ment problems all the way to medical problems. These topics are discussed at national seminars on the needs of young adults with CF. The information discussed is sent out in a newsletter called Young Adult Focus to young adults with cystic fibrosis. Pamphlets directed at employers are also written by this group.

Obtaining more visibility and support for the young adult with CF on the federal government level is another activity initiated recently by the Cystic Fibrosis Foundation. Its young adult coordinator participated in the first joint meeting of the youth auxiliaries of major national health organizations. 80

The Professional Education Program places its major emphasis on early recognition of CF. General family practitioners and pediatricians are the main target for mass mailings and other educational approaches. This program includes the publication of the Guide To Diagnosis and Management of Cystic Fibrosis, the Quarterly Annotated References, and audiovisual materials such as "Pathology of the Lung in Cystic Fibrosis."

The Professional Training Program supports clinical fellowships for physicians and for CF Center personnel. In 1976, fourteen fellowships were awarded. During 1976, two new programs were developed. Center Personnel Development and Visiting Professorships were initiated to provide advanced training specifically tailored to the needs of individual Centers. Personnel travel to other centers or invite specialists

80 Ibid., p. 5.
to their own center to benefit from expertise in particular areas. 81

The Government Relations Program seeks to improve the medical, emotional, and financial circumstances faced by cystic fibrosis patients and their families. 82 A Washington-based office is being used to strengthen ties with the branches of the federal government. This is accomplished by speeches and publications which emphasize the importance of Pediatric Pulmonary Centers and Crippled Children's Services.

Health Education is another program of the Cystic Fibrosis Foundation. Pamphlets for teachers of CF children and genetic pamphlets are put out by this program. The major function of Health Education, however, is to publish a "Directory of CF Pediatric Pulmonary and Gastrointestinal Centers." This is a valuable resource for the referral of families with CF children to sources where they can receive medical care. 83

The Public Relations branch of the Cystic Fibrosis Foundation keeps very busy. Their goal is to widen the range of communication and understanding, to increase public awareness and participation, and to provide greater informational services to all communities. 84 The public relations department works to secure sponsors for CF. Some of the sponsors are 81Ibid., p. 7.
82Ibid., p. 17.
83Ibid., p. 15.
84Ibid., p. 14.
Alpha Chi Omega, Miss Teenage America Pageant, Association of Tennis Professionals, and Knights of Pythias.

Local television stations have given more than $800,000 worth of network time for cystic fibrosis and other related diseases. Recently, mini-telethons and TV auctions have been held to raise money. 85

The Foundation's Kiss Your Baby education program was started in 1975. The program theme educates parents to one of the most easily detected symptoms of the disease, a salty taste to the skin. 86

The public relations committee takes an active part in spreading the word that people in wheelchairs are not the only "crippled" people. Due to this work, the National Institute of Health awarded a $290,000 contract to provide for a study of cystic fibrosis. 87

Guidance - Action - Projection (GAP) conferences are held during the year. These conferences are designed to fill "gaps" in the existing knowledge in a particular field.

The National Cystic Fibrosis Foundation is clearly very involved in research. The Foundation, however, realizes that more than research is involved in CF. For this reason the variety of programs they offer is great.

85 Ibid.
86 Ibid.
87 Profile 1 (Spring, 1977): 3.
Chapter VII

PSYCHOSOCIAL
PSYCHOSOCIAL

"No one who has a CF child can live a normal life. Every phase of living is affected. Savings evaporate; spare time is at a minimum; energy is exhausted. Sleep is broken regularly at night to attend the coughing child. Cooking is restricted. No smoking is allowed in our house. We haven't had any new furniture since a CF child came into our lives eleven years ago. We've had no vacations except visiting relatives. It's just plain hard to make a happy life for my family. But somehow you manage to go on meeting your responsibilities." 88 These were the words of the mother of a CF child.

Cystic fibrosis is a social as well as a medical problem. When the problem is diagnosed, a variety of reactions can ensue. The family can experience any or all of the following emotions: grief, guilt, anger, anxiety, or apprehension. These emotions are usually temporary. Once the family has accepted the illness, they subside.

Once this occurs, the family must concentrate on the essential coping process involved in long term illness. "This process may be divided into two basic parts of which safeguarding the family relationships and home life is the first. The

second is the coping process of the child. 89

Family Relationships and Home Life

The marriage is often put on unstable grounds when a cystic fibrotic child is found. One or both of the parents may feel that the other spouse is to blame. Another problem which commonly occurs is a failure in communications. One parent may be so involved with the child that he/she neglects the needs of the spouse. This communication gap is often noticeable in the hospital or the doctor's office. Once the professional sees this problem, he/she must take the initiative of referral. Often social workers are in close contact with the family, and if notified of marital problems, will help the husband and wife work through their problems. "A child's illness does not inevitably destroy the parent's marriage. To the contrary, among a group of families of children with cystic fibrosis, it was found that the divorce rate was lower than in the general population. However, the period of coming to terms with the illness is one of severe strain in most marriages." 90

Siblings of the CF child also play a part in family relations. The CF child's siblings should be given as much explanation as is practical for them. They should understand


90 Ibid.
why attention and care is diverted from them so they don't develop feelings of personal rejection or of jealousy. Often, if CF is left unexplained, siblings feel responsible for the illness.

Grandparents and close relatives may blame the disease on the other side of the family. It is important to discuss with them that both sides of the family are equally involved. Because of their concern, family members may try to help in unwanted ways, such as giving the child sweets or allowing the child to do as he pleases. By showing the family ways to help (visiting the child, helping with housework, babysitting), hopefully their concern can be shown in a constructive manner.

The Child's Coping

The child with cystic fibrosis knows he is sick. His anxiety level will be very high until he finds out what is wrong with him. By explaining the disease to him, several things are accomplished. The parents and the family don't have to worry about saying something 'wrong' in front of him. If he understands the illness, the child with CF will not be so embarrassed about his differences, e.g. cough, body build. He can explain the disease to his friends thus making it more acceptable to them. Hospitalization is not so frightening if the child understands why he is there. One of the main concerns with a CF child is the family's worries over discipline. Some parents feel that the child suffers enough without having to give up some of the things he likes. They eventually find
out, however, that the cystic fibrosis child is no different than any other child. If not disciplined, he will not grow up with the proper socialization skills necessary for school, friendships, etc.

As the CF child becomes older, he realizes the burden, both financially and psychologically, that he places upon his family. At this point the child may experience guilt feelings. This is a good time to begin allowing the child to take an active role in his own care.

A psychosocial adjustment problem is judged to be present when there is an abnormality of behavior, emotions, or relationships which is sufficiently prolonged to cause handicap to the child himself and/or distress or disturbance in the family which is continuing up to the time of assessment.\(^91\)

In a study by Tropauer, Franz, and Dilgird, twenty children and twenty-three mothers were selected on the basis of their availability for psychiatric and psychological examinations. Three basic aspects were studied:

1. adaptation of the child to illness
2. patterns of defense and adaptation seen \(^92\) in the mothers
3. effects of cystic fibrosis on the family

Adaptation of the Child to the Illness

Most of the children had a good understanding of CF, but it was found that an accurate and realistic concept of

\(^91\)Carol L. Cooper, Julian Ferholt, and Beckett Rodgers, "A Screening Tool to Detect Psychosocial Adjustment of Children With Cystic Fibrosis," *Nursing Research* 23 (September-October, 1974): 421.

cystic fibrosis did not always ensure a cooperative attitude toward treatment. Likewise, although there was a general absence of overt depression, this did not mean that the children were free from morbid thoughts dealing with their illness. About one third of the mothers reported that their children had voiced concern over death. Many parents responded with false reassurances. The value of this type of reassurance is small. 93

Young children with CF complained chiefly about play interruption, dietary deprivations or the physical limitations. Adolescents, on the other hand, were more concerned with death, disability, and lack of acceptance by peers. 94 Many children, no matter what age group are concerned about their small, frail appearance. Boys are usually small in stature. Girls do not develop as quickly as non-CF adolescents. 95

Some of the behaviors in CF children as noted by their mothers include disciplinary problems, excessive dependency, over sensitivity, and shame about having cystic fibrosis.


94 Ibid., pp. 426-27.

These were seen more commonly in families where the parents did not rely on each other for support and did not face problems openly.\textsuperscript{96}

Children with acute or chronic illnesses will experience anxiety at some level of consciousness. Its effects depend upon the child's emotional reserves, his coping mechanisms, and the degree of support he sustains from his immediate environment. It is not the existence of anxiety per se that handicaps the sick child and intensifies his invalidism, but rather its degree and his methods of dealing with it. Neurotic symptoms, inhibitions, immaturity, behavior problems, and resistance to therapy are signals of the patient's inability to contend with inner stress, and warrant further explanation.\textsuperscript{97}

Patterns of Defense and Adaptation Seen in Mothers

Mothers of CF children were disheartened by the sense of uncertainty and inevitability of the disease. Guilt was one of the strongest feelings, especially when the child had setbacks.\textsuperscript{98}

When cystic fibrosis is first diagnosed, the parents are encouraged to become active in the care of the child. Many times, by working to help the child live, the parents are helped to work through their guilt feelings.

Other methods of handling guilt were found in the study. Some mothers became very overprotective. Mothers would build the mother-child relationship and exclude all others. On the other hand, some mothers became overly


\textsuperscript{97}Ibid., p. 428.

\textsuperscript{98}Ibid.
rejecting. This is shown by missing clinic appointments and allowing the child to resist his treatments. 99

Perhaps the most useful gauge of successful adaptation is the ability of the mother to continue functioning in a supportive role for the child, despite internal conflicts and psychological distortions of reality. Her problems become disabling to herself or the child when they either retard communication, interfere with educating the child about his illness, or prevent her from perceiving his needs and feelings. 100

Effects of Cystic Fibrosis on the Family

Even when the CF family's adjustment was successful, siblings often complained about their sacrifice. Young children frequently pretended to have cystic fibrosis or some other complaint in order to get attention. Problems that the siblings had, e.g. learning problems or delinquency, were attributed by the parents to the strain imposed by a chronic illness. 101

Cystic fibrosis children were unusually attuned to the feelings of others whether they were expressed overtly or covertly. Resentment was perceived as dissatisfaction with themselves and the burden that their care entailed. Although it is true that there are problems in the family related to them, the problems are often magnified by the child. 102

99 Ibid., p. 429.
100 Ibid., p. 430.
101 Ibid.
102 Ibid.
Today more than 50 percent of cystic fibrosis patients live past eighteen years of age. It has been found that most males with CF are born with obstruction of the vas deferens. Although this obstruction does not impair sexual function, the man is unable to father children due to no sperm reaching the semen. Women with cystic fibrosis have delayed menarche, irregular periods and late breast development. In our peer-oriented society, these aspects of CF could carry psychological implications. Peers may compare body development, women may not want to marry a man who cannot father children, or men may be afraid a CF woman is too frail to risk pregnancy. Presently the Cystic Fibrosis Foundation's Young Adult Program is working on these problems and ways to help CF patients deal with them.

Although there seems to be much going against CF patients, they do have some things going for them.

Outside of Cleveland, Ohio, there is a campground. For two weeks out of every summer the camp is set up for cystic fibrosis children. The camp is run primarily by donations from the community. This gives the children a chance to be away from home and to talk with other CF children. It also gives the family a much needed rest from the routine of care required by the CF child.\(^{103}\)

According to Dr. Paul R. Patterson, one of the "Founding Fathers" of the Cystic Fibrosis Foundation, "Out

of forty-two patients who entered college, forty actually graduated. Now you may not be impressed with this fact until you realize that only fifty percent of all individuals who enter college ever graduate."\textsuperscript{104}

Although cystic fibrosis is a lifelong disease, many people have learned to live with the disease. Many CF patients find it hard to take the strain, but perhaps with more knowledge and counseling the burden of cystic fibrosis can be lessened.

\textsuperscript{104}Newsletter - Cleveland Chapter, National Cystic Fibrosis Foundation, July 1975.
Chapter VIII

INTERVIEWS
Lori Mattix

Tell me about your daughter.

Rachel's Father

Tell me about your daughter.

Rachel is seven years old now. She was diagnosed with cystic fibrosis at 20 months. It's strange - during the first year she was really active. She never had any colds. Then after her first birthday she became tired and listless. We took her to the doctor. He said it was whooping cough. She was on medication but she didn't get better. She wouldn't eat so we took her to another doctor. He looked at her and said he thought he knew what it was. He didn't tell us, though, until after the sweat test.

What did you think when you found out she had CF?

I didn't know what to think. The doctor gave us some pamphlets and talked with us about it. He set it straight with us. When Rachel was diagnosed the life expectancy was 13 years. Now it's closer to 18 years. He told us that 10-13 years old are the critical years. This is because the lungs are developing. Rachel is in better shape than most CF kids.

What kind of treatment does Rachel get?

She used to sleep in a mist tent at night and for her naps. It had Bronchosol E in it. It made her really cough. We quit using the tent and now she seems...
What kind of medications is Rachel taking?

Better. She doesn't cough near as much. Sometimes she wheezes. She has a postural drainage table for those treatments. She gets those 2-3 times a day. Rachel also has a breathing machine (IPPB). She uses that mainly when she's sick.

She takes cotazyme. It comes in packets like sugar. She takes about six packets with each meal and she has to take some with snacks, too. If she's getting too much enzymes her bowel movements get like diarrhea. They're pretty expensive. It costs $40 for a box of 250 packets. They have cherry flavor ones, too, but they cost twice the amount of regular ones. Rachel also takes vitamin E. She takes Organidin which is an expectorant and Erythrocin. Both of those are liquids. Here, let me show you my bills. It cost $688.09 for medications in 1976-77. At first it was $125 per month for prescriptions. Rachel sees the doctor every month. That's $16 per visit. She sometimes goes in two or three times a week for shots.

Did you buy the equipment, too?

No, thank God. Ball Hospital loaned us an IPPB machine until we could get one from Crippled Children's Services. I know they cost at least $400. Her postural drainage table was given to us by the Odd Fellows. I tell you, CF can break you financially. Emotionally it's hard, too. The doctor recommended that we not have any more children because of the chance of have another CF kid.
Where can you go to get financial help? I'm really lucky. My insurance through work (Traveller's) pays 80 percent of the bills after I pay the $50 deductible. The other 20 percent is paid by Crippled Children's.

How did you find out about and get Crippled Children's? The doctor told us we should go over and fill out the forms. It wasn't bad at all.

What about the CF Foundation? They don't give you any money. All their money goes to research. There are Cystic Fibrosis Centers in Indianapolis. Rachel goes to Methodist periodically for a check-up. They do throat cultures, check her mucus and take x-rays. It's really nice there.

Is it expensive? No, it's about the same as here.

How do you feel about having a daughter with cystic fibrosis? Sometimes I get really sad. One time at Methodist we met a 4 year old and her parents. Rachel was only two then. She looked bad—she was really thin. She died pretty soon after that. It helps to talk about it, but when I look at her I can't think of it. She seems so healthy. Maybe they'll find the cure soon. I like to think that.
Mr. ___________ - stepfather of seven year old CF child (Rachel's stepfather)\(^{106}\)

**Lori Mattix**

**Rachel's Stepfather**

Tell me about Rachel.

As you probably know, CF is very expensive. Insurance companies won't cover CF children except through large corporations with major medical. She takes several medications such as Organidin, Cotazyme and Ampicillin. Rachel gets percussion and postural drainage and has an IPPB machine. She knows what she can and can't eat so we don't worry about her when she goes to a friend's house or out to eat. Smoke bothers her. She tells me sometimes. I feel guilty then. Maybe I'll quit.

How did you and your family feel about Rachel having CF?

Well, my parents weren't unhappy. They were concerned but they really like Rachel. My brother came up to me and said, "How can you marry a woman with a dead child?" I hit him clear across the room. (Silence) Cystic fibrosis kids die. It bears on my mind. I know it bothers Janette (Rachel's mother) too. Sometimes when we're all in the living room Janette's and my eyes meet. We both look at Rachel and we know. It's hard, but you just have to make the best of it.

If I get too personal just let me know. Does it affect your marriage?

No, it doesn't affect the marriage, but yes, it does.

---

\(^{106}\)Mr. ___________, interview with the stepfather of a CF child, Muncie Indiana, October 20, 1977.
Janette has a hard time dealing with the fact that Rachel will die. It makes our relationship tense sometimes. I think Janette feels guilty. She had to get married and then her baby had CF. It was all kind of a shock. Hopefully, we'll be able to work it out. Rachel is my baby. I want to stay here.

Does Rachel know that she has CF and that it is fatal? She knows she's sick. I don't know if she knows she'll die or not. I just don't know.
Mr. __________ and I picked Rachel up from school. Rachel is seven years old and has cystic fibrosis. She is in the first grade.

Hi, Rachel. How was school today?

Tell me about your medicines Rachel.

Mr.-Rachel, I have someone here I'd like you to meet. This is Lori Mattix. She and I have been talking about you and about what's wrong with you. Do you know what's wrong with you?

R.- You mean my cough?

Mr.-Yes, and what else?

R.- I don't know.

Mr.-Your trouble with food.

R.- Oh, you mean because I can't digest foods?

Mr.-Yes, that's right.

R.- It was OK. I went out on the playground on the swings. There was a big puddle and I got my feet all wet.

Mr.-Are they still wet?

R.- No, they're dry now. I felt sloshy for a while though. I didn't cough hardly at all today, Pa.

Mr.-That's good, Rachel.

R.- I take this one medicine to make me cough and I take another one that tastes bad. I sprinkle enzymes on my food when I eat.

107 Rachel __________, interview with a seven year old girl with cystic fibrosis, Muncie, Indiana, October 20, 1977.
Are there any foods you can't eat?  

R.- I can't eat chocolate or fatty foods.

Do you get therapy?  

R.- Yes, sometimes. I use a machine but that's usually only when I'm sick. I get pounded on sometimes, too.

How often?  

R.- Well, I don't know. I haven't had it for the last few days.

Do you cough a lot?  

R.- Sometimes. It just depends—some days I do and some I don't.

Since Rachel does not know the full extent of her disease, I did not question her further. We sat and talked for about twenty minutes. She seems perfectly normal.
Chapter IX

NURSING CARE PLAN
### Objectives

1. To establish and maintain proper nutrition

2. To prevent or treat respiratory infections by thinning secretions and clearing them from the respiratory tract

### Intervention

<table>
<thead>
<tr>
<th></th>
<th>1. high calorie, low fat diet</th>
<th>1. Intermittent aerosol therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. water soluble vitamins</td>
<td>a. 3-4 times daily</td>
</tr>
<tr>
<td></td>
<td>3. give pancreatic enzymes</td>
<td>b. prior to postural drainage</td>
</tr>
<tr>
<td></td>
<td>with each meal</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. increase salt intake in hot</td>
<td></td>
</tr>
<tr>
<td></td>
<td>weather</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5. feed slowly to avoid</td>
<td></td>
</tr>
<tr>
<td></td>
<td>coughing and/or vomiting</td>
<td></td>
</tr>
</tbody>
</table>

### Rationale

1. CF children cannot metabolize foods as efficiently as normal children. For this reason, special care must be taken that they receive adequate nutrition. Since CF children are prone to infection, good nutrition is necessary to give them strength to fight the infection.

If no pulmonary toileting is done, the CF child will get a respiratory tract infection. Infection can lead to lung damage. This damage causes scar tissue which becomes fibrotic tissue. As this occurs, less of the lung can be used for air exchange.

---

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Intervention</th>
<th>Rationale</th>
</tr>
</thead>
</table>
| 3. To understand which medications are given and why they're given | 4. Breathing exercises  
   a. exhaling slowly  
   increases the duration of exhalation  
   thus alleviating some of the obstruction  
   which results from the pressure change. | It is important to keep antibiotics on a regular schedule in order to maintain the blood level of the drug. Should the child become ill, it is important to know the actions of the various drugs so that the correct drug will be given. Because most drugs have some adverse effects if given over long periods of time, it is essential to be alert for these effects and to report them so that perhaps the medication can be changed. |
| 1. Antibiotics  
   a. broad spectrum  
   1. prophylaxis  
   b. narrow spectrum  
   1. to treat specific infective agents | | |
| 2. Expectorants/mucolytic agents  
   a. to thin secretions  
   b. to increase expectoration of mucus | | |
| 3. Bronchodilators  
   a. to increase width of bronchial tubes  
   1. allow air passage into lungs  
   2. allow easier expectoration of mucus | | |
| 4. Know side effects of drugs. | | |

109 Ibid.
<table>
<thead>
<tr>
<th>Objectives</th>
<th>Intervention</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. To provide proper hygiene</td>
<td>1. Good skin care</td>
<td>With young children especially this is important. Skin breakdown requires proteins and vitamins for rebuilding. This takes the needed nutrients from growth and development. By starting the child off with good care, he may learn the proper way to care for himself.</td>
</tr>
<tr>
<td></td>
<td>a. prevent breakdown of skin</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Keep diaper area clean</td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. reduce odor of stools</td>
<td></td>
</tr>
<tr>
<td></td>
<td>b. prevent diaper rash</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Change clothes frequently as the child may easily perspire</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Good oral hygiene</td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. remove taste of mucus from mouth</td>
<td></td>
</tr>
<tr>
<td>5. To support the child's emotional, psychological, and intellectual needs</td>
<td>1. Explain procedures and medications to the child</td>
<td>Any illness is frightening. By supporting the child's needs you can establish a trust relationship, and once this is established, the child is more open to learning. By being honest with the child you will set the standards he will live by. If you allow him to believe he's crippled - he will assume that attitude. By allowing him to express his fears and then discussing them, he will learn that help is available.</td>
</tr>
<tr>
<td></td>
<td>2. Allow child to show his fears, frustrations and feelings by talking, crying or complaining</td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. comfort him by talking to or holding him</td>
<td></td>
</tr>
<tr>
<td></td>
<td>b. do not label his expression as silly or childish</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Provide diversional activities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Help child assume responsibility for his treatments</td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. stay with child at first</td>
<td></td>
</tr>
<tr>
<td>Objectives</td>
<td>Intervention</td>
<td>Rationale</td>
</tr>
<tr>
<td>------------</td>
<td>-------------</td>
<td>-----------</td>
</tr>
<tr>
<td>6. To encourage parental participation in learning to care for the child and to cope with the disease.</td>
<td>b. Praise him when he does it correctly c. don't overburden the child</td>
<td>By helping the parents learn proper techniques in caring for their child you can be relatively sure that they will continue proper treatments in the home.(^{112})</td>
</tr>
<tr>
<td></td>
<td>5. Talk with family and child to express feelings on CF</td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. child may feel like a burden b. parents may feel guilty(^{112})</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1. Provide opportunities for parents to observe care and teach how to do it.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Refer family to Visiting Nurse Association or other community agency</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Assist parents in finding financial aid a. Welfare b. Crippled Children's Services</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Allow parents to voice their fears and concerns about CF</td>
<td></td>
</tr>
</tbody>
</table>

\(^{112}\) Ibid.

Parental teaching is a very important aspect in the care of the CF child. If parents do not realize the importance of treatments, and medications, the child's life span could be shortened by years.

Here is the teaching program suggested by the Lippincott Manual of Nursing:

1. Parents must have a thorough understanding of the dietary regimen. Help them to know what types of foods the child is allowed to have and those restricted. Talk about ways to make each meal or certain foods attractive.

2. Help parents become thoroughly familiar with the pulmonary therapy regimen. Do not rush your explanation; take time to demonstrate and explain procedures. Then allow parents to demonstrate all the treatments to be done at home.

3. Help the family to plan the most normal family pattern of living in relation to treatment of their child. Consider the marriage needs of the parents and the needs of other members of the family.

4. Help parents to understand and provide emotional support of their child. Explain that he will experience the usual problems of growing up in conjunction with the problems of cystic fibrosis and hospitalizations.

5. Impress upon the parents the importance of regular medical follow-up care.
   a. Routine immunizations - measles vaccine and influenza given early in infancy.
   b. Continual evaluation and supervision in home management.
   c. New developments through research that may change therapy.
   d. Detection of or prevention of complications.

6. Future in society.
   a. With the medical advancements that have occurred, there is every reason to believe that the child

---

with cystic fibrosis may grow to adulthood, depending upon pulmonary involvement and complications.

b. Play and school participation depends upon severity of illness.

c. Have parents discuss the child's problem with the school nurse, teacher, and other responsible adults who have close contact with the child.

d. Encourage parents to allow the child to participate as well as take additional responsibility in his care and treatments as he gets older. 

115 Ibid.
Chapter X

RECOMMENDATIONS
RECOMMENDATIONS

The Cystic Fibrosis Foundation supports much research. In the author's opinion, however, a larger percentage of their money should go into patient care. Cystic fibrosis is an expensive disease. Families with CF children lose a great deal of the "normalacy" of family life. By helping with the financial aspect, the Foundation could make life a little easier.

Indiana has no CF clubs that the Indiana CF Foundation knows about. Parents of children with cystic fibrosis need emotional support. No one understands the problems of the CF family like another CF family. Perhaps by publishing a CF directory for Indiana, the basis for city or county CF clubs could be started.

The public is very unaware of cystic fibrosis and just what it entails. It needs to either be brought to public attention by advertising or better yet in the school system. Health classes are required for high school students. Showing them the "Kiss Your Baby" movie would be an effective way of letting the parents of tomorrow know what to look for in their children. Also physicians and other medical personnel could use this kind of learning. Too many times CF is misdiagnosed.
Parents of cystic fibrosis children need more education and explanation of the disease. I realize that there is no way you can make parents do the treatments regularly, but maybe if they realized the consequences of not doing them, they'd be less reluctant to carry out the procedures.
Appendix A

CYSTIC FIBROSIS

POSTURAL DRAINAGE - INFANT CHART 116

1 - UPPER LOBES, APICAL SEGMENTS
Sitting, baby leans back 20° on pillow supported by parent's arm. Clap above collar bone one side at a time.

2 - UPPER LOBES, POSTERIOR SEGMENTS
Baby leans forward 20° across pillow. Clap over each shoulder.

3 - UPPER LOBES, ANTERIOR SEGMENTS
Place baby on pillow across lap, face up. Clap just below collar bones.

G. S. Peoples, M.D., State Health Officer - South Carolina State Board of Health, Cystic Fibrosis - Postural Drainage - Infant Chart, Crippled Children's Division.
4 - RIGHT UPPER LOBE
Place baby on left side, resting against pillows to maintain ¼ turn toward face down. Clap over right shoulder blade.

5 - LEFT UPPER LOBE
On right side, place extra pillows under head and right shoulder to raise chest 12 inches higher than hips. Clap over left shoulder blade.

6 - RIGHT MIDDLE LOBE
Raise hips 12-14 inches higher than head. Place baby on left side, head down, roll ¼ turn backward. Maintain position by pillow under right side from shoulder to hip. Clap over right supra-mammary area at angle of shoulder.

7 - LEFT LINGULA
Hips 12-14 inches higher than head. Place baby on right side, head down, roll ¼ turn backward. Maintain position by pillow under left side from shoulder to hip. Clap over left supra-mammary area at angle of shoulder.
8 - LOWER LOBES, ANTERIOR SEGMENTS
Place baby on back, head low. Clap over lower ribs.

9 - RIGHT LOWER LOBE, LATERAL SEGMENT
Place baby on left side, head low. Clap over lower ribs.

10 - LOWER LOBES, POSTERIOR SEGMENTS
Place baby face down, head low. Clap over lower ribs.

11 - LEFT LOWER LOBE, LATERAL SEGMENT
Place baby on right side, head low. Clap over lower ribs.

12 - LOWER LOBES, APICAL SEGMENTS
On level, baby lying on pillow across knees, face down. Clap just below shoulder blades.
### ANTIBIOTIC THERAPY

<table>
<thead>
<tr>
<th>Classification</th>
<th>Drug</th>
<th>Dosage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Penicillin</td>
<td>Penicillin G procaine</td>
<td>300,000 units every 12-24 hours</td>
</tr>
<tr>
<td></td>
<td>Penicillin V potassium</td>
<td>250 milligrams every 6 hours</td>
</tr>
<tr>
<td></td>
<td>Methicillin sodium</td>
<td>6-12 grams daily</td>
</tr>
<tr>
<td></td>
<td>Oxacillin sodium</td>
<td>500 milligrams every 6 hours</td>
</tr>
<tr>
<td></td>
<td>Cloxacillin sodium</td>
<td>250-550 milligrams every 6 hours</td>
</tr>
<tr>
<td></td>
<td>Dicloxacillin sodium</td>
<td>250 milligrams every 6 hours</td>
</tr>
<tr>
<td></td>
<td>Nafcillin sodium</td>
<td>250 milligrams-1 gram every 6 hours</td>
</tr>
<tr>
<td></td>
<td>Ampicillin</td>
<td>2-4 grams daily</td>
</tr>
<tr>
<td></td>
<td>Amoxicillin</td>
<td>125-250 milligrams every 6 hours</td>
</tr>
<tr>
<td></td>
<td>Carbenicillin</td>
<td>1-2 grams every 6 hours</td>
</tr>
<tr>
<td>Cephalosporins</td>
<td>Keflin (cephalothin)</td>
<td>4-12 grams daily</td>
</tr>
<tr>
<td></td>
<td>Loridine (dephaloridine)</td>
<td>0.5-1 grams-3 times daily</td>
</tr>
<tr>
<td></td>
<td>Keflex (cephalexin)</td>
<td>1-4 grams daily</td>
</tr>
<tr>
<td>Sulfonamides</td>
<td>Sulfisoxazole (gantrism)</td>
<td>1-2 grams every 4-6 hours</td>
</tr>
<tr>
<td></td>
<td>Sulfadiazine</td>
<td>Dosage depends on severity</td>
</tr>
<tr>
<td></td>
<td>Bactrim</td>
<td></td>
</tr>
<tr>
<td>Tetracyclines</td>
<td>Tetracycline Hydrochloride</td>
<td>250 milligrams every 6 hours</td>
</tr>
<tr>
<td></td>
<td>Terramycin</td>
<td>250 milligrams every 6 hours</td>
</tr>
<tr>
<td></td>
<td>Declomycin</td>
<td>100-300 milligrams every 6 hours</td>
</tr>
<tr>
<td></td>
<td>Vibromycin</td>
<td>50-100 milligrams every 12-24 hours</td>
</tr>
<tr>
<td>Aminoglycosides</td>
<td>Streptomycin Sulfate</td>
<td>0.5-1 gram-2-4 times daily</td>
</tr>
<tr>
<td></td>
<td>Neomycin sulfate</td>
<td>1 gram every 4-6 hours</td>
</tr>
<tr>
<td></td>
<td>Kanamycin sulfate</td>
<td>1 gram daily</td>
</tr>
<tr>
<td></td>
<td>Gentamycin sulfate</td>
<td>2-3 milligrams per kilogram per day</td>
</tr>
<tr>
<td></td>
<td>Tobramycin</td>
<td></td>
</tr>
</tbody>
</table>

---

<table>
<thead>
<tr>
<th>Classification</th>
<th>Drug</th>
<th>Dosage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Macrolides</td>
<td>Erythromycin</td>
<td>250-500 milligrams every 6 hours</td>
</tr>
<tr>
<td></td>
<td>Chloramphenicol</td>
<td>2-4 grams daily(^{118})</td>
</tr>
</tbody>
</table>

\(^{118}\)Ibid.
BIBLIOGRAPHY
BIBLIOGRAPHY

Books


**Periodicals**


Boat, Thomas F. M.D.; Boxerbaum, Bernard, M.D.; Doershuk, Carl F., M.D.; Matthews, LeRoy W., M.D.; Primiano, J.; Stern, Robert C., M.D. "Cystic Fibrosis - An Obstructive Pulmonary Disease of Children and Adults." Department of Pediatrics - Case Western Reserve University School of Medicine


Cooper, Carol L.; Ferholt, Julian; and Rodgers, Beckett. "A Screening Tool to Detect Psychosocial Adjustment of Children With Cystic Fibrosis." Nursing Research 23 (September-October 1974): 420-425.


Profile 1 (Spring, 1977): 3.


Pugh, R. J., M.D. "Cystic Fibrosis." Nursing Times, February 17, 1972, pp. 209-211.


Pamphlets

Cystic Fibrosis, Cystic Fibrosis Foundation, Atlanta, 1976.
The Genetics of Cystic Fibrosis, Cystic Fibrosis Foundation, Atlanta.
Good Business ... Hire Young Adults With CF, Cystic Fibrosis Foundation, Atlanta.

Marty has Cystic Fibrosis, Cystic Fibrosis Foundation, Atlanta.

Newsletter - Cleveland Chapter, National Cystic Fibrosis Foundation, July, 1975.

Research: Top Priority of the Cystic Fibrosis Foundation, Cystic Fibrosis Foundation, Atlanta.

A Teacher's Guide to Cystic Fibrosis, Cystic Fibrosis Foundation, Atlanta.

Your Child and Cystic Fibrosis, Cystic Fibrosis Foundation, Atlanta.

Peoples, G. S., M.D., State Health Officer - South Carolina State Board of Health, Cystic Fibrosis - Postural Drainage - Infant Chart, Crippled Children's Division.
I feel that I have basically achieved my objectives. The only one I don't feel I achieved is working with children with cystic fibrosis. Although I spoke with one CF child, I did not get a good view of all that cystic fibrosis means to a person with the disease. I would have liked to have gone to a Cystic Fibrosis Center. Perhaps, since I'll be at Riley Hospital, I'll have a chance to see their Center.