in my class! ")

Joshua said, "my teacher is really nice. She lets me sit down if I have a breathing problem", and "lets me call home if I need to". He says if there was an emergency at school she would "call 911 and take care of [him] until an ambulance or [his] mom and dad got there". He adds that he doesn't think that teachers know much about asthma. He says there is "not much emphasis or any classes in the teacher's convention that teach--about how to take care of things when this happens". Joshua feels there should be "a course [for teachers] on how to deal with this until an ambulance or [the parents] arrive". Joshua feels that teachers should know that asthma "can be very harmful" and "very severe", and that "these children need very special care". He adds that teachers must also "have some sort of medicine available at all times". He wants his teachers to know he has "a very bad blockage" (tracheo malaisia), and to know "how to take care of [him]".

Joshua has stated on many occasions how very important it is to him that his teachers welcome him back when he returns to school following an illness. He says "people feel left out when they haven't been at school". Joshua feels "left out" if no one welcomes him back, and he feels "happy and comfortable" when he is welcomed back, because he knows that he is "recognized at school".

When I asked Joshua to talk about an ideal school designed for children with asthma/allergy, he said, "there would be very concerning teachers-- very care-full. And lots of janitors, and very clean". He says it has to be clean because "people with asthma--dust makes them feel bad and when the school's not clean, its all dusty, it makes your asthma--it kinda summons your asthma". Joshua thinks this school would be "just for children with [asthma/allergy]" because "all schools are good for kids who don't have asthma". Joshua feels that children who do not have asthma/allergy would feel "left out" in this special school anyway.

Joshua reports that Frank and I are doing a "really good job" of managing his health problems. He says, "I get better really quick 'cause my parents are really nice to me". He adds that it takes a lot of time to take care of his health needs. He says that Frank and I have to take "lots of days off work", and are always "running around making sure [he's] okay". He also says we "pay close attention to [his] health". Joshua also understands that we "have to spend lots and lots of money on medicine".

Joshua is learning to take care of his own health too. He listens to his body and "when [his] body tells [him] to do something" he does it! He says he tells us immediately if he has an "ache or something". He watches for "hard breathing and wheezing" too.

When I asked him if his asthma/allergy gets in the way of him having fun, he replied, "Well, I could run more and have a dog!" He feels different from other kids because he goes to the doctor so much, and other children "don't have to worry about keeping a puffer in their backpacks". Joshua is very conscious of taking his medicine around his peers. He says taking "meds." at school is okay if nobody sees him. He feels okay if his friends at home see him take medicine (pills), but he feels "funny" or "embarrassed" if they see him with his mask and his machine (to do Ventolin treatments), or inhaling his Pulmicort. If Joshua had a friend who had to have these medical treatments he "would think, 'they have a problem and they need it', and [he wouldn't] make fun of it".

Frank's Story

Frank is my husband and Joshua's father. He is a 42 year old man who loves his only child very much. To Frank, Joshua is a very special individual who is "bright, insightful, caring, sensitive, and fun to be with". Frank is a very involved father and plays a major role in the management of Joshua's health. He has worked in youth care management for many years. His work schedule is regular and flexible, allowing time to be with our family, especially in times of illness.

One of Frank's own stories is that of being the father of a child with asthma/allergy. He views "allergy and asthma as being the same sort of thing". He sees both as "a reaction to an external stimulus, whether that be ingested or taken in through the airways or through the skin". In Joshua's case his asthma is not severe, however, he has a narrowing in the windpipe which complicates the condition considerably. It has been difficult for doctors to know which condition is the culprit in Joshua's frequent illnesses, the asthma or the narrowing. Frank notes that Joshua's allergies are still being revealed to us as the years go on, and that he is unsure as to what extent they are responsible for the asthma and illnesses.

Frank describes the family experience with Joshua's health as unfolding in stages. For the first few years there was a search for what was causing the frequent illnesses and respiratory problems. Gradually over months and months of recurrent illness we began to link the varied medical problems, wondering how they all fit together. We found ourselves looking for a diagnosis. The doctors were hesitant to label Joshua as asthmatic, but by the age of two, Dr. A. was consistently using the words asthma and asthmatic as a diagnosis.

Frank identifies the second stage of Joshua's medical history as one of drug experimentation. This stage involved trying to stabilize Joshua's health by the use of many different types and doses of medication, some of which were quite scary to us in terms of their physical and emotional side effects.

The third stage, in Frank's opinion, being the stage we are in now, is where we are considering other options for maintaining Joshua's health. Although he is physically much more stable than he has ever been, emotionally he is presenting a challenge. Frank is not convinced that the medication has nothing to do with the swings in Joshua's emotional stability, although the doctor has assured us that it could not possibly have anything to do with the medication. Frank speaks of the worries in the following way:

> I think because we've gone through stages, the worries have changed. At one point in time I was most concerned for his immediate well-being, and fearful

> that an attack could be VERY dangerous, perhaps life-threatening, but also may result in more long term damage--continued attacks. I think we've gotten by that now. That may be a sense of false security, I don't think so. I think that he's by the worst part of that now. And at one time we were happy to trade the long term doubt for short term security. Now that we have the short term security we want to take a look at the long term doubt, and make sure that we're okay with his current medication and the impact that will have on him. I don't think its now so much a matter of his illness that is of concern to us, as the medication itself. (Mar. 22, 1994)

Frank continues, "[there were] lots of doctors, lots of hospital stays, seemingly no improvement, often times seeming that there was more deterioration than improvement. For a long time that was a concern. He had a seizure--although not related, you can't help but think it may be related". There were so many tests and so much waiting to hear the test results. Frank was especially worried

> ...when they were doing exploratory stuff...When there were polyps that developed, that concerned me, thinking that there was a connection between those polyps and whatever his physical dysfunction was...I guess for a while I wondered whether or not there was, you know, these diseases like Lou Garrick's or something...that we [didn't] know. "These are all the symptoms. We may not have ever heard of the disease but these all may be symptoms that point directly to that disease." (Mar. 22, 1994)

Frank now feels quite confident that this is not the case, as Joshua is older and has seen so many specialists that we would know by now. He says "the hardest thing is being uncertain about his future. Now we have reason to be concerned in two different ways. One certainly was his health, again, I put that as a secondary consideration now, second to the impact of the medication that keeps him stabilized". We all hope that as time goes on, the amount of required medication will decrease, which seems to be the case at this point.

Frank agrees that living with a child who is ill has been very stressful and Joshua's chronic health problems have impacted the family in many ways. Joshua's social development seems to have been delayed by his chronic illness. Frank describes Joshua as a "Mommy's boy", adding that he is beginning to take some bigger steps towards independence. Joshua has experienced minor problems with peers at school. It is difficult to know if this is due to him being an only child, him being the youngest in his class, or him being sick for most of his life. Frank adds, "I think that its a stressor to know that Joshua's limitation excludes him from a lot of activities with other kids, and although that shouldn't be a stressor, you like to think that your child would not be excluded from any group for any reason. And when he is excluded, and he shows the emotional let down of being excluded, that's a stressor [for us]".

Frank also notes that the lack of sleep has been a significant stressor for our family, especially "if you look at all the times we've been up [at night] with Joshua. During the crisis', people manage pretty well, but its [during] the after impact of those crisis' [when] the stress shows".

Hospitalizations have been very stressful for all of us. Frank tells of such times using these words:

> Well, you can't take your little boy to the hospital and watch him having difficulty breathing without feeling a great deal of stress. You can't see him on a machine [air compressor and mask] three times a day, as a four year old, without feeling some sort of stress and sorrow for that kid. (Mar. 22, 1994)

Frank recalls all of the time it has taken to care for Joshua. "Because of his illness, he has been pampered. We've spent a lot of one-on-one time with him. We've had to sit with him, calm him, read books with him while he's doing medication, that type of thing".

Our family activities have been affected by Joshua's respiratory condition and by his foot problems, although it is to a lesser extent in recent years. Frank says, "Going hiking and stuff like that are things

I would like to do more of and I know we're limited...Joshua would love to have a pet. I'd love to have a pet, and I still hope to be able to have a pet actually, for Joshua. I guess that may not be reasonable to hope, but I think that at some point in time it may be a possibility".

Joshua's condition has also fueled "a lot of discussions/arguments about what is appropriate in terms of medicating Joshua...We both agree that we have to be in some sort of control over Joshua's path to wellness... So we have to be in agreement [on] that, and we aren't always in agreement over how to reach that goal. That's a stressor" (Frank's Interview- March 22, 1994).

Regardless of these stressors, Frank feels strongly that "for as much as it has been very stressful, and it has been very stressful, it certainly hasn't been stressful to the point of having a long term negative impact on our family. I think its had a long term positive impact actually, which is kind of odd to think about" (Frank's Interview- March 22, 1994). He continues, "I think its been hard, and its been hard on everyone, but I also think its been a very rewarding experience...I think that with a child that may not have required our attention so much, we probably wouldn't be as close as we are now...We are much closer now, as a result of Joshua's illness and I think that sure is true with our relationship with him. " Frank believes that at times, we have been desensitized to how tough it has been, but that overall, the long term effect of living with a child who is chronically ill has been a positive one.

When asked if he feels he has enough support from family, friends and professionals, Frank did not hesitate to answer "no". He continued, "I think that when you are in this kind of situation, you feel awfully alone and I'm not sure that there is ever enough support...I think you always want more support". We have friends and relatives who have special health needs in their family, and Frank says, "we were not as sensitive to their children's illnesses as I think we might expect them to be to our child's illness...So it would be pretty hard for me to be excessively judgmental of those who don't provide support for us." We do have friends who are great to talk to, but Frank questions whether they fully understand the impact this has on our family. He even wonders if our friends feel that we overstate things because Joshua appears to be quite well.

Frank does not describe any special coping strategies that have helped us through the tough times. He adds, however, "I think that one of the things we did right was not having a second child. I think that having two children, especially given our first six years or so with Joshua, would have been a real tragedy, because I think the second child would likely not have gotten all of its needs met." Frank does say that we have shared the responsibility for Joshua's care evenly, and that we have always managed to pull together in the times of crisis.

From the beginning, Frank has played a very active role in the management of Joshua's condition. He feels that as parents,

> ...we are certainly sensitive to his personality and his needs. So we play the leading role in terms of identifying when there are problems for Joshua, and [in] trying to help him [on] an emotional level...We don't do the prescribing of 'meds.', although we certainly like to be involved in that, but we offer counsel to Joshua in terms of how to cope...And [we make] sure it doesn't impact him to a greater degree than is necessary...I think in my mind now its clear that we're in charge of our young man's health. (Mar. 22, 1994)

We know our child better than anyone else and are more able to recognize signs of illness. It is our responsibility to be attentive to the physical, behavioral, and emotional signs of illness, and to minimize the impact of the illness. We must be sensitive to his sense of well being and help build his self-esteem.

Specifically on the issue of dealing with medical professionals, Frank says, "we have had to argue on behalf of the fact that we know our child better than they do". In our experience doctors are not always aware of the signs that Joshua is having difficulty coping, in terms of the illness or of the medication. Frank feels a doctor must be in tune with Joshua's needs, and responsive to our needs as a family. A doctor must be attentive to Joshua, and listen to Joshua, and to us. Unfortunately, we have found that some doctors are not good listeners. A doctor is a very important resource to our family and must be chosen carefully. A doctor is engaged to assist us in assuring that Joshua lead as normal a life as possible. Frank adds that if a doctor does not meet our family needs we will not engage him or her.

Frank expresses a general dissatisfaction with the medical community. The following passage illustrates this point:

> The long and the short of it is, I don't believe the medical profession in general, understands asthma anywhere near as well as I would have expected them to...I certainly would not view the medical field as being really competent in terms of dealing with [Joshua's] situation. I don't doubt for one second that they were doing everything within their limited scope of power to try to help Joshua. I wouldn't question their desire to be helpful to Joshua, but I really think that [the field of] medicine doesn't understand asthma/allergy as well as it probably could...I would expect, particularly given the number of people who are asthmatic, that there would be more knowledge about it--that there would be more impact from medication. (Mar. 22, 1994)

Frank feels he has a fairly good lay person's understanding of asthma/allergy, and continues to be surprised by the level of knowledge of asthma/allergy held by medical people, and by the inability of the pharmaceutical companies to develop a wider range of medication to help control asthma/allergy. He says, "There may be individuals who understand it far better. Certainly his specialist has been pretty good with him, and a little more knowledgeable, although you find yourself in a tug between a specialist and a GP, and one disagreeing with the other". Several doctors were initially unable or unwilling to give us a diagnosis, and since the actual diagnosis we have been told both that he does not have asthma, and that he does have asthma.

Frank's speaks of his experience with doctors, saying, "[they] are not all capable of keeping in mind Joshua's history, and I think that's a very important job for a parent...Its definitely our job to make sure that they are aware;...that they recall that he's been on medication this many times over the course of the past few months; that they recall that Amoxil is less [effective] than Pediazole, or vice versa; that they recall that he has a foot pronation".

Frank also questions our doctor's manner, saying, "I don't know whether Dr. A. responds better to males or not." Frank senses that Dr. A. "sees mothers as being somewhat prone to emotional instability". Our doctor seems to afford Frank more respect than he does me, and yet he has told me not to send Frank when Joshua visits his office, as fathers are not as in touch with their children.

Frank describes our role with medical and school personnel as one of strong advocacy. When Joshua is at school we are not with him as we are at the doctor's office. We must have people in the school who are well informed about asthma/allergy and who will advocate on Joshua's behalf. Frank says:

> For as much as I would like [teachers] to know everything about asthma, and particularly our son's problem, I'm not sure that I expect that of them...I think that...it [should] be mandatory that one person in every school become the expert in that area. And that any consideration for cleaning agents or new carpeting, or any of that stuff be--that it be a matter of course that individuals be notified of those kind of things. I think it would be great if every teacher knew all about the impact of asthma. I think though, that it is enough that somebody in the school act as an advocate for those kids. (Mar. 22, 1994)

Frank believes that teachers are already asked to do far too much, and is aware that they have many children and families with special needs. Our experience at Joshua's school has been that most staff members are very conscientious, and that for the most part they recognize Joshua as having a unique health situation. He says, "I think they have taken [a] whole account of his situation, more than just listing him as asthmatic on their book". The teachers who spend the most time with him are, of course, more aware of his situation. Frank explains:

> Its all a very individual thing. Some take it more seriously than others. Some people say, 'Oh yes, I understand asthma', and that's the end of it, and [they] don't really take the opportunity to look at the individual...And I don't think the topic is clearly understood. The problem is that some people view it as being a very general form of sickness that is easily managed. Others are aware more of the specifics of the individual. One teacher that he has is very aware of what is being introduced to Joshua's immediate environment and asks us about that. Others don't know, and some don't care-- I don't doubt that for a second. I think though, happily, for the most part, our experience is that those [who] are ignorant, are ignorant. Its not a matter of choosing to be unconcerned, its just that they are not well informed...[There is] an individual who...shows absolutely no interest in his special needs as an asthmatic, and would rather discount [the asthma] than count [it] as...a factor in his life. Overall, our experience has been pretty positive...And if we take the time, and we have the time to offer them, making them more well informed certainly has been to our benefit. (Mar. 22, 1994)

Joshua's health situation likely appears inconsistent and confusing to Joshua's teachers, as he is seldom ill at school, or even absent anymore. The personnel who are most responsible for Joshua's well-being have not doubted our word that he still has special health needs, even though these needs are not often noticeable in class. Frank adds, "Two years ago they would have seen the impact more of his medication than of his illness in the classroom". Now, with the exception of emotional symptoms, which may or may not be related to the medication he is currently on, teachers do not often see evidence of chronic illness at school. Frank believes it is "our job to make sure they are up to date, and make sure that they understand that he is not by some miracle, a well boy. He's certainly better controlled [by medication]". We have made Joshua's teacher aware of the fact that his health has been stabilized with steroid medication, and that we are monitoring this drug carefully. She does not, therefore, assume that he is suddenly well because he is ill less often.

Frank feels that schools must be more aware, and far better informed about asthma/allergy. He places this responsibility upon the school boards rather than upon teachers in general. He emphasizes that school districts are responsible for students who have asthma/allergy, but that they have been ignoring the needs of this sizable group of children. He adds,

> They've had their heads in the sand for a very very long time, and its only the acts of individuals such as the teachers and principal in our school that keep our son healthy. Its not because of school board policy...But happily, the individuals, at least in our case, have picked up the slack. (Mar. 22, 1994)

This is not the case in all schools. It is clear, Frank says, "that there is a very very dangerous lack of knowledge regarding asthma, and there's not the advocacy I would expect" in schools, where, for example, students with asthma/allergy are not allowed to carry their inhalers.

Frank freely shares that he does not spend much time wondering why our family has to deal with chronic illness, adding that he doesn't feel it is productive to do so. He has at times, however, wondered why Joshua has asthma/allergy and why other children don't. He talks about the guilt of knowing that genetics plays a role in this, but adds that "genetics also provided [Joshua] with some very positive things". Frank feels that Joshua's "limitations are somewhat insignificant compared to [his gifts]". As a Christian, Frank believes that Joshua was given to us because we are capable of helping him and of dealing with his special needs. Frank feels we are very fortunate, and by comparison we are in a pretty reasonable position. Some families are afflicted with all kinds of things that, through no fault of their own, they are less able to deal with. Frank feels that "we have our lives under control and we know where we are going with Joshua, or have a sense where we're going". He hopes that Joshua is developing the immunity to fight illness more on his own, and that he will require less medication as time goes on. Frank worries about the quality of our air, and hopes that with time human kind is becoming more aware of what we have been doing to our air, and will succeed in turning it all around.

Frank concludes, "I wanna advocate on behalf of families who deal with allergies and asthma, and I want there to be greater understanding, but that also goes along with the understanding that I suspect in each family [people] have their own issues to deal with." But Frank also empathizes with teachers and, tries to keep the well-being of all children in mind. He cautions, "We have to be careful not to become so focused on our own children's maladies, and disregard the issues that other children may be facing."

The Underwood Family Story

Al and Pat Underwood live in a large urban setting with their sons Cameron and Emile. Cameron is their biological child, and Emile is their life-long foster child. Emile's older brother, Eric, has also been a foster child in the Underwood home at various times over the years. Al is a member of the media and works evenings, while Pat works full-time days in the field of science. Neither Al nor Pat are from the city originally, and have no other family members living near them. The children see their grandparents only occasionally as it is a long journey to visit them.

Al is a person who has severe allergies and asthma. He considers asthma/allergy to be a "normal part of life", and to be something you "just deal with". Cameron, the Underwood's youngest child, has also developed asthma/allergy. Living with Al, and preparing food for him for many years, has in many ways prepared Pat to meet Cameron's medical and dietary needs. When Al and Pat made the decision to have a child they anticipated that the child may have asthma/allergy, however this in no way colored their decision to have a child. Knowing how effectively Al had managed his asthma/allergy left them confident that they would all manage fine, should their future child develop asthma/allergy.

Over the years, and by a process of trial and error, and information seeking, Pat and Al have learned how to effectively manage Cameron's medical condition. They now believe that with the proper medication there is no need for Cameron to have a serious asthma attack, or to have his activity limited by his condition. They have come to trust their own instincts, to question medical people, and to monitor the effects of all medication. They especially value the approach taken by their current doctor, who tells them to do what they feel will work for Cameron, and call him if they have any doubts or concerns. This attitude and advice sits well with Al and Pat for several reasons. First, because they are now confident that they know how to effectively medicate Cameron at home. Second, because they feel confirmation that the doctor trusts their ability and judgment in treating Cameron's condition. And third, because they trust the doctor to give competent advice in situations where they are unsure of what to do for Cameron.

Al and Pat have had experience with medical professionals with whom they were not comfortable. The examples which they site are of situations where medical people were not frank, honest, compassionate, and most of all, well informed and competent. Pat is especially incensed when a doctor implies a psychosomatic cause for her or Cameron's symptoms, or when a medical person does not listen carefully to what she is telling them. Pat appreciates a doctor who takes the time to talk to her and reassure her that she is not causing Cameron's difficulty. She likes a doctor who is fair, makes eye contact, does not make her feel rushed, and assures that she understands what is being done and why. Neither Al nor Pat appreciate being treated as though the are not well informed, or not intelligent.

Pat feels that asthma is not one of the "bad" chronic conditions. She compared her family situation to that of families living with

Cystic Fibrosis or Down's syndrome, and feels grateful and relieved that her family is able to cope with asthma/allergy as well as they are. She empathizes with the families of less fortunate children, saying how hard it would be in more severe situations where no improvement was in sight. She also compares asthma/allergy to a cold for which there is little relief, stating that at least with Cameron's asthma he can get quick relief with medication. Pat feels lucky that Cameron's most severe allergy is to nuts rather than to something more common and harder to detect, such as egg, corn or dairy products. Al too, compares his situation to that of a another family, empathizing with a co-worker who's teenage daughter suddenly developed asthma/allergy, saying how tough it must have been for them.

Pat states that asthma/allergy is "nothing [they] can't deal with", and both Al and Pat accept it as a very matter of fact thing in their family life. Eventhough both Al and Pat describe the impact as minimal, living with a chronic condition has had a significant impact on the Underwood family. One major stressor throughout Cameron's life has been the lack of sleep experienced by the entire family, but particularly by Cameron and Pat. This lack of sleep was largely due to Cameron's colic in the first two months of his life, however, interrupted sleep has remained a symptom of his medical condition. The second significant contributing factor to the sleeplessness was the fact that Pat and Al had two infants at the same time. The boys are only ten months apart, with Emile being the older of the two. Having two children in itself is reason enough for parents to have their sleep interrupted more frequently, whether the children are close in age, ill, or not.

The lack of sleep and the resulting lack of energy affected many areas of daily life. There was little time or energy to meet the needs of Emile's brother, Eric, who lived in the home during those sleepless years. The effects of fatigue and illness were evident at home, and at Pat's place of employment. Vacations taken to drive to see the grandparents were also adversely effected by the serious shortage of sleep in the family. Indirectly, the lack of sleep also influenced the decision as to whether or not to have another child.

So for many reasons, sleep deprivation has had a major impact on the family.

Freedom of movement has been another area of family life which has been effected by asthma/allergy. Both Pat and Al describe situations where the family freedom of movement is in some way effected by asthma/allergy, stating that they tend to do things more insularly as a family. Pat reflects on how they are "not as free to just get up and go as other families seem to be". They have become accustomed to "weighing the pros and cons" of any activity, with respect to asthma/allergy, before they embark on an outing. On vacation for example, there would not only be a new set of environmental allergens, there would also be the need for medication, and electrical apparatus for administering medication. There is also the added risk with respect to allergies, at other people's homes and in restaurants, where food is prepared by others. Freedom of movement was also affected by the task of finding a baby-sitter who was mature and responsible enough to deal with two young children, one of whom has asthma/allergy.

Within the home there are issues unique to the families' situation. Upon discovering that Cameron was allergic to dust and to animal dander, Al and Pat removed all the carpeting from their home. Mealtime is an added challenge at the Underwood household. There are a great many allergies to be considered when planning meals. Al and Pat believe in having all family members eat the same meal, as far as possible, so that food allergies do not single anyone out at mealtime. Al's shift work makes it more difficult for Pat to know what he has eaten during the week, which in turn makes following a rotational menu slightly more difficult. Overall, however, it is quite clear that "watching out for what you eat" is a very ordinary thing in the Underwood family, and doesn't really "get in the way" a great deal.

Possibly the most consistently felt effect of Cameron's condition is the worry. Pat describes the worry and fear as being of special concern. She tells the story of how someone in Al's past fed him a nut in utter disbelief that anyone could be allergic to nuts! Both Al and Pat tell of their worry for the time when Cameron is out on his own more, and for when he is at school with all the other kids, some of whom "can be so mean". Although Cameron's severe allergies are by far Pat's greatest fear, and although she, Al and Emile are constantly trying to train and protect Cameron, she has not told Cameron that nuts could cause him to die. She feels he is too young to comprehend such a concept, and has chosen, for the time being, to impress upon him that "nuts will make him very, very ill, and he must not eat anything he is not sure of". Al and Pat focus on the need to educate Cameron about his allergies, and work with him until he internalizes the importance of guarding against nuts, and is capable of protecting himself when he is not by Mom or Dad's side. Although Al and Pat agree that the hospitalization was the hardest thing they have undergone with Cameron, the constant worry, especially with regards to the severe allergies, is a big part of the impact that Cameron's medical condition has on the Underwood family.

The impact of dealing with a chronic condition is felt in many ways by the Underwood family. Pat adds however, that although none of these factors are things with which they cannot deal, "all the little things tend to add up". It may be that these stressors impact this family less than other families in similar situations because of Al being a person with asthma/allergy himself. Because of this and other factors, the family seems to cope well with this chronic condition. Presumably, their successful coping strategies lessen the impact of the medical and dietary needs on the family. Their confidence comes from Al's personal experience, trial and error, and from the success they have had with the current medications. Pat, of course, takes her lead from Cameron who is quite capable of communicating his needs to her. If he refuses a "Puff", Pat will go with his decision and continue to monitor him closely. Pat respects Cameron's knowledge of his needs, although there are times when Cameron does not want to have a mask treatment and his Mom and Dad need to over-ride his decision. At times like this Cameron is acting out of dislike for the treatment, rather than on what he knows about his health needs at the moment.

Information and medication seem to be two highly valued resources in the Underwood family. These are issues that appear over and over again in their stories. It is evident that medication is extremely instrumental in maintaining Cameron's health, and providing him with the opportunity for a normal childhood. The need and search for information about asthma/allergy has been clearly stated as a priority in this families' story. Support groups such as PACE and AAIA (Asthma/Allergy Information Association) have been a major source of information for Al and Pat. Both Al and Pat have worked hard to be informed and involved parents. They have educated themselves about asthma/allergy through personal family experience, through conversations with medical personnel, by reading widely, and through their involvement with information support networks such as PACE and AAIA.

Al and Pat accept that it is up to them, as Cameron's parents, to provide school personnel with the information they require to safely care for Cameron at school. Al and Pat feel it is essential that school personnel be well aware of certain things about Cameron's condition. Al believes that school personnel are receptive to such information about their students, however, for the most part it is a matter of them being unaware and poorly informed. They must be educated about the signs of an asthma attack or an allergic reaction, and know how to deal with the situation. They must be willing and able to medicate Cameron at school, and have the medication readily available at all times. They must respect that Cameron will be able to tell them what his needs are, and they must listen to him carefully.

Al and Pat speak a lot of their desire for Cameron to be "normal" and to have a "normal" life. They realize of course that special attention must be given to Cameron with regards [illegible] severe food allergies, however, they want to minimize the extent to which Cameron must be seen as "different". If Cameron can do everything that other kids can do, with the aid of his medication, then the medication plays a role in helping maintain normalcy for Cameron. Al and Pat want Cameron's condition to seem normal to him too. If he sees it as a normal part of his life he may be more able to make it normal for others when he is faced with a reaction, or having to use medication, at school or in other public places. Al and Pat carry on their everyday lives as though this were all quite normal. Pat feels it would be more difficult to cope if a person did not think that their situation was normal. It is apparent that Al and Pat model this philosophy for their family.

Al and Pat do not spend time wondering why their family should have this situation of chronic medical problems. They do not philosophize about the fairness or the reason. Pat believes that when you make the decision to have a child you must be prepared to accept the entire package that comes along with that child. She feels that children are by nature a "problem", and "parenting is not meant to be easy or even fun all the time". She feels that each of her children, and all children, have their own set of "problems". Cameron just happens to have asthma/allergy as one of his. She cannot say that Cameron has been more of a challenge because of his medical condition than Emile has been because of his particular set of issues.

The fact that there are two children in the Underwood family has both a positive and a negative impact on the family. As mentioned, two children means two sets of demands on parents, however, there are some very pleasant pluses to Cameron having a sibling. Emile plays a protective role with his little brother, by monitoring and even tasting the foods that Cameron comes into contact with. Cameron has spent much of his free time at home, as do many preschool children. Home is the safest place for Cameron to be because of his allergies. For a child who spends a lot of time in his home and little time in other children's homes, having a sibling means having a live-in playmate. Cameron and Emile have always been best playmates, and Pat and Al sincerely hope that they will remain close as adults and always be able to count on one another.

It is clear that Pat and Al love their children very much and are proud of them both. Pat says they do not spoil Cameron or put him on a pedestal because of his special health needs. She sees him as "just a little boy who needs some medicine now and again". Family is important to Al and Pat and they try to give each family member whatever they need most. Having two children means making every effort to give equal attention to each of them. The individual well being of each child is of great importance to Al and Pat. Pat goes on to say that the things they hold dear about their children are not based on special needs, but on the fact that they are their children, and are therefore "special".

Cameron's Story

Cameron Underwood is four and a half years old. He appears to be a very bright, verbal boy, with a good sense of humor. He is a sensitive boy who likes to snuggle with his mom and dad, and waits up at night to say good night to his dad, who works evenings.

Cameron lives in a cozy house with his mother, his father, and his brother, Emile. Emile is five and a half years old. Emile has been a member of the Underwood family since before Cameron was born. Cameron and Emile play together often and, according to their mom, are "good buddies". They also watch out for each other at home and at daycare. Cameron and Emile have been in daycare since they were infants. They enjoy swimming and gymnastics, and many other things that children like to do. Cameron tells me he can run "faster than the wind"! He hopes to play on a soccer team some day soon. He loves animals, and spends a lot of time at the zoo with his family.

Pat refers to Cameron as a happy healthy little boy. He is allergic to nuts, dust, animal dander, mold, pollen and dairy products, although he is tolerating some dairy products at the present time. He is a slight child, who has moderate asthma and severe allergies. Allergies, illness and cold air will trigger Cameron's asthma. He is severely allergic to nuts of all kinds, although it is not clear whether he would suffer anaphylactic shock (a severe allergic reaction involving respiratory distress and increased loss of body heat) should he ingest nuts. He has an Epipen (injection device) containing Epinephrine (pharmaceutical adrenaline effective in increasing blood pressure) at home and at daycare, which he has not needed to use to date. Cameron's parents operate on the assumption that with repeated exposure, Cameron could very well have an anaphylactic reaction to nuts. Cameron is very aware of any asthma or allergy symptoms, and speaks up loudly and clearly when he needs adult assistance. Cameron's parents feel he is forceful enough to demand the attention he needs when he is reacting with allergy or asthma, and they intend to teach him to be "pushy" about his medical needs.

Cameron says that his allergies can cause him to get "red spots" (hives) on his stomach. The red spots are "very itchy" so his mother has to "give [him] some--this thing that they put all over the bumps" [Calamine Lotion]. But Cameron says "you wait a very long time and then it gets better and then its gone".

Cameron knows he must be very careful not to eat any food which may contain nuts, because nuts will make him extremely ill. If he does not know what ingredients are in a food, he has been told he must not eat it, just in case there are nuts in it. Cameron's mom, dad and brother help him watch out for foods with nuts. Cameron says "[Emile] just breaks it [a cookie] open and looks inside and tells me if there's peanuts". Cameron reports that Emile will tell his mom, dad or daycare teachers if Cameron is "having asthma". Cameron is told that when he is older he will be totally responsible for what he eats, so he must practice being very careful about food.

Cameron speaks highly of his daycare centre. He says all his daycare teachers know about his allergies and asthma. They do not serve Cameron any food which may contain nuts or cow's milk. Next year Cameron will be in kindergarten. Snack is served in kindergarten so Cameron's parents are teaching him to find out what is in his food before he eats it. Cameron has been instructed to ask his teachers to help him find out what is in the snacks he eats. He must assure that his teachers ask the snack makers or read the snack package to discover what the snack is made of.

Cameron's asthma symptom is coughing, not wheezing which is more commonly the symptom of asthma, and his allergy symptom is hives. Although he is seldom ill, Cameron is chronically "stuffed up" because of his allergies. He had frequent minor cold symptoms as a baby and toddler. He also had a moderate case of colic until the age of two months, for which he was not medicated. Cameron has been very healthy, and does not visit the doctor often, nor does he miss daycare often, as a result of illness. His mother reports that he has a good attention span and has never exhibited behavior problems or hyperactivity as a result of having allergies and asthma, although certain medications do make him very active.

When Cameron "has asthma" he begins to cough. He says his "breathing goes away and its time to have asthma". He will feel "weak" and "can't talk as much". Cameron does not worry when he has asthma, because his "mom and dad will take care of [him]". Cameron says that his mom or dad give him medicine when he is "coughing too much". Cameron has "Dragon Medicine" for his asthma. The medical name for "Dragon Medicine" is Ventolin (a bronchodialator). Cameron calls it "Dragon Medicine" because of the way the steam rises up from his face mask when he does his "Dragon Medicine". (This treatment can be easily done at home or in hospital with the use of an air compressor.) If Cameron is out and about, he can take a "Puff" of Ventolin from an inhaler, whenever he starts to cough. Cameron tells me he also has "Goggle Medicine", which he takes to help him prevent, or control the frequency of, his asthma attacks. The medical name for "Goggle Medicine" is Pulmicort (an inhaled corticosteroid medication). Cameron calls it "Goggle Medicine" because when he is doing his "Goggle Medicine" with his face mask and nebulizer machine (air compressor), he wears swim goggles to protect his eyes from the medicated mist.

Cameron's parents chart his medication usage on a large wall calendar and adjust his treatment according to the ability of the current medication and dose, to effectively control his symptoms. They feel that it is their responsibility to monitor Cameron's condition and medicate him properly in a manner which will allow him to participate as fully as possible in normal childhood activities.

Cameron appears to handle his medical condition very well. He seems to be a very independent boy who does not view himself as "sick" or "handicapped" in any way. Nor does he look or act like he is "sick". His parents say that he accepts allergy and asthma as a normal part of his life and does not complain about the restrictions placed upon him by his dietary needs. He does not like having asthma, (although it is of no particular bother to him) because he has to take a lot of medication that he does not like. He complains, "That bugs me. I hate the 'Goggle Medicine' ...'cause it has too much medicine and it gots to get down and outa this smoke" (the nebulizer has to empty before he is done). He does not like doing his medicine, but he says "it makes [him] feel better".

Sometimes Cameron has to go to the hospital because of his asthma. He says the hospital staff "try to" take good care of him, but he does not like them because "[he doesn't] like white, and they wear white clothes." Cameron had one three day hospital stay, at two and a half years of age, when he was extremely ill from asthma. Shortly thereafter, he was treated for asthma in Emergency, on two or three occasions, but did not have to be admitted. Cameron's parents feel that since they have received extremely reliable medical advice from their new doctor, it is not likely that Cameron will need to be cared for in hospital for asthma, unless his current needs change significantly. They strongly believe that Cameron's hospital visits could have been avoided if they had the information they needed to effectively medicate him at home. Since beginning Cameron's current drug regime, they now feel they are quite capable of managing Cameron's condition themselves, following the competent advice of their new pediatrician.

Emile's Story

Emile is Cameron's brother. He is five years old and goes to kindergarten. He is a large, muscular boy who loves to roughhouse with his dad. Although Emile is a foster child, he refers to Pat and Al as Mommy and Daddy, and to Cameron as his brother. On weekends Emile visits his "other Mommy" and his biological brother, Eric.

Emile is somewhat shy, but we had a pleasant conversation, wherein he told me a bit about himself. He says his favorite thing at school is gym. He lists his favorite color is red, and his favorite TV show as Power Rangers. His favorite toys are dinosaurs. According to all accounts, Emile really likes food, especially peanuts and pizza. Emile complains that he can only eat peanuts outside his house because Cameron is very allergic to nuts. He says, "When its summer time I get to eat nuts...'cause they won't get on the floor". So he anxiously awaits summertime when he will be allowed to eat nuts outside. Emile says summer time is "taking too long" to come.

Although Emile tells me he does not understand a lot about asthma/allergy, he seems to know all about the things Cameron and Dad should not eat. Emile says he watches out for Cameron at home and at daycare, especially for things Cameron is allergic to. If Cameron has asthma at daycare Emile says he just tells the teachers, or phones his mom or dad. Emile says that he worries about Cameron when he has asthma or "red spots".

Emile and his mom are the "taste testers" for Cameron and Dad. Emile says that being a taste tester means "you taste something [before] [they] taste it...and then you "give it to [your]self". He says if he tasted something with nuts in it he would "gobble it up" so Cameron or Daddy couldn't get it. If Emile sees Cameron with any kind of food containing nuts, he will "take it", "eat it", and tell his mom or his dad. When asked what he does to take care of Cameron, Emile says, "I don't take care of him, my Mom and Dad [do]". It is clear this is not entirely the case. Emile notices that "it takes a long time" for Mom and Dad to take care of Cameron when he has asthma. Emile says sometimes he wishes he could have asthma too. He wants to have "Dragon Medicine" and extra time with his mom and dad, just like Cameron. But his parents tell him that he is like his mom, who does not have asthma, and Cameron is like their Dad. Emile says he does not have asthma because, he has "no allergies".

Emile says Cameron goes to the doctor a lot. He remembers a time when Cameron was sick and was in the hospital. Emile visited Cameron in the hospital. He recalls Cameron having "stickers on his tummy" and "having a bath with Grover" to soak off the stickers! Emile says he is a very healthy boy, although his mother says he goes to the doctor more often than Cameron, due to chronic ear infections.

Al's Story

Cameron's father has lived with asthma/allergy all of his life. He shared with me stories of times, when as a child, he thought he would die from asthma as he waited for the early, slow-acting medication to work. Al has spent many years managing his health and dietary problems on his own. He has always had to be very careful about what he eats, and he follows a rotational diet to assure that he does not ingest too much of any one food which he may react to. He explains that he is allergic to many foods, and severely allergic to some, which he must avoid altogether. It seems to me that Al accepts this condition as a normal part of life. He made it clear to me that he does not describe himself as "sick". From all accounts, he does not complain, and he seems to carry on with his daily life as though he were hardly aware of the limitations placed upon him by his asthma/allergy.

Al is a young man, who shares his condition with his son Cameron. I sense that this has created a unique bond between Cameron and his dad, which has helped to make it all quite "normal" for Cameron. Al says that when Cameron complains about having to take his medication, the two of them compare medicine stories. Al tells Cameron, "When I was a boy, I had 'Yecky Green Medicine', or a little green pill which took twenty minutes to work".

It is easy to see that Al plays a key role in the positive adjustment which Cameron and the family have made to living with asthma/allergy. Having extensive knowledge of, and first hand experience with, asthma/allergy has made Al more aware than most parents of the issues faced by a child with asthma/allergy, and by his or her family. He is accustomed to the problems of this chronic condition, and approaches any episode calmly and assuredly. He is not confused or unduly frightened by his son's condition, nor does he tend to panic when Cameron has an asthma attack or an allergic reaction of any sort. It seems that he knows what to do and has always modeled calm effective action. Al also feels that because of his personal experience he did not come to the task of dealing with doctors with the attitude that doctors are "gods who know everything". Al tells me that he feels more prepared than most parents to deal effectively with medical personnel. He says:

> I think if you really think about it, if you have a child who is chronically sick, and you've been through all the rigmarole that goes on, you're more prepared to be aggressive and proactive, to go out there and say, "No doctor! I think you're wrong! I'm gonna get a second opinion! " (March 21, 1994)

Al clearly expresses his belief that having dealt with his own asthma/allergy has helped him tremendously in accepting and managing Cameron's condition. Because of his long history with the condition, Al has been able to identify very early signs of an asthma attack, as the following story describes:

> Well its probably different than a lot of fathers who don't have asthma. Having asthma myself, I'm probably a little more aware. In fact, the last time Cameron had the nebulizer with the Ventolin, just the other week, he was in a rotten temper. I'm looking at him being in a rotten temper--and he has a temper! Pat was going somewhere and I said "Come on Cameron we're gonna give you Ventolin". [He said],"I don't want Ventolin!" And Pat says, "Why don't you give him a puff?" And I said, "No, I think he needs [the nebulizer]". And as soon as he had his nebulizer, he sat there and watched his cartoon, you know, he was fine. He was having an asthma attack. He just didn't [know it]...He doesn't always wheeze, so I could see that, you know, he was in a real rotten [temper]. His face was real flush[ed]. It just sounded to me that he was having trouble breathing...I can remember when I was a kid when I was having asthma, my temper was just, you know, a fuse about thirty seconds long...He wasn't tired, you know, wasn't sick, just rotten temper. And he's normally not in a rotten temper. He's usually a pretty good little kid. (March 21, 1994)

Al considers asthma to be "a normal part of life", and "something you just deal with". He tells me he does not worry that Cameron would die from an asthma attack because modern medication is so fast acting, and Cameron does not seem to have serious attacks without warning. Al does, however, worry about Cameron's severe food allergies. He says:

> But with the allergies its always a big [worry] you know, especially when you hear about teenagers dying of anaphylactic shock when eating in a restaurant or whatever...I mean all you can do is try to get it in his head to ask. 'It doesn't matter how much you want that brownie or whatever. Ask! If it has something in there, and you don't know what it is, tell them you are allergic to nuts and see what they say'. (Mar. 21, 1994)

Many of the worries Al has are "just worries that any parent has of any child going out there in the world today. The concerns of school and that sorta stuff--probably the biggest". He continues:

> You don't really focus on the asthma so much. Again the allergies--there is a concern there that's sorta sitting there. And there's ideas of, "What are we gonna do when he hits grade one, or even kindergarten?" 'Cause they have snack, and that's a big scare! ...He'll have to take snack every day and then he'll be different. 'Cause you don't know what the parents are gonna put in the snack. The big snack is celery and peanut butter...Most parents get fairly active at the kindergarten level, so if we can get in there and say, 'Our kid has allergies', and send a note to all the parents [saying] 'This will kill him!' (March 21, 1994)

Al is quick to say that he wants Cameron to fit in and be 'normal'. As much as he and Pat want school personnel to be highly aware of Cameron's situation, they do not want Cameron being singled out because he has asthma/allergy. So trying to maintain normalcy is another issue Al anticipates when Cameron enters school.

Entering school will mark a transition for Cameron. Al says that they have not had to accompany Cameron on daycare field trips thus far, however, he does anticipate doing so in kindergarten, where outings are more frequent. From Al's current knowledge of the school Cameron will attend, he assumes that there are no pets in the classroom, except fish and possibly a gerbil; there is minimal carpeting throughout the school; and the school has a constant supply of fresh air due to the air-to-air heat exchangers. There is apparently one teacher who has asthma/allergy in Cameron's school. Al expressed to me his hope that this teacher will serve as a catalyst for information, and will act as an advocate for all people with asthma/allergy in the school. After speaking to Al, I can see that, at this point in time, Al feels quite comfortable with Cameron entering the neighborhood school.

Just for the sake of wishful thinking, I asked Al to describe for me the ideal school for children with asthma/allergy. Al did not have to think about this ideal school at all. He jumped right into describing a school with tile floors, which are easy to clean, and radiant floor heating, which prevents dust from being blown around the building. He imagines an air-conditioned school with excellent ventilation. He explains, the air-conditioning, being a sealed system, would help keep the pollens outside during the bad allergy seasons. This ideal school would also have unfinished concrete block walls, thus avoiding the contaminants of modern building supplies and finishes. There would be no carpeting or upholstery in this school. Furniture would be covered with vinyl fabric. Al cautions that if wooden shelving and drywall are used in the construction of this ideal school, a good air circulation system would be essential due to the off-gassing from such building materials. We had fun envisioning this perfect school, and I do feel we must have our ideal goals in mind. But we also had a little laugh when we concluded that we would have to build this school, and leave it vacant for months or years, until the contaminants from the construction process dispersed, leaving the environment safe for all children with asthma/allergy.

When asked what he wants Cameron's future teachers to know about his medical condition, Al responded with the following advice:

> Well, they have to be able to recognize the signs of an asthma attack, and they have to realize that asthma is not psychosomatic or psychogenic. When a child is having an asthma attack he's not putting it on! He's sick and you have to deal with it. And if the cold weather is a trigger, you have to be prepared to keep the child in, even if the child wants to go out. If its a certain temperature and the parent says "Cameron should not go out today because its minus thirty", and everyone else is gonna go out; or you know its humid and he's gonna be sick. So, just be aware. And also to know that there are medications on site, where the medications are, that they're not under lock and key, and you can get them in a moment's notice. (March 21, 1994)

Al feels that the best approach to the school issues ahead of them will be to become very active and involved in informing school personnel of Cameron's needs. He hopes to arrange for the school to receive the school package on asthma/allergy, from the Ontario branch of the Asthma/Allergy Information Association. He shares another school-based plan, which he calls his "flying squad" idea, in the following passage:

> I think the way to do it--we've talked a bit about this at PACE--is a flying squad--is what I call it. What you do is say to a parent who has a kid going into school, or in school, 'Okay, we're gonna hit this school'. And you go there and you talk to the principal and say, 'We're coming to do a presentation about asthma, and we're gonna do it for the grade 1's, 2's, 3's, 4's'. And you tell [the teachers] what it [asthma] is, and why, and what allergies are, and what happens. That could really work. (March 21, 1994)

Although Al did not directly address the constant worry of having a child with asthma/allergy, he openly shares many stories of such worry. Even though he is very capable of coping positively with the task, it is clear that Al finds it worrisome to be the parent of a child with asthma/allergy.

Pat's Story

Pat Underwood appears to me to be a simple, practical, non-pretentious woman. I find her very easy to talk to and she shares her story willingly with me. About mid-way through our main conversation, I began to feel very connected to Pat. I could relate so vividly to her stories. The lack of sleep, being a zombie at work, deciding not to have another child, the agony of hospitalization, and comparing our story to others'--these are all such real issues in my story. I drove home after a very long talk with Pat feeling very connected to her. I couldn't help thinking how different our "interview would have been if I had been an impartial, objective "interviewer", rather than a fellow mother of a child with asthma/allergy.

Pat's story, like mine, is that of a mother whose son has asthma/allergy. For Pat, it is a matter-of-fact story of searching for accurate information, dealing with things as they come up, and getting on with it. It is a compelling tale filled with solutions and optimism. It is also a story of conviction and emotion. Pat is angry, terrified, thankful and relieved as she recalls and retells the story of her family and asthma/allergy.

Pat shared with me the stories of the early months of Cameron's life when no one knew Cameron had asthma/allergy. She describes Cameron as "fussy", and says he did not sleep well. Pat seldom had a full sleep herself, and became exhausted, "grouchy" and eventually ill. She wonders now why the doctor wouldn't use the "A" word--asthma! She knew the likelihood of Cameron having asthma/allergy. After all, Cameron's father has had it his whole life. "You couldn't have knocked [her] over by using the word asthma!" She adds, "What was the big deal?" She feels if the doctor had been more direct, she could have dug into the literature on asthma earlier and "gotten on with it".

Pat comes across as a very logical person and many of the things Cameron's first doctor did made no sense to her. He wouldn't refer Cameron to an asthma specialist, even though Pat had requested he do so. He wanted Pat to use Ventolin (a bronchodialator) instead of plain saline, to dilute Roto-caps, which is another form of medication, and Pat felt so strongly that that made no sense! Pat also believes that the lack of knowledge of that doctor lead to Cameron's first hospitalization. She is totally convinced that Cameron's serious illness and the hospitalization could have been avoided if she had received adequate information from this doctor. She bases this opinion on the pattern of illness and wellness since Cameron has been on his current medication regime. Pat also feels that the doctor did not listen to her. She recalls the anguish and trauma of the hospitalization with anger in her voice, saying, "It made me really angry...because it didn't have to be!" She shares the hospital story with me. Cameron was a very sick little boy. He was two and a half years old. He was in hospital for three days. He had oxygen for two days, and an IV for a day and a half. Pat called the IV his robot. He was on Ventolin constantly for three days. He had monitors taped to his belly and he didn't want to move around much. His nose was bleeding from the tubing, and he was very thirsty. Pat stayed in the hospital and held Cameron the whole time. She recalls how one person reacted to her concern, and to her way of caring for her son:

> The IV wouldn't stretch to the fridge, so I asked a nurse or a doctor passing by if she would please pass me a bottle. And she gave me a big long lecture on not spoiling children who are sick, you know, treating them special and pampering them. Gimme a break! You know, he's having a breathing problem and you want me to put him down so he'll start crying more and use up his available oxygen, so I could go get a bottle that you could just hand me! (March 24, 1994)

Pat expresses regret that she was poorly informed about allergie' and allergy management during her pregnancy and for the first three years of Cameron's life. She wonders how things would be different for Cameron if she would have been advised, based on Al's history of allergies, to avoid certain foods during pregnancy. Given the information available to her at the time, Pat truly feels she did everything she could have done to assure that her child was born healthy. If she were to become pregnant again, however, she would do things a lot differently in the hope of preventing such food sensitivities in the child she was carrying.

Pat has learned a lot through experience, and from Cameron. She wishes that she had learned more about asthma/allergy from her obstetrician and from Cameron's doctor, but she did not, so she joined PACE and made a decision to change pediatricians. The first doctor had been a nice enough person, but Pat feels that he was not providing her with the information she needed. All she wanted to do was learn what to do for the asthma. She needed to know how to medicate Cameron and what his medical needs were.

Now that Pat has a satisfactory relationship with Cameron's new doctor, things seem so much easier. She believes that she is "in control" of Cameron's health situation, and that the doctor is a valuable resource to her and to her family. She especially values the freedom that she has to make minor adjustments in Cameron's medication without running back and forth to the doctor all the time. Pat tells me that she trusts this doctor, but she does not trust all doctors. She says that she tries to respect what a doctor is telling her, but she has learned to rely on her own common sense. In describing her role in the daily management of Cameron's condition Pat likens her role to that of "doctor". She monitors Cameron's health, decides whether or not to treat or to medicate him, and she adjusts any medication or treatment regime that Cameron may be currently following. She adds that this role has come about largely as a result of the amount of time she spends with Cameron in the evenings when Al is at work. She says the roles could easily be altered if Al were the one who was home in the evening. It is clear to me that Pat feels very confident in her ability to manage Cameron's condition successfully, given the current status of his health. She believes that she and Al know more about Cameron's needs than any other person in Cameron's life. She gladly welcomes the role as advocate for Cameron, and is prepared to fight for his rights and well-being. Pat describes her approach as one of calm, polite communication, but she is quick to add that she is also willing to go to any length to advocate for Cameron. (And she loves "a good fight" if the need should arise.)

Pat has told me that she finds the worry of Cameron's allergies far more difficult to deal with than the issues surrounding his asthma. She shares her greatest fear with me, saying the hardest thing for her is the fear that someone will feed Cameron a nut. This really scares Pat. She describes herself as being both "paranoid" and "terrified". She says that because the reaction to nuts is so immediate, the allergies are much more frightening than the asthma. She worries about "some mean kid in school giving Cameron something with nuts in it for a joke"; or the mother of a friend feeding Cameron nuts in disbelief that any child could be that allergic to nuts. She asks, "Would that be considered manslaughter?" This really is her worst fear.

The worry comes in other forms too. Pat generally describes parenting a child with asthma/allergy as "worrying". She especially worries when the Ventolin doesn't work. This has happened at home and in the hospital. She really counts on the medication to keep Cameron safe when he has an asthma attack, so she finds it extremely upsetting when the medication fails.

Having ready access to medication is one of Pat's concerns with Cameron entering school. We have talked about where the medication should be stored at school, and when Cameron will be old enough to carry it on his person. Pat feels certain that Cameron is able to state his health needs clearly and forcefully. She hopes that teachers and other school staff will always listen to Cameron, and will know what to do for him if he should become compromised during the school day. Next to the fear of Cameron having food containing nuts, the medication issue seems to be Pat's primary concern with regards to school.

Since Cameron has been attending daycare in the school building where he will attend school, Pat feels confident that the allergens in the school environment will not present too much of a problem for Cameron. She recalls the advice of a speaker at a PACE meeting:

> I like what the psychologist said too. If possible, try to keep your kids in the same school, 'cause then all the kids--it'll be more like a family and they'll all know each other's idiosyncrasies and they won't try you out or make fun of you. (Mar. 24, 1994)

From speaking to Pat at length, I believe that Pat feels fairly relaxed at this point, about Cameron attending the neighborhood school. She says that she and Al plan to become very involved in the school program by way of informing staff, students and parents about Cameron's severe nut allergy. Pat repeatedly states that she will impress upon the school staff the seriousness of his nut allergy. She expects that the staff would "keep this information foremost in their minds", and would not feed Cameron anything without being fully aware of the ingredients. She says, "I'll teach him to be pushy. If he can't read, have the teacher read it. Make sure! Ask them twice, or don't eat it!" Her intense concern of such an error is evident in the following words:

> And I don't know what it would be for manslaughter. If a teacher feeds a kid a walnut cookie because they carelessly didn't read the ingredients, would that be manslaughter? If you get in a car and you run over somebody, even though you're not drunk, you just were careless, that's manslaughter. I wonder if there's ever been a court case. (March 24, 1994)

Pat shares with me her worry about Cameron eating in the lunch room at school. Apparently Cameron doesn't react to the smell of peanut butter, and he would know enough not to eat anything that he knew contained nuts or peanut butter. But, Pat explains, there is a significant risk of there being peanut butter on a table surface, or of him being given some food item which contains concealed nuts or nut oils, or which may have been prepared with a knife that had been used to prepare a peanut butter sandwich, for example. Of course Pat and Al have been teaching Cameron not to eat anything which is not served to him by a "trusted adult", but Cameron is still very young and, according to Pat, he has made mistakes with food already. And when Cameron is older and not as closely supervised by his parents, he is bound to have to make far more decisions about food on his own.

Pat has faith that growing older also brings maturity, responsibility, and hopefully an improvement in the manageability of the condition. Pat feels that seeing an improvement, either short-term through the use of medication, or long-term improvement in the severity of the condition, is a very important factor in coping with the worry of asthma/allergy. When comparing asthma/allergy to other chronic conditions she says, "...especially if there is no improvement in sight. That would be the hardest". When speaking of asthma she says, "At least with proper medication there's improvement. With age there is improvement".

Cameron has his school career ahead of him, and Pat is well prepared to advocate on his behalf, and to continue fostering self-advocacy skills in her son. Time will tell what issues will arise around school attendance, and what amount of cooperation and communication will be required between home and school, in order to keep Cameron safe. I feel strongly that Pat will do all she can to assure that school is a safe and happy place for Cameron, and for all children.

Chapter 5

Themes

Upon sharing with you the narrative accounts of our lived worlds, I intend to outline the process by which I have searched for themes, and by which I have come to construct meaning from this research experience. As we revisit these mutually constructed stories I will describe how I have conducted my search for common threads of meaning.

Narrative Threads And Emerging Themes

The process of reading and re-reading data, and of searching and re-searching for themes and narrative threads, is one that requires time and reflection. At many points on my research journey I was quite confused by what sense I was making of my findings. I was uncovering recurrent key words as I went over and over my notes, but I was not aware of any emerging concepts which may have been themes. As my search for themes continued, I returned to my research journal for a helping hand. The passage below is an excerpt from a piece of writing done on June 29, 1994, following one of my many journal read-backs (Progroff, 1992). It illustrates how my research journal has helped me to realize what it is that I am coming to know as my study progresses.

> Having done another journal read-back, and upon further reflection of the data I have gathered, certain narrative threads are revealing themselves to me today. [I believe that I am constructing these threads within myself.] I realize now that my knowledge of such connecting threads has been lying just below my level of awareness these past weeks. I thought I was 'stuck', and I was becoming discouraged, but by using my research journal, and by writing to think, I am now aware of many of the things which I am coming to know. I have been busily searching for similarities

> between the narrative accounts of the Underwood family and my family. I had been reminded by Roberta at the onset of this investigation to be alert to both similarities and differences, however, it is clear that I have not made sense of her words until today. Through my own life experience, I have had to construct this knowing for myself and connect it to my own work.

Upon clarifying my thoughts in this manner, I set to recording the following narrative threads which had been coming up over and over again in conversations, interviews and my journals.

The differences between the Underwood family story and the Wingrove family story, and the differences between the stories of each individual participant, have become significant in my work. The differences themselves serve to highlight the fact that we are all unique people who happen to share the common experience of living with asthma/allergy. We have different life worlds, and we are at different stages of adjustment. We have different concerns and views, and we have developed different coping strategies. We must help teachers, doctors and others to understand that, although we, as families of children with chronic health problems, share some common experience, we are not a homogeneous group and we do not have the same health issues, nor the same needs.

There is however, value in sharing our different, though connected stories with teachers and medical personnel. This study consists of the stories of only two families, and I am mindful of this as I write. However, I strongly feel that these stories, including all of their similarities and their differences, have a personal quality which in some small way, reaches out to the reader. It is my hope as the researcher, that these stories will touch the lives of those who read them, and will ring true for them in some meaningful way. That these stories will connect the experience of the teacher or the doctor, with the experience of the family, for a brief though powerful moment, is the expressed purpose of this research endeavor. In this moment of shared vision, rudimentary bridges may start to be constructed between the people who play key roles in the lives of children who have chronic health conditions.

There are of course similarities and common elements in our stories. Common threads have emerged amongst the similarities that are worth consideration at this point.

The chronic or constant worry, albeit subconscious much of the time, seems to be the most significant commonalty between the stories of our two families. Along with worry there is fear, although fortunately, we are visited by the intense fear far less frequently than by the worry. For me, the worry is like a childhood nightmare. It is not always at the front of our minds, but each time it comes to us it is more powerful in magnitude because of the many previous encounters. We know its always there although, from time to time, we can almost forget it exists. Then each time it reappears we are overcome by the cumulative impact it has had on our sensibilities. Unlike a nightmare, we know its real. This however, does not stop us from wondering how much of it is in fact real, and how much of it is being generated by our own minds in this weakened state.

The fear is also real, and at times, paralyzing. During crisis' and periods of hospitalization, the fear takes its strongest hold. We feel compelled to protect our children from harm and from death by telling our children's health stories to all who come into our children's lives. We do not have the power of other special needs parent groups because we are in no position to fight the 'system' *with* our children. That is, we cannot take our children to school, while we work out the problems that arise at school as a result of our children's special needs. We cannot register our children and *then* proceed to educate the school personnel, because our children could be at considerable risk if awareness is not heightened in advance of any trial school experience. The safety and well-being of our children depends so heavily upon the school personnel being compassionate and so very well informed.

As I read and re-read the data, control seems to be an emergent theme of some strength. Control in the sense that, we as parents of children with asthma/allergy, desire, even demand, to be afforded some amount of power or control over what happens to, and for, our children. There is clearly a connecting thread of control drawing one story to the next, and pulling all of the stories together.

I now see it in my own story, right from the very beginning. Decisions were made, and procedures were performed by medical personnel from day one, without input from me or Frank. I feel like I want to go back and examine the hospital records to see what else was done that we played no part in, or what else was known about Joshua's health that we were not informed of at the time. And in my story I see the struggle for both respect and control as I wrestle with my role as the mother of the young patient/student. I have been working through this issue of control for eight years, especially as I relate to the medical people in our story. I see that I have gone from relinquishing all control to doctors, to wanting to keep as much control, and have as much input as possible. I see too that the issues and uncertainty surrounding the medication which Joshua has had to have, have been a source of both frustration and fear for me. I realize that I cannot totally control what medication, or how much medication Joshua takes, but I do feel that I have a lot more options, and therefore, a lot more control, than I once thought I had.

In the school setting, it was actually our doctor who motivated me to claim respect and control, as the "expert" where Joshua was concerned. My gaining of control with the medical personnel and with the school people, seems to have come about simultaneously. It was when I had to challenge the doctor as to why he would not provide the school with the requested documentation, that I in fact learned to ask for some control at school. This appears to be when I began to play a more active and fulfilling role at Joshua's school.

I see too that my seeking out support and information was a form of gaining control. I needed to understand, and to know what to do and what to ask, in order to play an effective role in maintaining Joshua's health. Looking back, I believe that it would have been very difficult to exercise any significant amount of control with the level of knowledge that I had in the earlier years, and with the tremendous lack of sleep that I endured.

Frank also highlights control as an important issue for him. He maintains that we have to have "some sort of control over Joshua's path to wellness". He identifies the question of "Who's in charge?", stating firmly that "We're in charge of our young man's health".

From early on in Al's family's adjustment, he seems to have had a stronger sense of his control over Cameron's well-being than Frank or I had over Joshua's well-being. This may well be due to the fact that he has had to manage his own asthma/allergy for many years, and feels quite confident in his ability to do so. He states that he has less of a problem standing up to medical personnel than some people he has spoken with. He seems to feel very empowered in that sense. Al respects his doctor's approach which, in fact, gives Al the control he expects in managing Cameron's health problems. Al also values information as an important element of control, and as a powerful advocacy tool.

Pat also seems to link information with control. Her story often makes mention of her strong desire to have the appropriate information to do an effective job of managing her son's condition. Pat regrets that she did not have this control, via information, in the earliest stages of her journey. When she is well informed, Pat feels she can be in control, and that her doctor serves as an important resource to her in this task. At times Pat seems to equate medication and control. She believes that she knows Cameron best and she should be in the position of regulating and controlling his "meds.". There is a strong sense in Pat's story that medication is the key to controlling Cameron's health situation. This may be a slightly different kind of control, but, nonetheless, a major connecting thread in Pat's story. Another very pressing matter of control for Pat is the absolute life-threatening need to control Cameron's exposure to nuts. As Pat's story attests, it is becoming more and more difficult to control Cameron's dietary intake as he grows older, which is a serious source of stress for Pat. Both Al and Pat discuss having to transfer a great deal of the control over, and responsibility for, what Cameron eats to Cameron himself. Self-advocacy, sibling advocacy, and parental advocacy are key issues of control for the Underwood family.

The narrative thread of control runs firmly through my story, and the stories of Frank, Al, and Pat. We all believe that we are the ones who know our children best, and that we are the ones who must have a great deal of input and control in the matter of caring for our children with asthma/allergy.

Communication, collaboration, and our need to achieve optimum communication between school or medical people and our families, is another common thread in our stories. Our accounts are bursting with references to the need to heighten awareness and maximize communication in all areas of our children's lives. We state repeatedly that we are prepared to accept full responsibility for providing all pertinent information to doctors, teachers, school parents, our children's peers, etc. Pat, Al, Frank and I are more than willing to play key advocacy roles for our children. We are also intent on teaching our sons to monitor their own needs closely and to advocate, or to communicate their needs, on their own behalf. Our boys are still young, but as they grow they are becoming more and more aware of the importance of listening to their bodies and speaking up immediately and clearly, should they become compromised in any way. We feel an urgency to be heard, and for our children to be listened to in a very special way. We need to know that when we are not right there, someone will react quickly to attend to our child's health needs and to keep him safe.

Informed, caring, competent, and compassionate teachers and doctors are part of what we are working toward. We want these helping professionals to try to get to know our children as individuals and to consider the whole child, and all aspects of wellness, when working with our boys. We want our children's voices to be heard and to be honored. We want to be respected by doctors and by school people as the "experts" on our children's health needs. We hope that these professionals will be patient with us, and not think us over-protective or meddlesome when we are so desperately trying to help them understand. We hope to encourage ongoing dialogue and conferencing between families and professionals. We believe that so much depends on the strong partnerships we are trying to build. Our motivation is so very strong to assure that the needs of our children are met. Our children could become very ill, or even die, if we fail to enact our duties and responsibilities as their parents, and as their advocates.

We try to deal with the pressure and the day to day tasks in effective and positive ways. Not much really 'phases us' on a daily basis. When our children are ill however, we do go through 'the wringer', and we count on the probability of rapid improvement to bring things back to "normal". Hope, and the promise of improvement, are identified in several ways as protective factors which lead to positive coping in our families. Fortunately, our children have medical conditions which are treatable by medication. We have often noted how the knowledge that things will improve has carried us through many bad times. On the same token, the fear of no improvement has terrified us in times of crisis. All four of us have expressed empathy for those parents who can not see improvement in sight. We have all compared ourselves to others and counted our blessings that our children 'only' have asthma/allergy. We express great hope that our boys will have bright healthy futures, and we are endlessly thankful that they can look forward to long lives, unlike many children with chronic health conditions.

We strive for some sense of normalcy, especially for our children. We do not want them to feel different, or to be treated as though they are abnormal. Of course, we hope that their special needs will be effectively addressed, but we do not want them to be thought of as 'different'. Like other parents, we aspire to have children who feel good about themselves and live life as "normally" as possible. We do not expect that our children receive preferential treatment or be handled with kid gloves, as though they were fragile. We hope that our children can be included in as many regular school activities as possible, and that they will not be singled out or excluded because of their asthma/allergy. It hurts us that they are set aside from their peers in some unavoidable ways, but it breaks our hearts to see them teased, excluded or ostracized because of their health needs. I suspect that most parents have, to some degree, felt similar pain in their own family lives, and can relate to this concern.

The self esteem and privacy of our children is also very important to all of us. Where our children are concerned, we strive for a balance between careful monitoring and isolation or exclusion. We hope that our children's conditions will not isolate them unnecessarily from their peers, or embarrass them in any way. Having to sit out in gym or at recess can be upsetting enough for our children. They do not want attention drawn to their medical difficulties. Having to take medication or do treatments in public can be very embarrassing for some children, especially as they grow older. We hope that the issue of medication at school can be handled in an effective and confidential manner, and in a manner which will protect our children both physically and emotionally.

It is crucial that the appropriate medication is readily accessible at school at all times. It is imperative that certain children be allowed to carry their own medications and take responsibility for the administration of such. In the case of "Puffers" and Epipens, this could make the difference between life and death. Schools and school boards must assure that policy and procedure allow for proper pharmaceutical management, and the necessary crisis management plans must be clearly outlined and in place at all times. Between school administration, teachers, parents, and children with asthma/allergy, we can develop effective practices which do not place any individual at risk. We know that the administering of medication has become second nature to us, and that it can be very frightening to teachers and other school people. We ask that teachers let us help them to learn and become confident in their ability to manage such situations at school. We will be there to handle the most serious episodes ourselves, whenever possible. We keep our children at home when they are especially vulnerable or at risk. We are willing to be at school when teachers need us, and to carry pagers if necessary. We have done as much as we can do to this point, and will continue to do so, but we need the help and support of school personnel. Our children are generally not too ill to attend school. With a little information, a lot of communication, and a good generous dose of good old fashion caring, we feel that the needs of our children are easily met within the school setting.

Frank and I have cared for Joshua at home on many school days. Absenteeism is a significant factor for children with asthma/allergy. Being run down, missing school, and returning to school at the tail end of an illness can upset the natural rhythm and cycles for children and other classroom members. It is not only the obvious medical distress that must be monitored. The social and emotional needs of all children also merit close observation. These are some of the issues that we, as parents, can help keep teachers apprised of.

In our case, and in the case of the Underwood family, we are more than willing to make daily contact with school personnel whenever necessary. We appreciate how very busy teachers are, and we realize that they have unbelievable workloads to deal with. We also know that many children in each and every classroom have important individual needs. We feel that teachers are in fact asked to do far too much as it is. For these reasons we know that it is not reasonable to expect that teachers become medical care-givers as well. We must be prepared to do everything possible to manage our child's health within the family, and I believe that we have done our best in this respect, and so have the Underwoods. But we feel such a pressing need to have school personnel on our team in this endeavor. We cannot do it alone.

Emergent Metathemes

Renata Tesch (1987) presents a clear explanation of what researchers refer to as the 'process of finding themes'. She distinguishes between two uses of the word 'theme', borrowing the term "metathemes" from Valerie Polakow, to describe major themes. Metathemes are defined as "major dimensions of the phenomenon studied" (p. 231). Metathemes, in their final form, are similar to the study's "results". They are larger and more abstract than individual themes, and are "usually formulated as a succinct narrative" (p. 234).

This distinction has been helpful to me in moving from tentative, preliminary themes, to broader aspects of my study. In an attempt to identify broader units of meaning from the text, I clustered the narrative threads (outlined above) into various arrangements, using flow charts, webs and lists. I think, at this point, I began to recognize emerging metathemes, but I was unsure of what I was 'seeing'. A type of advocacy and the concept of yin and yang (Cooper, 1981) seemed to arise as metathemes at this point.

Using a Progoff (1992) technique called Twilight Imagery, I was able to make sense out of the excessive amount of data spinning around in my mind. By re-reading my flow charts, lists and webs, I "seeded" the imaging experience and sat in stillness to wait for the images to come to mind. While engaged in this imaging exercise, I was aware of bits and pieces of knowing springing back to my level of awareness, which I had not remembered ever coming to know. There were words and ideas from mentors, my journals, research classes, writing classes, my lived experience, my field texts, and my literature review, surfacing every second. Part of the imaging process is to write down what ever images and concepts come to you. As I wrote all of these words, I realized that they were evidence of the layers of knowing which I have been constructing for myself throughout my Masters program. The concepts connected at lightening speed and the sheer embeddedness of this kind of thinking was remarkable. There were many images of balance and harmony, such as a see-saw and the visual arts. There were many contrasting concepts side by side, such as life/death, stormy/calm, dark/light, and harmony/chaos.

The next step, according to Progoff, is to reflect on the imagery and to write a response to the Twilight Image. What follows is my written response to this particular imaging activity:

> Advocacy [came up] less than yin and yang. Harmony and balance are important. ... I'm not sure how harmony and chaos fit in with my thesis, but the "theme" of chaos came to mind with a great force. ... Did harmony come out of chaos in our lived world? Is that a theme? Positive/negative? Harmony/chaos? The word Pandemonium comes to mind. Does adaptation transform chaos into harmony? Is "order" harmony? I am surprised that the "weakest" of all connecting threads [yin and yang] became the

> strongest. I wonder how that happened? (Research Journal, Aug. 18, 1994)

At this stage of my research I clearly saw two strong metathemes emerging. The first is the yin/yang, or positive/negative aspect of the lived experience of the participants. Yin and yang are the "two forces through whose essences, according to Taoist cosmology, the universe was produced and cosmic harmony is maintained" (New Webster's Dictionary, 1991). I see this as the concept of opposite, yet complementary forces emerging in my study. For every negative there seems to be a positive. Cooper (1981) defines yin and yang as "alternating forms of the creative force as it is manifest in the world. ...The yin is the physical, emotional, cerebral, inertia, the square; the yang the intelligence, energy, the spiritual, the circle" (p. 13). "They are two aspects of one and the same power, but in polarity as distinct from absolute duality" (p. 14).

Frank first referred to the concept, in terms of positive and negative, when he said, "You wonder why it is that he [Joshua] has been afflicted and others have not. ...Happily genetics also provided him with some very positive things too, so I guess its a give and take situation" (Mar. 22, 1994). At a later point in our interview, Frank added, "...his limitations are somewhat insignificant compared to the very positive things that he has" (Mar. 22, 1994).

Pat Underwood actually used the words yin and yang when speaking about the trials and tribulations that go along with having children. She said,

> If you wanted to say, "Why me?", then you wouldn't have had kids! (laugh) I mean kids are a problem, it doesn't matter what. They come in a package. You just accept it. I mean they're gonna be a pain! They're [children]! That's what they're supposed to be. If they have a sickness to go with it, okay so that's another pain. ...[Emile] is five and a half and he still wets his bed. [Cameron] has been dry since three. Which kid gives you the more problems? ...(laugh) I mean there's yin and yang. (March 24, 1994)

The words yin and yang also appeared as I arranged sticky-notes on a large piece of cardboard to help me make sense of the data. It was a lonely little notation with no obvious connection to anything else. Then, the concept emerged as a very strong metatheme in my imaging work. Many pairs of complementary opposites have come out of the field texts: differences and similarities, disabilities and gifts, worry and ease, uncertainty and certainty, doubt and faith, powerless and empowered, fear and courage, hope and despair, optimism and pessimism, negative coping and adaptation.

As stated above, the stories of the participants are marked by significant differences. The story of the Underwood family is quite a different tale than the story of the Wingrove family. Each story has marked elements of yin and yang embedded within. The Underwood story has a strong seam of a mind-over-matter way of thinking. They simply do not think of Cameron as being ill. Statements such as, "No, he's not sick. I don't think he thinks of it as sick."; "He's been a very healthy boy too." (Pat's Interview- March, 27, 1994); "No [I don't get sick with asthma]. You just get asthma and then you cough" (Cameron's Interview- March 19, 1994); "He wasn't particularly sick"; "He wasn't tired, he wasn't sick, just a rotten temper [a sign of asthma]" (Al's Interview- March 21, 1994); illustrate this strain of thinking. And yet, in the Underwood story, there is also a strong theme of control, in the scientific sense, especially where medication is involved. The following excerpts from Pat and Al's interviews seem to support this assertion:

> But its [Cameron's condition] being controlled by the medication. ...We've been keeping records as you know. If we don't aggressively treat it he would be having major attacks all the time. ...As soon as we hit every four hours [administering Ventolin]...then we slapped him on Pulmicort and we did the three for five days or four days, then two, then we went on one every day, and then skipped one every two days. ...We'll pre-med. [pre-medicate] him...get him used to

> the idea that this "med." is gonna keep you going (Al's Interview- March 21, 1994).

> And the doctor we have now, I think he understands that I'm fairly intelligent. I phone up and I say this is what we're doing [with the medication], this is what I'd like to do, does this make sense? He says, "Yes, it makes sense." I do it. It works! ...You can medicate it [the asthma] so that he can lead a normal life, if you medicate it properly. ...But I'm in charge of giving this kid medication. I'm not going to have him bouncing off the walls with medication he doesn't need. But I want to give him the medication he needs, and that's why I joined PACE, because I need to know how to medicate him and I need to know what his needs are. (Pat's Interview- March 24, 1994)

The Wingrove story also carries the yin and yang theme throughout. Our lived experience was chaotic for many years because of the illness, worry, fear, and uncertainty. It seems that for what ever reasons, a semblance of order evolved out of this chaos over time. We progressed from a stage where we entrusted our doctors with all decision making authority, to the stage which we seem to be in at the present time, wherein we are trying to maintain as much autonomy as possible. We are now at a point in our story where we have time to reflect upon the chaotic experience, and work towards a more harmonious solution to Joshua's medical situation. These words from the field text help support this manner of thinking:

> Even though people continue to look at us and say "Oh, it must be terrible having to deal with that", well in some ways we have our lives under control and we know where we're going with Joshua, or have a sense where we're going. (Frank's Interview- March 22, 1994)

> We had it tough over the last two years--colic, illness, hospitals, and NO SLEEP! Its no wonder we are both enjoying life now. Its a bit easier. We get enough sleep most nights. Josh still wakes up, especially when he's ill. No sleep makes me mental. ...And with the extreme stress with [Frank's] Mom's health and Joshua's health--God! How do we manage? I can sure see, especially at this time, why we both want to enjoy some normal, calm, family life for a while! (My Journal- February 6, 1988)

> Our experience has changed our lives in many ways. ...But I hope it will be easier now. Things are fairly stable at the present time for Joshua. (My Story- December 5, 1993)

I see both family stories as containing a yin and yang drama of sorts. I was not aware of this pattern until I spoke to one of my professors about the connection between the chaos/harmony images which appeared in my Twilight Imaging, and the yin and yang metatheme which seemed to be emerging. My conversation with my professor helped me piece together bits of knowing which seemed unrelated until our conversation. I now believe that there is not only a thread of yin and yang within each family story, but there is also such a thread connecting one story to the other. The lone sticky note, which read "yin and yang" on my clustering board, functioned as a very small seed which would eventually draw my attention to the yin and yang aspects of this study.

It is important to note that there is no good/bad or right/wrong association in the yin and yang philosophy. There is simply polarity--action and reaction. "An inevitable dualism bisects nature, so that each thing is a half, and suggests another thing to make it whole." (Emerson in Cooper, 1981, p. 6). The elements of yin and yang are evident in both family stories. Each family, according to the individual personalities and orientations, makes sense out of their lived experience in different ways. The Underwood family relies on a medical technical model of thinking in the management of allergy/asthma, and in their approach to adaptation. The Wingrove family seems to be living out a story where order is gradually evolving out of chaos.

Frank and I began this research journey at a very different starting point than did Pat and Al. We were naive in every aspect of dealing with allergy/asthma. We did not have the information or techniques necessary to claim the degree of control that we now want. Pat and Al, on the other hand, had years of experience in managing Al's chronic medical condition. Presumably, because of differences such as this, our stories unfolded in two very different manners.

Several yin and yang concepts, or contrasting word pairs deserve mention at this time. The first is a phenomenon which has been well addressed by Clandinin and Connelly (1986). It is the rhythms and cycles of classroom life, or the ebb and flow. My attention has been drawn to the rhythms and cycles of our lived experience. Clear issues of rhythms and cycles arise for students with chronic asthma/allergy. Absenteeism, and the ebb and flow of classroom life which comes with it, is something that has been a concern for Joshua, although not for Cameron to this point in his life. Joshua's many stories are quite explicit about the need to give some consideration to the transition in and out of school due to illness. He says, "I like her [the teacher] to say something like, "Welcome back", and give me some sort of folder of the work that I need to do. (Interview- Feb. 27, 1994)

Coping and adaptation are another prominent pair of words in this study. The difference between positive and negative coping becomes obvious when reviewing the literature in this area. Florence Stewart Poyadue (1993) writes, "The word coping strikes a negative chord and the concept of coping conjures images of weakness, constant sorrow, and a sense of just hanging on, tolerating, or making the most of a bad situation" (p. 96). The word adaptation, on the other hand, implies a positive and dynamic manner of 'coping' in response to the stressful experience of living with a chronic condition (Patterson, 1993). Adaptation tends to apply when a family believes "that the demands of the task do not exceed their resources to cope" (Garland, 1993, p. 73). Seligman and Darling (1989) point out that "our task should probably be to understand why some families disintegrate while others thrive" (p. 93). They also call for future investigation which will differentiate family characteristics that distinguish families that cope well from families who do not. This study may serve to highlight characteristics of two families which seem to be adapting well.

Hope and despair are the third set of yin and yang words which warrant special attention here. Ronna Fay Jevne (1991, 1994) has done remarkable work on the meaning of hope. Her fog metaphor (1994, p. 153) is especially striking to me. She likens hope to the sense we get that the end of the bridge is indeed there although we can not perceive it in any real way through the thick fog. The parent participants of this study refer to hope in several important ways. They rely on hope to hold them together in times of crisis. They compare themselves to other parents whose sense of hope may not have as firm a hold in their family situations. Hope for a bright and healthy future rings clear in the stories of both families in this study. Joshua speaks plainly to his own sense of hope in his Asthma Story. The concept of despair also rears its head in this study. Although we feel fortunate, and do rely on hope, we are easily reminded of the power of despair during any medical emergency. Pat's words exemplify this feeling: "And the one time he was having an attack the Ventolin wasn't helping--actually our nebulizer [mask treatment as opposed to "puffer"] wasn't helping, which really worried us" (Interview- March 24, 1994).

The second metatheme, which originally appeared as a type of advocacy, has developed into something very much like Nel Noddings' ethic of caring (Noddings, 1984, 1986). Advocacy is a word which comes up over and over in the field texts, however, in my opinion, it is not a word which captures the flow of information and concern for which we are "advocating" as participants in this study. I have used the words advocacy, advocate, and self-advocacy many times to this point in this text. I feel that it is important to clarify my use of the terms. The New Webster's Dictionary (1991) defines an advocate as "a person who pleads on behalf of another, especially in a court of law; a person who speaks or writes in support of some cause, argument or proposal". Advocacy is defined as "support for a cause or recommendation of a line of action". To me such words brings to mind a conflict or a fight with opposing sides. Advocacy makes me think of lobbyists and of a strong need to control information. This legal or adversarial connotation of the word advocacy is not at all part of the meaning which I am getting as I re-search the field texts, and re-think the context of this study. Until my conversation with my professor, I couldn't express what it was about the word advocacy that bothered me. What I kept going back to was what Joshua said when I asked him what the ideal school for children with asthma/allergy would be like. He said, "Very concerning teachers--very care-full!" (Interview- February 27, 1994). In listing what we might be 'advocating' for I found myself writing that we, the adults of this study, want caring, compassionate, well-informed teachers, doctors, etc.. It became clear that Joshua, Pat, Al, Frank and I were all 'advocating' for the same thing. Our need to 'advocate' is not about controlling information, persuasive arguments, or "them" and "us". What we really seem to be striving for is an open, caring, cooperative relationship between our families and those people who also find themselves in a position of 'caring' for our children. We desire an atmosphere of compassion, mutual concern, and effective communication. We would hope that our sons' teachers and doctors would have the best interests of our children in mind at all times, and that they would take the time to learn from us what our children may need at school or when they are ill. Nel Noddings (1984) speaks of caring in the following way:

> When my caring is directed to living things, I must consider their natures, ways of life, needs and desires. And, although I can never accomplish it entirely, I try to apprehend the reality of the other (p. 14). ...Caring involves stepping out of one's own personal frame of reference into the other's (p. 24).

Noddings' kind of caring is what we hope to move towards, as we share the stories of our lived experience with the readers of this study. My aim is to have the reader step out of their own world and into our life-world for a brief time. This study may also assist the reader in coming to know the "natures, ways of life, needs and desires" of its participants. If it contributes to either of these goals, then I will measure this narrative study a successful beginning.

This chapter has explored the common threads and themes which I have constructed from the accounts of lived experience. I have attempted to walk with you through the process of making meaning from the field texts. I have tried to illustrate the complex process by which I began to make sense of the data and construct meaning from the research experience. From here I wish to take you on a reflective tour of where we have been. Chapter six will review our research purpose, our journey, and our findings.

Chapter 6

Reflections

Reflections On Each Aspect Of The Study

This chapter will reflect upon the expressed purpose of this study and examine what this journey has meant to me the mother, me the teacher, and me the researcher. I will reflect upon the ways in which I may be seeing and acting differently having experienced this research journey.

In looking back to my research proposal session of January 1994, I am reminded of the valued advice offered by Dr. Myer Horowitz. He felt that future researchers may benefit from seeing how I conducted my research. He suggested keeping a running record of the process, method, and techniques, especially with reference to conducting research within my own family. I have done so in my research journal. As a researcher I appreciate when fellow researchers break their research process down into simple steps, and then report on the efficacy of such methods. For these reasons, I have chosen to include reflections on each aspect of my research process.

The Research Questions

Having reflected upon chapter four, I feel that I have been successful in addressing my first research question. Chapter four holds the narrative accounts of the lived worlds of the participants. It is the storied chapter. It is the telling chapter. It holds the essence of this body of work. I have served as a scribe for all participants. We have mutually constructed accounts of their lives with asthma/allergy. I feel satisfied that I have captured their stories accurately, and pleased that they were able to confirm their own stories. I also feel honored that they have allowed me to be their storyteller. I am also satisfied that my own stories, and Joshua's own stories, are honest, accurate and from the heart.

Research question number two deserves special mention here. What are the educational implications of this investigation? It has been my intention for the educational implications to be gleaned from the narrative accounts. I hope that the reader has been able to make many connections to his or her own lived world. I have tried to uncover the educational implications of this work by simply writing compelling stories with which readers may relate. I have avoided drafting a 'proposal' for school boards, or a 'list' of implications, however I feel it necessary to reflect upon the implications which this body of work may have for education.

Me The Teacher

I find myself in a unique position as I write the final words of this research text. I am now teaching two classes of preschool children, each of which includes a student with severe asthma/allergy. I am told that in one case at least, the family chose my classroom for their child, partially because of my experience and understanding of asthma/allergy. I also have one student with Celiac disease, which means there are many foods which she cannot tolerate. In conversation with the parents regarding the special health needs of these students, I have been impressed by the sheer relief evident in their voices and postures as they discover what I know about special health needs at school. They are saying to me, "Oh, I'm so glad to hear you say that! That's just the way we hoped you would see it." These parents literally heave sighs of relief when they talk with me about the special needs of their children. Not that I feel that I know much about these particular families as of yet, for I have only recently met them, however, I am obviously conveying a message of understanding.

My experience has taught me to look at each child as a unique individual, and at each family situation as unique, even though, some of their needs may be similar to one another. I still feel somewhat nervous as I come to know these children and their special needs. I worry that I may not be as sensitive to their unique needs as I feel I should to be. I still do not know how they will respond to our classroom environment, even though we will not knowingly introduce allergens or irritants. I can only imagine how unsettling this teaching assignment might be for a teacher who has little previous experience working with children with special health needs. I also feel that these children and parents are relying on me to be on my toes, and to monitor the child's health needs closely. I take comfort in the helpful manner of these parents. They appear to be willing to provide any support I may need to help make their child's school experience a positive one.

I am now thinking that the written information given me about these children is only a drop in the bucket with regard to the special needs of these children. I must read and process this kind of information, but I must take it one important step further. I must take a more intimate approach than simply reading their medical fact sheets. I must come to know these children and their families in a more personal, caring manner, as with all of my students and families. It will be through personal contact and communication that I will come to better understand the needs of these people. I will need to see and to listen in a special way in order that I get a true sense of who these special students are and what they need.

Teachers begin every year with an attitude of discovery. What will this class be like? What will these children need? I think teachers are on the lookout for the things that will require a certain approach or sensitivity. What are the things that I will really need to be on top of this year? This will be different every year of course. As I get to know the children and the families I will be able to recognize certain 'red flags' as they appear. This doesn't mean that I will always have every special need of every child foremost in my mind, but I will learn to watch for the red flags, and rely on them to pull the crucial information to the front of my mind.

I know teachers can not possibly attend to all special needs at all times throughout the school day. This would certainly be asking too much of any individual. How I think I make this a more manageable task is to internalize all the red flags, and respond to them promptly as they come up. A response may only need to be a conscious monitoring of a situation, or it may mean crisis intervention. Based on my experience as the parent of a child with special health needs, and judging by what other such parents are telling me, it is important to pick up on the red flags at an early stage of difficulty. In this way I may avoid any serious compromise to my students' health, and any undue upset to all of us in the classroom community.

As a teacher, I have learned from this research experience. I have learned that parents want school to be a healthy safe place for all children. Parents of children with special health needs want their children to have the opportunity to go to school along with all the other children, and have as "normal" a childhood as possible. They want their children's school experience to be as much like that of "regular kids" as it can be. The more I understand about the needs of any child, the less I will have to draw attention to their differing needs. I feel that if I am well informed and closely in touch with the child, I am able to monitor their health situation in a discrete and effective manner.

I find myself checking the corners of our old school for dust. I have spoken to the custodial staff about what cleaning products he uses. I have inquired as to the rug cleaning schedule. I am considering asking the parents of the children with special health needs to lead a cleaning committee for monthly "spring cleaning".

I follow up on all smells. I do not wear perfume, even though I love it. I assure that all art and science projects take place in well-ventilated spaces. I speak to visitors and substitute teachers about cologne, hair spray, etc.. I also check for excessive pet hair on the clothing of students and visitors, and of course, screen all pets who may be visiting our classroom.

I never bring peanut butter to school. When there is food involved in a school activity, I supervise the activity myself, as I do not feel parents or visitors should be asked to do so unless they have had the proper training. We never plan a social event at our school without careful consideration to food sensitivities. I have taken to investigating all food that is "smuggled" into the classroom in back packs. The parents have all received an in-depth newsletter outlining our strict food policy, and all special dietary needs are posted in the snack area.

I am constantly aware of the outdoor air quality, and limit the amount of time spent outside when environmental allergens are at high levels. If we are involved in school activities away from our classroom, I assess the space to insure that it will be safe for all of our children. When we are at gym, music, or on a field trip, I stay with the children who have special health needs until I know how they will react to the new environment. We never leave our school without the fanny packs of medication, and I always know where I can put my hands on the appropriate medication. I carry a list of emergency contact numbers, and check the ambulance response time to any alternate locations.

My ears are keenly tuned to the sound of breathing distress and coughing. I watch for scratching and flushed skin. I speak to the children with special health needs frequently as they work and play, and watch for signs of over-exertion.

This may seem like a lot to keep in mind, but I really don't seem to spend much time doing it. I guess it has become second nature to me. Although I am hesitant to add to the load of school people, I strongly believe that what ever we can do to be more sensitive to the needs of children with asthma/allergy will benefit all members of our classroom communities.

The Method

As this investigation comes to a close, I am amazed at the ever-changing nature of our stories. As each person tells and retells his or her story, and as I read and re-read their story, I am reminded of the circular process of narrative inquiry. The stories of all participants have changed my story--as a mother, as a teacher, and *as a researcher. Each time I re-process the information given to me* through story, I see and hear in a different, and much deeper way. I bring layer upon layer of knowing to each reading or telling. Time and expanding knowledge have shaped this research story in a way in which I could not have fully anticipated. I could not have set a hypothesis in the beginning, nor could I have followed a 'recipe' of narrative inquiry, to arrive where we find ourselves today. As I return to my list of preconceived ideas of what I would find during this investigation (mentioned in chapter three). I see that neither of the metathemes constructed during this study were anticipated by me in January, 1994. It is clear from this list, that I did in fact enter this investigation with plenty of previous experience, interest, knowledge and information on the topic, just as Tesch (1987) suspects most researchers do. However, I was not able to identify the major themes that were yet to unfold from this study, and it is in my opinion, the surprises or the serendipitous findings which are most telling.

Narrative methods have heightened my awareness of the importance of time in this research process. Our past experiences, our present situations, and the sense which we are yet to make of our futures, are all encompassed in this research story. Where we have come from, who we are, and part of what we will soon be, as families living with a chronic medical condition, is evident in the pages of this study.

The method supported and fed itself as I worked through the various stages of the research. I had a sense of trust in the method, even though, prior to beginning, I had a great deal of difficulty anticipating how I would use this methodology, and how the research would unfold. With this trust and a patient attitude, I was able to discover where to go next as I made my way along my research journey. It is now clear, that although I had read about narrative inquiry, I could not conceptualize the process accurately until I was in the heart of the research.

Using this methodology has confirmed my belief that a story belongs to the storyteller. Although the teller may choose to share the story, and although pieces of that story may entangle with my own story, the story does not belong to me. It is, at best, loaned to me for the purpose of contributing to this research. Each of my participants' stories belong to him or her, and that sense of ownership is important. I have gained a powerful appreciation of the magnitude of the gifts which have been shared with me throughout the duration of this study.

The input of my participants has been invaluable. I have taken care to return to them with my interpretations of their stories, and to assure that they are able to confirm both the content and the message which I have included in their stories. The following excerpt from my research journal speaks to the importance of this point:

> I feel good that Joshua was able to confirm [his] story today. I have been trying so hard to capture the essence of the story, without jeopardizing the trust he has placed in our research/family relationship. The agreement outlined in our consent form has been foremost in my mind as I conduct this investigation. His feelings and his need for privacy are very important to me. If he is happy with our story to date, I feel content that our research relationship is working. (June 3, 1994)

I am now keenly aware of the great amount of time required to conduct a narrative investigation. If time had allowed, I would have liked to spend many more hours in conversation with my participants, having them retell their tales. This would have allowed for more mutual reconstruction of narrative accounts and, I believe, more deep description, reflection, and sense making. I suspect, however, that regardless of the amount of time given to the process, we would not have achieved closure in any real sense, we would have merely arrived at more beginnings to explore.

Conducting Research Within One's Own Family

Although Frank, Joshua and I have been living this story for eight years, and speaking openly about it to people, it is quite a different matter to make our lived experience the focus of my Masters research. I was cautioned by several people, especially at my proposal session, to be mindful of the difficulties which would inevitably arise while conducting research within my own family. This was welcome advice, as I had not given as much thought to it as I needed to. I had conducted myself ethically, and my family was informed and willing to participate, but there were issues which I had not considered. The following entry from my research journal describes a serious consideration that I had not thought through:

> I've given a lot of thought to research within my own family. My ethics review was temporarily blocked because of [this very issue]. "Doctor's don't do surgery on their families" was one reviewer's comment. I had to decide whether I'd discontinue the study if Frank and/or Joshua withdrew. I can't see it happening, but must assume it could, and what would I do? I would quit. I'd redesign my study based on other families! I met with Frank and Josh on Wed. Mar. 2, 1994 to see what they thought. I told them [that] my Ethics Review [had been] blocked and what decision [I] had [to make]. They were light-hearted about it and gave me no reason to worry that they would ever drop out. I told them they could "without penalty"...I told them that if they had to withdraw for any reason I would discontinue my study. We stood in the kitchen, held hands, and had a family hug. (March 4, 1994)

And so we had agreed. Should Frank or Josh change their minds about their participation in the study, I would abandon the study. I then had to resubmit the Ethics Review documents, stating explicitly that this was my intention. Upon doing so, my Ethics Review was approved without further delay.

Other issues arose. Early on in the process I found myself worrying that if Frank's stories differed from my stories the research would seem of poor quality. I thought maybe he would dispute my recollections, feelings, reactions, medical facts, etc.. I knew he would think and feel differently. I wrote in my research journal,

> Well then, what am I worried about? I trust my interpretations of our experience to be accurate and trustworthy. His view will expand and broaden the story, as will Joshua's. I must not fear that their stories will be different. I must expect that they will be and be prepared for surprises. Ahh! I feel better! (Jan. 16, 1994)

The complications of interviewing my own family were evident during Joshua's first interview. I found I had all the accurate history, so I kept interjecting. I also knew when to probe if things came out inaccurate. I realized I was giving lots of verbal and non-verbal feedback. Joshua really seemed to look for that feedback. These things would have been different if Joshua was a child whom I had just met.

I ran into an ethical issue following the same interview with Joshua. Frank came into the room and we played back part of the interview for him. Frank said, "Isn't it private?" Joshua and I said, "No". But Frank was right of course. I would not have played Cameron's interview for him. I had to rethink what I would share with Frank and Joshua and what I would not.

Joshua surprised me on several occasions. I felt it necessary to conduct a second formal unstructured interview with Joshua due to the quality of the first audio tape. It was clear that he resented the extra time. I think he had a certain commitment in mind when he agreed to participate, although I told him there would be more than one interview. I wondered if I had been clear enough in advance. Informed consent is a more difficult issue with a young child.

Frank was very easy to interview. He had well ordered thoughts, and it was clear that he had given a lot of thought to our situation with Joshua's health. While interviewing, I did far less talking with Frank than with any other participant. I didn't want to interrupt. I wanted him to forget I was his wife and to feel free to say anything he wanted to say. I really tried to stay out of his story. I did, however, choose with some care, *when* to interview Frank. Our lives can be so fast paced and I felt the timing had to be right. At one point he and I were in the midst of a several day disagreement about consulting a homeopathic doctor for Joshua. Although this was at the time that I was planning to interview Frank, I held off for a week or so. I feel we had a much more open interview atmosphere than we may have had prior to airing our concerns about homeopathy.

Joshua was quite strict about what he would allow in the research text. He speaks up loudly and clearly. I was left wondering how much of the "good stuff" he would veto. I wonder if eight year old children are more difficult to interview than five or six year old children. It seems like so much more is private now that Joshua is eight. He used to tell all, and let us share all of his cute stories with people, but just in the past six to twelve months I've noticed that he is far more private. I sure realize that I must closely consider his privacy, in general, and in my study. The following is an entry from my research journal:

> Panic struck my heart today as I realized that Joshua could veto so much of my writing. I am growing to greatly value the gift of his story, and to deeply respect that he owns his story. (June 21, 1994)

When I was writing narrative accounts from their interviews, I thought I had to keep my self out of Frank and Joshua's stories. I found it difficult to do, but I tried very hard and the stories ended up stilted and in need of rewriting. I realize now that I could not stay out of my husband's story or my son's story, unless they were to write them totally on their own. The important thing has been to confirm all stories with each of my participants, as I went along.

I also realized some significant benefits to conducting research within my own family. During the interview portion of this study I felt that the process of interviewing really enhanced communication between Frank and I, and between Joshua and I, with regards to our experience with asthma/allergy. I found out how they felt and what they believed about our situation and about asthma/allergy. I especially discovered what sense Joshua was making of his experience with chronic illness. There were several opportunities to discuss his condition and medical history with him, and to add to his understanding. I was grateful for the chance to correct certain misconceptions on his part. For example, Joshua told me in an interview, "[I worry] that I'm gonna have some kind of asthma attack and faint or die or get paralyzed or something like that...Well, asthma can be very harmful sometimes and people could have heart attacks and die". (Feb. 27, 1994)

The process of narrative inquiry calls for honesty and trustworthiness. I wrote in my research journal, "This narrative stuff sure keeps you honest. Knowing that every word must be confirmed by the participant keeps me on my toes" (Apr. 19, 1994).

I was very aware of the way in which I stated things and the importance of double checking every point.

From The Participants

On September 15, 1994, I returned to the Underwood home to confirm my final writing with Pat and Al, and to engage in a reflective conversation about the research journey which we have recently come through. I invited their feedback as well as their reflections on our lived experience to date. I explained my interpretation of the research 'findings', and asked for their response to these interpretations. I also asked to hear the stories of the children returning to school, especially the story of Cameron entering kindergarten.

Pat, Al and I gathered around the dining table with tea and Pat's homemade cheese crackers. Both Cameron and Emile were playing nearby, hovering around the table periodically to nibble on cheese crackers and to see what they may be missing. I asked them how school was going and they both shared happy stories with us. Emile announced that he is learning math, and that he likes going to gym. Cameron shared a lost shoe incident which resulted in him missing his recess. Pat added that Cameron was enjoying kindergarten, especially the wonderful variety of snacks. It seems he has a keen interest in the novel snacks provided by the kindergarten parents. Now that he is off to school and out in the 'big' world, he will be exposed to far more food which is not prepared by people he knows well and trusts. This is just what Pat and Al had anticipated, so they have already taken every possible opportunity to inform the teachers and the kindergarten parents of Cameron's severe nut allergy. Al accompanied Cameron on his first regular day of school. Pat has been to school twice already, and has attended the parent meeting as well. Pat has provided the teacher with the medical information sheet on asthma and anaphylaxis. Upon speaking with the teacher to follow-up on any questions she may have, Pat discovered that the teacher had not yet read any of the emergency medical information. Pat, sensing that it was time to emphasize the urgency of this situation, chose to use graphic language such as "dying", "death", and "funeral" when discussing the seriousness of Cameron's nut allergy. The next day, the teacher reported that she had not only read the medical information, she had approached a fellow teacher who also has severe allergies, for further information.

Pat, Al and I discussed how busy teachers are, especially a new teacher at the beginning of the year. Pat's point was that teachers are not too busy to watch that a child doesn't run across the road while on a field trip, nor are they too busy to stop a fight on the playground. Why is it then that school people are more sensitized to this type of danger, and far less aware of the possible fatal dangers of asthma/allergy? Has there been a concerted effort to heighten teachers' sensitivities to traffic dangers and fights? Can we take a page from that book and develop a campaign of sorts to increase awareness and sensitivity to the needs of children with asthma/allergy?

Something that Pat said during our latest conversation has helped me once again to see differently. She retold the story of not knowing Cameron had asthma/allergy. Even though Al had had it all of his life, neither Al nor Pat recognized it in their son. How could this be? Well, as Pat explained, Al is a "wheezer" and Cameron is a "cougher". Two people, being biologically connected, manifest quite different symptoms of asthma/allergy. If Al and Pat could not recognize asthma/allergy in their own son, what does this mean for a teacher? If, for example, I had a child like Al in my class one year, and a child like Cameron in my class the next, what previous experience would hold true from one year to the next? What could I take from "Al's" situation to help me understand "Cameron's" situation? First, I must not assume, "Oh, here is another child with the same needs". I am sure that any information I had internalized about the actual condition of asthma/allergy would remain helpful. However, as I have stated above, I would have to take it one step beyond the medical information. If I had developed a caring and compassionate manner of communication with my "Al" student and his family during the previous year, I could draw from that experience to become more intimately involved with my "Cameron" student and his family. This may well be the most significant thing I have learned as a teacher, from this study. Children with the same 'label' and the same condition, and the same medical fact sheets, are not the same. They are unique individuals just like every other child in the class. And their family situations are also unique. So the only common ground may be the open, caring style of communication which will be developed between people.

Pat, Al and I discussed the need for a caring style of communication. As I shared my interpretations of the major themes which I have constructed in this investigation with them, I was pleased to have the opportunity to record their impressions of these themes. They agree that teachers must try to be sensitive to the varying needs of different children and families. Pat says we can not be "pigeon holed" or "lumped together". She speaks at length about the "little supportive environment" at Cameron's school. She identifies the small school size, and the fact that her boys attend a child care centre just down the hall from their classrooms, as factors which contribute to the caring school community. She says there is very little staff turnover at their school, so there is a sense of familiarity there. Pat and Al both identify a teacher who also has asthma/allergy as a strong protective factor at Cameron's school. They are so pleased that this teacher is there and that her experience may serve as a guide for other school people.

I shared with Pat and Al my ideas about Yin and yang, and about order growing out of chaos. To my surprise Pat felt that both concepts spoke clearly to their situation. She says, "it only takes one chaotic trip to Emergency, and you get organized!". They now keep a backpack containing medications and other emergency supplies hanging on the doorknob, and they never leave home without it. Pat adds that she is now extremely organized with food and snacks, especially when away from home.

As for the need for careful charting and monitoring of Cameron's condition, Al tells me that it was Cameron's doctor who suggested the charting, although this was news to Pat, as she was not involved in that particular doctor visit. Pat and Al feel that they are, by nature and from experience, quite relaxed about Cameron's condition. They do chart and monitor closely because they need certain information to effectively manage Cameron's condition, but they do not see themselves as methodical or scientific in their approach to Cameron's condition. They do exercise "control" over the situation, and they do appreciate having a doctor who allows them that control, but they do not see themselves as particularly "control" oriented people. As I come to know them better, I tend to agree with Al and Pat on this point. I find them remarkably relaxed about Cameron's condition, and about Al's condition, even though the situations call for careful management and "control". This brings to mind the different though complementary forces of the yin and yang concept. By relying on both relaxatio and control, Pat and Al have achieved some sense of harmony. Not all parents could approach such a situation so calmly. Certainly this is in contrast to how Frank and I have handled Joshua's condition. I do think, however, that I am learning from Al and Pat. Their story has indeed colored my story, even though we have two quite different stories.

Family Stories

I feel fortunate to have had the opportunity to create written stories out of my journalized life experience. Rereading my journals and logs, and retelling my story has helped me to construct new meaning for myself. It has also changed my story, as I look backwards and forwards in the writing of my story. My story is one interpretation of where I have been. My story is a record of where I am. My story is the foreshadowing of where I will soon be.

I value Joshua's Asthma Story as something very different than the story I have written with and for him. It is fortunate that he is old enough to have captured parts of his lived world in written story form. His words are so very telling, especially when we consider his words written in times of wellness, alongside his words written in times of illness.

Journal Writing

As I poured over the years of logs and journals which I have kept, I see more and more meaning in the words. Progoff (1992) refers to this activity as Journal Read-back. Reading back journal entries to myself, especially aloud, helps me take the journal process to a deeper level of understanding. I find it a powerful tool, both personally and in my research. The reading back and the writing of a response helps me become more aware of my personal growth, and to make connections between what I am coming to know and my earlier written attempts to understand. The read-back technique has facilitated the formation of original thought and knowledge as I have proceeded along this research journey. It has been an extremely valuable tool during this investigation.

To have a body of longitudinal 'data' such as I have in my journals, offers a rare and inviting challenge to someone like me who loves the research way of knowing. There is so much recorded between the covers of these volumes that it would take many years to exhaust the research possibilities. For now, I have borrowed what seemed relevant and left the rest for my own reading pleasure, for my family, and for future investigations, should that ever seem appropriate.

This study has incorporated a strong journal component. Not only was much of the data in journal form, but I also relied heavily on my research journal. Journal writing as a research tool has proven to be a highly effective way for me to organize my thoughts, use reflective techniques, and make sense of what I was coming to know. At the onset of this study I determined to use a research journal to help me create my own knowledge as the study progressed. I feel that I did indeed rely on my research journal to serve this function, especially at the times when my thinking seemed to be "stuck".

Data Collection

Relationship is key to an effective "interview" situation. I feel that I was able to achieve a comfortable, trusting relationship with my participants, partially due to our common experience. I feel that the participants were comfortable with me and with the purpose of the study. I also feel that my being the mother of a child with asthma/allergy has enhanced the relationship between me and the

Underwood family members. I especially felt that I could relate to Pat, as she and I share the role of 'mother'. I believe she was able to speak freely to me about her experience as the mother of a boy with asthma/allergy because she knew I could easily relate to her story. The following words from my field notes illustrate this point well:

> In a sense, I couldn't have participated so fully in the conversations and interviews if I weren't a fellow parent of a child with a chronic illness, however, being on the same side of the 'tracks', but further on down the line, left room for me to "judge" their [the Underwood's] situation retrospectively against where we have been. An impartial, objective "interviewer" would have never gotten the depth of conversation, but would have been free from comparative judgment, one case to the other. (The "interviewer" wouldn't have had a similar "case".) (March 25, 1994)

This familiarity has come with both benefits and drawbacks. I have had to be careful to bracket the familiarity in a way which would allow me to see and hear my participants' stories as clearly as possible.

Data Analysis

I feel somewhat tentative about my findings in this study. The reason for this feeling is based on something which I have internalized during this research journey. Experience is layered, and knowing is so dependent upon the layer of experience and knowing which has been laid previously. I know that when I look back on this study in a few weeks, months, or years, I will see different things emerging from the data, and I will construct new meaning for myself. As I add new information and experience to my own story, my ability to see will be altered in an irreversible manner. Nothing will appear quite as it does today. This is not a conclusion. This story is indeed 'to be continued'. This is the nature of knowledge. This is good.

Me the Mother

What does this research say to me the mother of a child with asthma/allergy? Do I see differently because of this experience? Do Frank and I see differently following this narrative investigation, and do we see Joshua in a different light? Will Joshua be different because we have changed? I believe that once you see things in a different light, you cannot help but act in a different way. This is what I hope for my readers. If it is to hold true for them, it will surely hold true for us.

I was aware early on in this investigation that my story was being colored by Pat's story. The same is true of all of the narrative accounts of participants. Writing, reading, re-writing, and re-reading my own story has changed what I know and how I think. I have also been changed by my review of the literature, and by the process by which I came to make meaning from my research data.

I see myself approaching Joshua's teachers with a different agenda from this point onward. I am now conscious of the problem I was having with my "advocacy" role, and with the word advocacy. I was constantly fearful of pitting school people against me, Joshua or Frank--"them" against "us". I wanted to share information and do all I could to help Joshua have a positive school experience, but I was having difficulty getting past the adversarial connotation of our advocacy role. I didn't want this type of advocacy, but I felt that, at times I was being perceived as this type of advocate, or at least I thought I might be seen in an adversarial role. What is important to me now, is building a community of caring people who will work along side Joshua at school. It is my wish to be accepted by school people as someone who cares deeply about Joshua's well-being. I wish for the time and opportunity for teachers to become more intimately involved with our family, and all families within our school community. I know that teachers can not keep all of the special needs of every student in mind every minute of the day. I only wish that through mutual concern for the well-being of all children, we can develop an ethic of caring (Noddings, 1984) which is conducive to open conversation, and the effective sharing of insights and information. I want to have teachers rely on us for help and for information. I also need to rely on Joshua's teachers to provide me with the insights and information they possess simple from being near Joshua all day. What I am searching for now is a way to open the lines of communication and to impress upon the people at Joshua's school that Joshua is a unique child and we are a unique family. I wish I could say, "Pull up a chair and let's get to know one another". I really need them to know what Joshua's needs are, and I don't want them to assume that Joshua is just like the "Al" or the "Cameron" they taught last year. The best way I see of accomplishing this is through conversation and true listening.

Closing Remarks

In reflecting on the purpose of this study, I feel that I have both achieved my goals, and encountered surprises along the way. Tesch (1987) was clearly correct in saying that researchers often choose to explore areas of study with which they are connected in some way. In this sense, I was quite well informed on this topic from the outset. On the other hand, there is no way of knowing what will emerge from a study of this nature. I hope that I have succeeded in illuminating the lived world of all participants. I intend to further heighten awareness of the life world of a child with asthma/allergy by publishing articles in periodicals which will land directly in the hands of school people and parents. I hope that these stories will hold the interest of the reader and draw them into the world of the student with asthma/allergy and his or her family.

I chose to story this research because I believed that it would be the perfect method for achieving my stated purpose. I have always valued the informal story telling done around the teachers' coffee table or at parent-teacher conferences. I have a great respect for the role that this type of sharing has played in personal and professional growth. I admire Vivian Paley (1986) for the success she has had with her school stories. I have intuitively felt that the Tracy Kidders (1989) and the Alex Kotlowitzs (1991) of the journalist world have something to share with we school people about the dissemination of educational research. The mass readership achieved by Kidder and Kotlowitz serves as a goal for educational writers. Their stories of school people have found their way into the hands of the general public, unlike any piece of educational research could have done. I only hope that the stories here will meet with a fraction of the success achieved by other stories of school people. I have a strong sense that narrative inquiry, especially that which originates in first hand experience, will become an even more powerful tool in the dissemination of school knowledge, and will be instrumental in leading the way to effective school reform.

In the future, I hope to have the opportunity to engage in conversations with school people about this study, and about the classroom life of children with asthma/allergy. The voice of other teachers is weak in this study. The scope and practical considerations of this study have not allowed for the inclusion of other teachers' voices. I would have liked to share the stories of this study with the classroom teachers who are working with our sons at this point in time. I would be very interested in what they would have to add to the ongoing story of students with asthma/allergy.

I trust that these stories will continue to be lived and relived, told and retold, and that the people who have given of themselves for this study will continue to grow and lead healthy storied lives.

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