

Caring For Young People at Home With Cancer

Now, more than ever, we are winning the fight against childhood cancers. Scientific and technical advances in cancer treatments have increased the chances of extending life and have increased the chance of cure for most types of childhood cancer. Furthermore, there have been important advances in controlling symptoms and side effects of treatment so that the quality of life of younger persons with cancer can be better now than it ever was in the past.

But these advances in cancer treatment have also made cancer care more complex. Treatment often includes surgery, radiation therapy, and chemotherapy. Frequent tests are required to monitor the effects of treatment. And cancer treatments often go on for months and then must be resumed if the disease comes back. As a result, younger persons with cancer and their families must be prepared to cope with a wide range of physical, emotional, and social consequences of the disease and treatments for extended periods of time. In addition, as time in the hospital is shortened and as more and more treatments are given in the clinic, family caregivers are taking on more responsibility for providing care. Therefore, family caregivers have become increasingly important members of the health care team. They are assuming many caregiving responsibilities that, until recently, had been carried out by health professionals. Health professionals now rely on family caregivers, not only to provide support and encouragement to the young person with cancer, but also to manage medications, help control symptoms and side effects, and report problems that require professional intervention.

It is our experience that family caregivers can carry out these responsibilities very well, if they have clear guidance from health professionals. Since family caregivers are members of the health care team, they need to deal with problems the same way that other team members do and to work cooperatively with health professionals. The home care plans give this guidance. They have been written by cancer care professionals with many years of experience and with help from home caregivers. The plans give you the information you need to solve problems, including understanding the problem, when to get professional help, what you can do on your own, possible obstacles, and how to carry out and adjust the plan. This is the same kind of information that health professionals use to solve medical problems.

The home care plans also help health professionals to monitor and guide care that is given at home. If family caregivers follow these plans, then professional staff know that family caregivers are following procedures recommended by cancer care professionals.

Furthermore, since the plans tell when to call for professional help, staff can be assured that, if the plans are followed, they will be kept informed when problems need their attention.

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Solving Problems Using the Home Care Guide

There are four key ideas that will help you to be effective in solving your caregiving problems and to make the best use of the home care guide book.

You can remember these four key ideas by thinking of the word COPE:

C for Creativity

O for Optimism

P for Planning

E for Expert information

Get **EXPERT INFORMATION** about the Problem and What You Can Do about It

The foundation for good problem solving is knowledge about the problem and about what can be done to deal with the problem. The home care plans give you five kinds of expert information needed to solve caregiving problems. Read the home care plans before starting to deal with a problem-then you will have a complete understanding of the problem and what you can do to deal with it. You should also re-read the plan periodically, especially if your plan does not seem to be working, to be sure that you are doing everything you can.

Develop an Orderly and Systematic Plan

Problem solving is done best in an orderly, systematic way. This means you should:

- **Get the facts** - Be clear about what is happening. Separate facts from opinions.
- **Review what you can do** - Read the home care plan and other written information about the problem. Ask health professionals for recommendations. Think back over your own experiences for ideas and strategies that worked in the past. Ask what you can reasonably hope to achieve.
- **Decide on the Best Strategy** - Compare the advantages and disadvantages of the different approaches you could take, and develop a strategy that has a reasonable chance of achieving your goal.
- **Consider Obstacles** - Think of what could interfere with your plan, and think creatively about what you can do to deal with those obstacles.
- **Carry Out and Adjust your Plan** - Set deadlines for yourself to be sure things get done. Keep records of how the plan is working, and keep calendars of important treatment dates. This will help you to monitor progress and to explain to medical staff what you have done and what the results were. If the plan is not working or you are not having as much success as you hoped, ask yourself if you are expecting change too fast and whether you should adjust your goals. Then repeat the problem-solving steps to develop a new plan, paying special attention to maintaining a positive attitude and expecting success.

Have an **OPTIMISTIC** Attitude while Being Realistic about Your Problems

- **Carry Out and Adjust your Plan** - Set deadlines for yourself to be sure things get done. Keep records of how the plan is working, and keep calendars of important treatment dates. This will help you to monitor progress and to explain to medical staff what you have done and what the results were. If the plan is not working or you are not having as much success as you hoped, ask yourself if you are expecting change too fast and whether you should adjust your goals. Then repeat the problem-

solving steps to develop a new plan, paying special attention to maintaining a positive attitude and expecting success.

- **Have a positive attitude** - One of the most important things you can do to help the young person you are caring for is to have a positive attitude. People who are dealing with the stress of cancer and cancer treatments need encouragement, and they need help noticing the good things that are happening. At the same time, it is important to be realistic about the seriousness of their problems so that they do not feel that their problems are being ignored or belittled.
- **Expect to Succeed** - If you think that there is a good chance of succeeding, you will do your best. If you think the problem is hopeless and that nothing will work, it will be hard for you to do your best at carrying out your plans, and the people who are around you will become discouraged, too. If you do feel discouraged and negative, then get help from someone who has a positive attitude and who is a good problem solver. This could be friends or family members, health professionals, and, if he or she is old enough, the young person with cancer. Read the home care plan for Parents' Depression for help in controlling negative thinking that interferes with effective problem solving.
- **Take Breaks from Caregiving** - Do things that you enjoy to take care of yourself so that you will be able to have a positive outlook, even when you feel under stress. Read the home care plan for Successful Caregiving for ideas and guidance about how to deal with your feelings as a caregiver. Also, read the home care plans for Parents' Anxiety, and Parents' Depression. They will help you to have the emotional strength you need to have a positive attitude and to solve the problems that come with caregiving.

Be CREATIVE

As a caregiver you will be constantly challenged to think creatively. Each person is unique and each problem is unique. Therefore, you must be creative in adapting your plans to fit each unique situation. Most plans will run into obstacles or road blocks. Overcoming or side-stepping these obstacles will also challenge your creativity. When your plans don't work out as you had hoped, you should see this as a challenge to your creativity. Here are three things you can do to help yourself think creatively when dealing with obstacles.

See the obstacle from someone else's point of view. Put yourself in the shoes of another person who can look at your problem differently and ask yourself what he or she would do.

Ask other people who have faced similar problems for ideas about how to get around your obstacle.

Ask how important or serious the obstacle really is. Does this obstacle really stop you from carrying out your plan? Sometimes you can ignore or work around an obstacle and still carry out your plan.

How To Develop Your Own Home Care Plans

The home care plans in this manual deal with only the most common problems that young people with cancer and their home caregivers have. You can also use the same home care plans as models for the information you need to solve other caregiving problems.

Understanding the Problem

The first step in developing your own home care plan is to understand exactly what the problem is you are trying to solve. You should also have a clear idea of your goal.

You need to find out what kinds of children have this problem, when they have it, what kinds of things can be done to help, and what is a reasonable goal to work toward. For medical problems, ask the doctor or nurse. For nonmedical problems, social workers, child life staff, and nurses are often very knowledgeable. Other caregivers and members of support groups can also help.

You also need to know the facts for your situation. Exactly what happened, when did it happen, how often did it happen, how severe is it, what was done in the past, and what were the results? Be sure that these are facts and not just opinions or impressions. Facts are the foundation for successful problem solving.

When to get professional help

For medical problems or problems that could endanger the health of the young person with cancer, ask the doctor, nurse, or social worker when and whom you should call.

What you can do to help

For medical problems, ask the doctor, nurse, or social worker what you can do on your own to deal with the problem-or to prevent it from happening.

For non-medical problems, you can develop your own strategies by using your experience and your creativity and by asking other people for ideas. Think back to what you did in the past that was helpful for similar problems. If something was just partly successful, think how you could use it with this problem. Be creative. Try to think of new ways to look at the problem and unusual ways to solve it. Try "brainstorming," where you free your imagination and try to think of unusual ideas. When you brainstorm, make the longest list of ideas you can, and don't criticize your ideas until after the list is finished. Then choose the best ideas from the list. The freer your imagination and the longer the list, the better are your chances of coming up with a creative solution. Finally, you should weigh the advantages and disadvantages of each idea and choose what to do based on your past experiences and what you think will have the best chance of succeeding.

Possible obstacles

Consider what could prevent you from carrying out your plan and how you are going to deal with these obstacles.

For medical problems, ask the doctor, nurse, or social worker about difficulties that other people have had in dealing with the problem and how to overcome them.

For non-medical problems, think of what obstacles could prevent you from carrying out your plan and how you will deal with them.

Carrying out and adjusting your plan

You need to know how to check on your progress. What changes should you be looking for and how fast should you realistically expect to see change? Ask health professionals or people who have dealt with similar problems for suggestions and advice.

How To Make the Best Use of Home Care Plans

First read the outline headings to know what information the plan contains. Then read the whole plan to fully understand what you can do and why.

The home care plans are organized as outlines. You can quickly read the topic headings in bold type and have a good overview of what the plans are saying. Topics with an arrow in front of them are actions you can take or symptoms you can look for. So, if you want to quickly review what you can do, just read the topics with arrows to the left.

We also recommend that you read all the information in a home care plan before you start dealing with a problem. Then you will have a complete understanding of the problem and what you can do to solve it.

Notice and deal with problems early

One of the most important ways that you can help the young person with cancer is to notice and deal with problems early. Problems are easier to solve when they are just starting, and early intervention can often prevent problems from becoming serious. If you read the home care plans before problems develop, you will be prepared if they occur, and, since some plans include how to prevent problems, you can even prevent some problems from happening

Successful Caregivers are Successful Problem Solvers

Caregiving involves solving problems. You have been solving problems throughout your life. The only difference now is that many of the problems that come with cancer are new to you. The home care plans will help you to solve these new problems; they will give you information and guidance organized in the steps you need to take to solve problems.

The plans are designed to help you. You decide what actions to take, you adjust the plans to meet your special situations. You carry out the plans, check how well the plans are working and make changes as needed. You also must develop new plans on your own to deal with problems that are not in this workbook.

You and the young person you are helping are in charge of dealing with your problems. You are not people who are just following instructions but are people who are making decisions and taking actions.

Successful caregivers work with other people to solve problems. The successful caregiver is also a team player-working with other family and friends, and working with medical staff to solve problems, and, as much as possible, the younger person with cancer.

The young person with cancer is central to the team. Success in carrying out home care plans requires his or her cooperation. The child with cancer should understand and participate, as much as possible, in all problem-solving discussions that affect him or her.

Health care professionals are also key members of the team. Caregivers work with them to ensure that the care given at home is consistent with the best medical practices. Since health professionals played a key role in developing the home care plans, you can be sure that, if you are following these plans, you are giving the best possible health care. Health professionals are also a valuable source of information and advice about how to handle non-medical problems that come with the illness.

Family members and friends who share in caregiving are also important team members. In addition to helping in practical ways, they give encouragement and emotional support, and they can share their experiences with and knowledge of dealing with similar problems in their lives.

Successful caregivers have a positive attitude toward caregiving. Successful caregivers emphasize the positive parts of caregiving. For example, some successful caregivers see their work as helping someone they love and care deeply about. Others see caregiving spiritually-"I think this is part of God's plan for me." Others feel that caregiving has enriched their lives. Others see it as a challenge and want to do the best job they can.

Caregiving can have important benefits. Caring for someone can give you a sense of satisfaction and confidence. Families who do caregiving often feel closer to each other and to the young person who is ill. You can also find new, rewarding friendships with other parents who are going through similar experiences. And you may discover inner strengths that you didn't realize you had.

You can also use the illness to open doors to new friends and relationships. This can happen from talking to other people who have faced the same problems, from meeting people who have volunteered to help with caregiving, and from family members and old friends who have grown distant but who are drawn together because of the illness.

Successful caregivers take care of themselves. Helping someone who is going through cancer treatments can be difficult and stressful. The more you take care of your own need for rest, food, enjoyment, and relaxation, the better you will be able to help the young person with cancer.

Your goals for being a successful caregiver are:

- To be an effective team player working with the person with cancer, health professionals, and family members and friends in solving home care problems
- To take care of your own needs during this illness so that you have the emotional strength to be an effective caregiver.

When To Get Professional Help

Ask for help from a doctor, nurse, social worker, child life staff, clergy, or other professional if any of the following conditions exist:

- You are experiencing severe anxiety or depression. Read the home care plans for Parents' Anxiety and Parents' Depression for a list of anxiety and depression symptoms, which indicate that professional help is needed.
- Communication between you and other family members has broken down or has become painful or difficult. The stresses that come with cancer-physical, psychological, financial, and emotional-can hamper your ability to communicate with the young person you are caring for and with others. If anxiety and stress levels have risen to where you aren't able to talk openly about important issues, you should get professional help from a counselor, member of the clergy, hospital social worker, or hospice staff member.

What You Can Do To Be a Successful Caregiver

Working and communicating effectively with the young person with cancer. This is your most important job. It can also be the most challenging. How to best communicate and involve the young person with cancer will be different for each child, depending on his or her age and personality. Your job is to involve the young person you are caring for as much as possible in making decisions and carrying out the plans.

Help the young person with cancer to deal with the diagnosis emotionally and to live as normal a life as possible. Some people with cancer try to deal with upsetting news by pretending that it didn't happen. This can be healthy when it helps them live as normal a life as possible. It can be harmful, however, if they do things that make the illness worse, such as avoiding treatment or doing activities that are physically harmful.

Support the efforts of the young person with cancer to live as normal a life as possible. But, if he or she is pretending that nothing is wrong, you need to be clear in your own mind about what is really happening. This is when your objectivity is important to be sure that he or she is benefiting from pretending and does not do things that could be harmful.

Create a climate that encourages sharing feelings and that supports his or her efforts to share. Talk about important or sensitive topics in a time and place that's calm and conducive to open communication-not in the midst of a crisis or a family argument. If your time for talking in your family is around the dinner table, that's the time to do it now. Try to think: When have you had important talks in the past? Strive to recreate that setting.

Communicate your availability. One of the most important messages you can communicate to the young person with cancer is this: "If you want to discuss this uncomfortable issue, I'm willing to do it." But leave the timing up to him or her. By not pressing the issue, you allow him or her to retain control over part of his or her life at a time when many issues and decisions are beyond his or her control.

When you and the young person with cancer disagree on important issues

Explain your needs openly. Sometimes you may need to ask him or her to do something to make your life easier or your caregiving responsibilities more manageable. Understand that conflict resolution doesn't always mean everybody's happy. On some issues, you'll have to give in, and on others, you'll have to ask him or her to give in.

Suggest a trial run or time limit. If you want the young person with cancer to try something (such as a new bed or a certain medication schedule) and he or she is resisting, ask to try it for a limited time, like a week, and then evaluate the situation. This avoids making him or her feel locked into a decision.

Choose your battles carefully. Ask yourself: "What's really important here? Am I being stubborn on an issue because I need to win an argument?" You can save energy by skipping the minor conflicts and using your energy and influence on issues that really count.

Let the young person with cancer be included in decisions as much as possible. Nurses, child life staff, social workers and physicians who care for your child are experienced in how to involve children of different ages in plans and decisions. Ask for their advice and guidance.

Taking care of your own needs and feelings

You need to be at your best if you are to do the best job of helping. Therefore, you should pay attention to your own needs as well as those of your child. Set limits on what you can reasonably expect yourself to do. You should take time off to care for yourself and your needs. And you should ask for help from others before stress builds up.

It is natural to have strong feelings when helping your child with a serious illness. Following is a list of common feelings that caregivers can have and strategies for dealing with them if they become severe.

Shock

Caregivers as well as the young person with cancer can feel overwhelmed and confused when they first learn about the diagnosis of cancer or when they learn that the disease is not responding to treatment or is progressing.

Try not to make important decisions while you are upset. Sometimes you must make decisions immediately, but often you don't have to. Ask the doctor, nurse, or social worker how long you can wait before a decision should be made.

Take time to sort things out

Talk over important problems with others who are feeling more level-headed and rational. If you are feeling very upset or discouraged, then ask a friend, neighbor, or family member to help. They can bring a calmer perspective to the situation as well as new ideas and help you deal with the problems you are facing.

Anger

There are plenty of reasons for you to become angry while you are caring for your child. For example, your child may, at times, be demanding or irritating. Friends, family members, or professionals may not be as helpful or understanding as you would like. Some people feel angry because they feel that their religion has let them down. It is natural to be angry when your life has been turned upside down, which often happens with a serious illness like cancer.

These feelings are normal! It is all right to feel this way at times. It is what you do with your feelings that is important. The best way to deal with angry feelings is to recognize them, accept them, and find some way to express them appropriately. If you don't deal with your anger, it can get in the way of almost everything you do.

Here are some things that other caregivers have done to deal with their anger:

- Try to see the situation from the other person's point of view and understand why he or she acted that way. Recognize that other people are under stress, too, and that some people are better than others in dealing with stressful situations.
- Express your anger in an appropriate way before it gets too severe. If you wait until your anger is severe, it will impair your judgment, and you are likely to make other people angry in return.
- Get away from the situation for awhile, and try to cool off before you go back and deal with what made you angry.
- Find safe ways to express your anger. This can include such things as beating on a pillow, yelling out loud in a car or in a closed room, or doing some hard exercise. Sometimes it helps to vent anger with someone who is "safe"-who won't be offended or strike back.
- Talk to someone about why you feel angry. Explaining to another person why you feel angry often helps you to understand why you reacted as you did and to see your reactions in perspective.

Fear

You may become afraid when someone you care for deeply has a serious illness. You do not know what is in store for him or her or for yourself, and you may be fearful that you won't be able to handle what happens.

Learn as much as possible about what is happening and what may happen in the future. This can reduce fear of the unknown and help you to be realistic so that you can prepare for the future. Talk with health professionals to see if you are exaggerating the risks.

Read the home care plan for Parents' Anxiety The ideas and techniques in that chapter will help you to control your anxiety so that it does not interfere with your caregiving.

Talk to someone about your fears. It often helps to explain why you feel fearful to an understanding person. This helps you to think through the reasons for your feelings. Also, talking to an understanding person will show you that other people understand and appreciate how you feel.

Loss and sorrow

A serious, life-threatening illness can bring on a great sense of loss and sorrow. You may feel sad that plans that you had for the future may not be fulfilled. You may feel the loss of

the "normal" child and the "normal" things you did before this illness. Memories of how he or she used to be may make you sad.

Talk about your feelings of loss with other people who have had similar experiences. People who have been caregivers for children with serious illnesses will usually understand how you feel. Support groups are one way to find people who have had similar experiences and who can understand and appreciate your feelings.

Read the home care plan for Parents' Anxiety and Parents' Depression Feelings of loss are often part of feeling depressed. The ideas and techniques in this home care plan can be used by you as well as other family members to help manage or prevent depression.

Guilt

Many people who care for someone with cancer feel guilty at some time during the illness. They may feel guilty because they think they did something to cause the cancer or because they should have recognized the cancer sooner. They may feel guilty for not doing a better job of caring for the young person with cancer. They may feel guilty because they feel angry or upset with him or her. And they may feel guilty because they are well and the person they care deeply about is sick. Some people feel guilt almost out of habit. They have learned from childhood to feel guilty when something goes wrong.

Although feeling guilty is understandable, it can interfere with doing the best possible job of caregiving. Guilt makes you think only about what you did wrong, although most problems have many causes and what you did is only part of the reason for the problem. To solve a problem, you have to look objectively at all of the causes and then develop plans to deal with the whole problem. For example, if you feel anger toward the child you are caring for, this is partly because of what he or she did as well as what you did. To deal with the cause of the anger, you have to talk openly with him or her about what you both did-and not just feel guilty about what you did and about feeling angry.

Talk to people who have had similar experiences about what happened and how they felt. It is often easier to see a situation objectively when it happens to someone else and they tell you how they coped. This can give you a perspective on your own problems.

Don't expect yourself to be perfect. Remember that you are human and will make mistakes from time to time.

Don't dwell on mistakes. Accept mistakes and get beyond them as best you can. The home care plan for Parents' Depression has useful ideas for controlling repetitive, negative thoughts, such as guilt, and for pushing them aside with positive, constructive thoughts.

Remember: You are at your best to help the young person with cancer when you feel your best. If feeling guilty makes you upset, it can interfere with being the best possible caregiver.

Possible Obstacles

Think about what could prevent you from carrying out your plan for being a successful caregiver. Here are some things that have stood in the way of others' being successful caregivers:

- "My child doesn't want to talk about feelings."

Response: Children repress feelings in many ways. Your job is to make sure the

opportunities are there to talk about them when he or she decides it is right and to express feelings in play or art.

- "What if she talks about things that I don't want to hear?"
Response: Even if what you hear hurts you, consider it in the larger picture of what it means to the young person to be able to express it. Remember that you don't have to solve everything or take care of upsetting feelings. You're helpful if you just listen.
- "I'm swamped with problems, so I don't have time to take care of my needs."
Response: This is the most common reason that caregivers become exhausted. They become preoccupied with problems and don't pay attention to themselves. You will be a better caregiver in the long run if you take the time, especially when stress is high, to do things that you enjoy and that relax you.
- "If I don't do it, it won't get done."
Response: Yes, it will. No one is indispensable. You should also sort out things that really need to be done versus what you would like to see done. It's OK to let some things, like housework or cooking, slide a bit when you take on new responsibilities.
- "I hate to ask other people to help me."
Response: There are two ways around this problem. You can get together socially with people who could help and let them volunteer or you could have someone else ask them to help you.

Think of other obstacles that could interfere with carrying out your plan. What additional road blocks could get in the way of your being a successful caregiver? For example, will the young person with cancer cooperate? Will other people help? How will you explain your needs to other people? Do you have the time and energy to carry out these responsibilities?

You need to develop plans for getting around these road blocks. Use the four COPE ideas (creativity, optimism, planning, and expert information) in developing your plans. See the chapter on Solving Problems Using the Home Care Guide for Young Persons with Cancer for a discussion of how to use the four COPE ideas in overcoming your obstacles.

Carrying Out and Adjusting Your Plan

Start using the ideas in this home care plan now. Don't wait until you feel overwhelmed. It is easier to develop good caregiving habits and attitudes early before problems get out of hand.

It is especially important to begin work early on the home care plans for for Parents' Anxiety and Parents' Depression. These plans can give you the strength and resources to deal with stressful situations. Use them early, and then have the strength and support available when you need it.

Checking on results

Every week or so you should take time to think about how you are doing as a caregiver. Look through this home care plan and ask yourself how closely you are matching the "successful caregiver" that is described at the beginning of this plan.

Be realistic about what you expect of yourself. Don't expect to be perfect. Everyone makes mistakes. It takes time to learn to be a caregiver for someone with cancer. If there are some parts of caregiving that are especially difficult for you, then ask others for help.

If you cannot do the things that are essential, then talk to the doctor, nurse, or social worker about getting the help that you need. If you become so upset that it interferes with your ability to do what needs to be done or if you are having severe depression or anxiety symptoms (see the home care plans for Parents' Anxiety and Parents' Depression), then talk to the doctor, nurse, or social worker about getting help.

Fever and Infections

Handling fevers and infections is very challenging. A fever is the most common (but not the only) sign of the development of an infection. This problem is more likely if the young person is being treated with chemotherapy because chemotherapy can reduce the white blood cell count. White blood cells help protect the body by fighting infection, and fewer white cells leaves the person at a higher risk of infection. This condition is referred to as neutropenia. If fever (or any symptom of infection) occurs when the white cell count is low, then it is especially important to identify and treat any possible infections early because the body is less able to fight infection on its own.

Your goals are to:

- call for help when it is needed
- lower high temperatures
- reduce the risk of getting infections

When to Get Professional Help

The first question is whether you need help from medical professionals. You should take a temperature and call the doctor or nurse immediately if any of the following are true:

- A temperature of 101 degrees by mouth at any time. It is very important to have a reliable thermometer that can be easily read. A digital thermometer is the easiest to use. When it is finished recording the temperature, it lights up and shows you the exact number. Ask the pharmacist or store clerk to help you pick out a digital thermometer. If you use a glass thermometer, then keep it in the mouth for 3 minutes or under the arm for 5 minutes. Don't place the thermometer in the rectum. Rectal temperatures may cause infection or bleeding in young people receiving chemotherapy.
- A temperature of 101 degrees under the arm at any time. It is very common to take children's temperatures under their arms. This is called an auxiliary temperature. The number recorded by a thermometer under the arm can be slightly lower than one recorded by mouth, but it is still accepted. If you use a glass thermometer, leave it under the arm for 5 minutes.
- A temperature greater than 100 under the arm or orally for 4-6 hours or longer.
- Any severe shaking chills, especially after flushing a central IV line. Chills warn you that a fever will probably happen. They often come before a fever. If the young person chills, take a temperature and call the doctor immediately. Chills that happen after flushing a central IV line may indicate that bacteria in the line were released when it was flushed. Take the temperature immediately and when the chills are over, and be sure to report that the central line was flushed before the chills.

Any of these symptoms (even if they occur without a fever). They all indicate an infection even if a fever is not present. All are easy to watch for, particularly the last one, when the younger person is "just not him- or herself." All are reasons to call.

- Too weak to drink fluids
- Frequent, painful urination
- No urine output for 8 hours for 2 years old and younger or 12 hours for over 2 years old.
- Any new redness or swelling
- New cough, shortness of breath, or rapid breathing
- Cold symptoms or sore throat
- New abdominal pain
- Diarrhea

- Increased sleepiness
- Irritability
- Too weak to play
- Just not him- or herself

Know the following facts when you call the doctor or nurse.

1. What were the temperatures and what times did you take them? If you don't know exactly how long the fever has been high, report the time that you took the temperature and the time that you first noticed any other changes, such as redder skin, sweating, or the young person complaining about feeling hot or feverish.
2. How much fluid did the person with fever drink since the fever began or in the past 8 hours? Report fluid intake as cups or glasses or bottles drunk over the past day or two. Reporting the amount of fluids drunk and the amount of urine passed helps the doctor or nurse determine if he or she is becoming dehydrated. Be sure to say if the amount of fluids, such as water, soda, juice, or soup, is less than he or she usually drinks in a normal day.
3. Has urine output been normal or is it less than normal?
4. When was the last chemotherapy and what drugs were given? Have fevers followed these drugs before?
5. What were the last blood counts? When and where were they drawn?
6. What is the young person's weight?

Always call the oncology staff treating your child! We will use your local doctor as much as possible, but we want to know what is happening.

Here is an example of what someone might say when calling.

"I am Joan Smith, Michael Smith's mother. My son is Dr. Harvey's patient. He's 3 years old and has leukemia. The homecare plan for fever says that I should call if shaking chills started. They did and when I took his temperature at 1 o'clock it was 101.4. He had chemo five days ago."

What You Can Do To Help

After you've called in, here are some things you can do at home.

1. Reduce any high temperatures
2. Prevent infections caught from others or the environment
3. Prevent infections caught from normal bacteria on the skin, mouth, urine, or stools

Reduce any high temperatures

Fever is lowered by acetaminophen, such as Tylenol and other brands, by helping the body get rid of heat, and by correcting or preventing dehydration. The drugs and other measures listed below will not take care of what is causing the fever, but they will help to lower a temperature and make the person more comfortable.

- Do not give acetaminophen unless you have been told to give it by your oncology physician or nurse. Acetaminophen (Tylenol and other brands) lowers high temperatures and makes the person with cancer feel less discomfort. Acetaminophen will not make the infection disappear. Give the right amount of acetaminophen by checking the child's weight and finding the dose (number of tablets or right amount of liquid) on the bottle that matches that weight. Acetaminophen should be given by mouth, not rectally.

- Do not give aspirin or ibuprofen. These drugs promote bleeding, especially in the gastrointestinal (GI) tract. When your child is receiving or recovering from chemotherapy, he or she is at a higher risk than normal of bleeding. Therefore, aspirin, ibuprofen (Motrin, Advil, Nuprin and other ibuprofen products) are not to be given.
- Give any other medications prescribed for fever or infection by your doctor. If an antibiotic has been prescribed, continue to give it as ordered.
- If chilly or shaking, keep the person warm and covered up with a blanket. Shaking chills generate more heat so the young person should be covered just enough to keep them from shaking. When he or she stops shivering, begin to remove layers of covers one at a time.
- If hot, remove heavy clothing, cover lightly with a sheet and put cool washcloths on the forehead. Cooling the forehead brings some relief to the discomfort of feeling very hot. In addition, the cool cloths also cools the blood that flows through the head close to the surface of the skin.
- Place in slightly warm water if the temperature is very high (over 103 degrees) and the child is not shivering. Place the young person in water that is slightly warmer than room temperature and let them play or enjoy the water. Avoid the extremes of a hot bath or cold water. Do not bathe in rubbing alcohol. This can be toxic to young persons if they inhale it. It is also absorbed through the skin. Stop any actions which cause shivering, dress the child, and wrap in a light sheet or blanket.
- Offer cool fluids every hour. Check the amount of fluid necessary for your child in the fluid chart (see Fluid Chart). The body needs more fluid when feverish. That's because more fluids than usual are being lost through the skin and through the lungs. The risk of dehydration when the fever is high.
- Dress the young person in light clothing. Light fabrics allow air to pass through to the skin and do not trap body heat under the clothes.
- Change damp clothing and bed linens. If the child with fever sweats, the moisture dries on the skin, and he or she can get chills from the moisture. This adds to discomfort and also can make the body cool down too rapidly.

Prevent infection caught from others or the environment

Infections caught from others or from the environment can be prevented by a combination of strategies.

- Caregivers should wash hands with soap and water before contact with the child. The most common way that bacteria and viruses are passed from person to person is on the hands. This can be prevented very effectively by thorough hand-washing with soap and water before contact with the young person or their belongings.
- Don't share a thermometer or toothbrush with anyone else. Anything that goes in the mouth should not be shared because it's easy to pass germs from one person to another this way.
- Avoid people who may have infectious and transmissible diseases like colds, flu, chicken pox, and cold sores. Asking others to wait to visit until a cold is over will lower the risk of catching it.
- Report if the child is exposed to chicken pox, measles, or shingles immediately. The viruses that cause chicken pox, measles, and shingles can seriously affect the young person receiving chemotherapy. When any exposure occurs, a dose of antibody is usually prescribed, which can temporarily increase immunity and possibly prevent development of an infection.
- Avoid unpasteurized raw milk, raw shellfish, and raw eggs. Uncooked eggs, unbaked cookie dough, and unpasteurized milk carry many bacteria that can cause severe

gastrointestinal diseases, such as those caused by salmonella. These diseases are associated with nausea, vomiting, diarrhea, and extreme weakness.

- Don't swim in ponds or rivers. Water can collect a lot of bacteria and the young person is more likely to get an infection from swimming in non-chlorinated waters.
- Wear shoes to prevent cuts and bruises. Even small cuts on the feet can let bacteria into the body.
- Wash any cuts right away with soap and water and bandage them for the first few hours. Cuts and scrapes need to be washed with soap and water and covered with a Band-Aid or gauze patch. These openings on the skin can easily get infected if dirt stays inside the cut.
- Avoid sunburn. Use a sunscreen lotion, wear hats or scarves, and stay out of the sun. Sunburn leads to blisters and open skin. Once the skin is open, it's easier to infect.
- Arrange for someone else to groom the pet, empty cat litter boxes, and clean pet cages. Pet feces contain high levels of bacteria and fungi which are easily transferred to humans. Get someone other than the young person to groom the pet, clean cages, clean fish tanks, or change litter boxes. Don't give pets away for this reason. Their love and company are very helpful for the young person, and it is fine for the young person to play with the pet.
- Give Bactrim if prescribed during chemotherapy. Bactrim is an antibiotic which is given to prevent a serious kind of pneumonia called Pneumocystis pneumonia. If prescribed, it is to prevent this problem.

Prevent infection caught from the body's normal bacteria in the skin, mouth, urine, or stool

Young people with cancer can also catch infections from themselves, from their skin, mouth, urine, or stool. The following tips describe ways to prevent infection from these sources.

- Wash the skin every day with a shower, sponge bath, or full bath. Good hygiene is very important. Daily bathing will decrease the amount of bacteria on the skin and decrease the chance of them causing infection.
- Wash hands frequently with soap and water, especially after using the bathroom and before eating.
- Use lotions and moisturizers on the skin to prevent drying, chapping and cracking. Lotions boost the ability of the skin to stay intact. There is less risk of cuts and openings where bacteria can break in and cause infection.
- Thoroughly cleanse the rectal area after bowel movements. Look for any sores or breaks in the skin after each cleansing. Girls should be taught to wipe from front to back after a bowel movement.
- Make sure the young person is resting during the day, eating well balanced meals, drinking plenty of fluids, and getting mild exercise.
- Avoid rectal temperatures and suppositories. Taking a rectal temperature or administering suppositories adds to the risk of infection because bacteria which normally live inside the intestine and rectum may be introduced into the bloodstream through tiny tears in the lining of the rectum.
- Encourage good dental hygiene four times each day (after meals and at bedtime). Check all surfaces in the mouth for sores each day. Brushing the teeth at least four times a day will decrease the number of bacteria in the mouth. This helps prevent infections.
- Use Peridex two times per day if it is ordered during chemotherapy. Peridex is a special mouthwash that kills additional bacteria. Use as recommended by the doctor or nurse.

- Replace toothbrushes every three months. Toothbrushes harbor bacteria. They are wet most of the time and attract different types of organisms. Replacing them as frequently as every three months reduces the chances of infection in the mouth.
- Get a new toothbrush after treating a mouth infection (usually thrush infection). Even though the mouth infection was healed after using an antibiotic, the toothbrush has been contaminated and the mouth or thrush infection can continue to grow on the bristles of the brush. Discard it.
- Plan visits to the dentist when blood counts are normal. Many dentists will give the young person an antibiotic to take before they clean or work in the mouth. Any child with a central IV line must have an antibiotic with any dental exam or work. The dentist will check with the child's doctor to find out what the blood counts are and whether or not dental work should be done at that time.
- The mouth has many kinds of normal bacteria in it and regular cleaning or drilling by a dentist can cut the gums. The young person with low white cells is at risk of an infection or abscess when these bacteria enter a small cut.
- Visit the dentist regularly. Care of the mouth and teeth is very important for the young person with cancer. If dental visits are not covered by insurance or the cost of a visit is too expensive and prevents you from making regular dental appointments, talk this over with the doctor, nurse, or social worker. Financial help can be arranged. For example, some rural counties have a free dental clinic that visits school districts once or twice a year. Some large hospitals have dental schools in them and dentists there see patients who use that hospital. Find out about your options.

Prevent infection from school, daycare, or siblings

Check with the doctor before any brothers or sisters get immunizations or vaccinations such as oral polio. General, "killed" vaccines, such as DPT, HIB, Pneumovax, hepatitis, and flu can be safely given. Check with your doctor before a sibling receives a "live" vaccine, such as oral polio.

Find a contact person such as a teacher or school nurse who will tell you about any outbreaks of infectious disease in your child's classrooms, daycare settings, or babysitters. You cannot always learn about outbreaks of infections, such as measles or chicken pox, quickly enough to know that your other children are potential carriers of these diseases and can bring them home. Ask the school nurse and teacher to call you about these outbreaks as soon as they know about them. If you don't have a phone, then have the nurse and teacher tell another adult who will find you and tell you in person. Although your other children may be good sources of information about what is happening at school, it's best to be sure that you'll get this important information and then tell your child's doctor about the problem. Sometimes, preventive medicines are given or special precautions are advised.

It is important to know if the young person receiving chemotherapy has been exposed to illnesses. Ask the school nurse and teacher to call you about any outbreaks as soon as they know about them. Sometimes preventive medicines are given to the young person with cancer, usually within 72 hours after exposure. Other special precautions may also be advised.

Prevent infection when counts are low

It is very important to follow all the previous suggestions to prevent infections when the white blood cell counts are low. An additional suggestion should also be followed to prevent infection and fever.

Make sure the young person avoids large indoor crowds. Think of alternatives to large indoor crowds when counts are low because the risk of catching an infection or cold is higher in this environment. You also will be advised if it is necessary to keep your child home from school. Don't restrict the young person from indoor crowds when counts are normal because the child wants to return to events that are fun and familiar.

Possible Obstacles

Think about what will stop you from carrying out your plan and how you will overcome the obstacle.

Here are some obstacles that other people have faced.

1. "The fever came down after I gave him acetaminophen, so I don't need to call."
Response: Whatever started the fever in the first place will not be fixed by one dose of acetaminophen. It is very important to find out if the young person needs to be treated for an infection.
2. "My son just doesn't look sick, but his temp is 102."
Response: People handle high temperatures differently. Some get very sleepy and weak, others take longer to show signs of not feeling well. Follow the guidelines for reporting temperatures.
3. "My daughter believes that if she brushes her teeth a lot, her gums will bleed from all of the scrubbing."
Response: The gums will bleed during and after tooth-brushing if she doesn't brush regularly. Bacteria cake onto the gums and break the tissues down, making them weaker. Sometimes they'll bleed after chewing or biting into a piece of food. Gentle regular brushing removes the bacteria and toughens up the skin that covers the gums and mouth.

Carrying Out and Adjusting Your Plan

Prepare in advance. Practice in your mind how you will carry out your plan and arrange transportation ahead of time just in case you need it quickly. When the time comes to act to stop a fever or infection, carry out your plan and make changes to fit each situation. Use this homecare plan as a reference and make sure that others who are involved with helping read this plan.

Checking on results

If fevers occur, do you know when to call for help and what to do to lower the temperature and make the young person more comfortable? Are fevers occurring less often? Answers to these types of questions will tell you that you have learned how to watch for and handle this problem.

If your plan doesn't work

If fever remains a problem, your plan does not seem to be working, or fevers are happening more often, there are two things you can do. Consider them in this order.

1. Check the [When To Get Professional Help](#) section of this care plan. If you answer yes to any symptoms on that list, call the doctor or nurse immediately.
2. If fever problems continue or you are not sure how to prevent them or spot them, ask the doctor or nurse during office hours for help. Tell them what you have done and what the results have been.

Loss of Appetite

The information in this homecare plan fits most situations, but yours may be different. If the doctor or nurse tell you to do something else, follow those instructions. If you think there may be a medical emergency, go directly to When to Get Professional Help

Understanding the Problem

Children with cancer lose their appetite for many reasons. Cancer treatments and other medicines can decrease the desire for food, as can emotional distress.

Losing weight can upset the person with cancer, especially when he or she sees it as a sign that the illness is getting worse. Rapid weight loss, however, can often be slowed down by treating its cause, such as stopping diarrhea and giving high-calorie foods.

Children need to stay well-nourished for normal growth and development, and so they have an additional need for calories. Depending on what is causing the loss of appetite, you can set several goals to solve this problem.

Your goals are to:

- call for professional help when it is needed
- encourage ways to increase the appetite
- cover up tastes and smells that are bothersome
- prevent an early feeling of fullness
- add more proteins and calories to what is eaten

When To Get Professional Help

The first question you should ask is whether professional help is needed. Show this homecare plan to your doctor or nurse and ask them to fill in the blanks.

Call during office hours if any of the following are true:

If your child has had very little to eat in * days. Ask the doctor or nurse when you should report a poor appetite. If nausea causes the loss of appetite, read the homecare plan section on nausea for steps you can take to relieve that symptom. When nausea lasts more than a few days and your child eats very little, it's important to understand how to control and prevent it.

If your child loses * pounds in one week. Ask the doctor or nurse when to call about weight loss. If the number of pounds lost is more than they say is reasonable to lose, then talk about this on a clinic visit or with the home health nurses if they are visiting the home.

If your child notices pain with chewing or swallowing. Painful chewing or swallowing interferes with normal eating and drinking. Pain can be caused by a mouth sore or an infection on the tongue, gums, or throat. If the appetite suddenly changes, ask your child if he or she is having trouble eating, chewing, or swallowing. Check your child's mouth for sores and if you find any, refer to the homecare plan section on mouth sores for steps you can take to ease the situation. * Ask the doctor or nurse for the numbers that fit your child. Call immediately if the following is true:

If your child has had very little to drink. (Refer to fluid chart.) It's important for children to avoid dehydration. Refer to the fluid chart, which your doctor or nurse fills out for your

child, to determine whether he or she is drinking too little. When you call, the doctor or nurse may ask you the following questions:

- When did the poor appetite problem start?
- If this problem happened before, what brought the appetite back or helped it improve?
- Does food taste different, such as bitter or metallic? If so, does this make eating less desirable?
- Which foods taste better and which taste worse?
- Is your child's mouth dry or sore, and is swallowing difficult?
- Do you have medication to help with mouth problems?
- Does your child feel full or bloated soon after starting to eat?
- Is he or she experiencing nausea, vomiting, or problems with bowels, such as constipation or diarrhea?
- When the appetite changed, was there a change in where or how he or she ate the food?
- Does your child have a better or worse appetite at certain meals or certain times of day?
- How much weight has your child lost?

Here is an example of what someone might say when calling for help:

"I am David Sondheim, Christopher Sondheim's father. My son is Dr. Greenberg's patient. He is being treated for medulloblastoma. The homecare plan for appetite says that we should call if he eats or drinks very little. He's taken only a few sips of liquids all day today."

What You Can Do To Help

You can use four approaches to solve child or adolescent problems with appetite.

Increase the appetite

Sometimes children with cancer lose their appetite because of treatments or emotional distress. You can take several actions to help stimulate appetite.

Encourage light exercise or walking before meals, in fresh air if possible. Any increase in activity just before eating also increases the appetite. Try going for a walk with your child five to 15 minutes or up to half an hour before meals. Fresh air always stimulates the appetite.

Have your child eat meals with family members or others whenever possible. Don't let your child eat alone. Eating with someone else distracts a child's attention from food and can increase the amount he or she eats. Sometimes meal habits change after a cancer diagnosis, because the person doesn't feel like eating, or the family schedule is disrupted by trips to clinics for checkups and treatments. Returning to normal meal times or planning to have the family eat together will help increase the appetite.

Serve meals nicely in a pleasant, relaxed atmosphere. Use small plates and serve smaller portions, or experiment with a combination of a small portion on a large plate. A small portion on a small plate can be arranged attractively and looks like something that can be finished. For some younger children, serving a small portion on a large plate may make it seem to be more manageable.

Serve lemonade or orange juice if the mouth is not sore. Juices contain acids that can stimulate appetites. A few ounces before a meal may enhance the appetite.

Cover up tastes and smells that are bothersome

Cancer treatments sometimes can change how foods taste to your child. You can do several things to make food appealing again.

Use plastic utensils. Plastic forks and spoons and knives take away a bitter or metal taste, which is a common complaint among people receiving chemotherapy.

Try new spices, such as basil, curry, coriander, mint, oregano, or rosemary. Spices make our mouths water and change the tastes of food. You may find a new spice that makes your child hungry again. Try old spices in new ways, because the chemotherapy sometimes changes the way food tastes. Avoid trying new flavors or foods on chemotherapy days, because that may condition your child to associate that food with a difficult experience, thus causing him or her to dislike that food in the future.

Add new flavors, such as lemon, pickles, salad dressings, vinegar, mayonnaise, relishes, or fruit juices.

Marinate meats in liquids, such as fruit juices, salad dressings, sweet and sour sauce, soy sauce, or barbecue sauce. Sauces and marinades change flavors of foods and make them more appealing.

Sprinkle more sugar and salt in food if these are not restricted. These decrease the metallic and bitter tastes that people with cancer sometimes complain about. Some people receiving chemotherapy cannot tolerate a sweet taste, so they use small amounts of sugar to taste.

Eat food cold. A cold temperature downplays the smell and taste of food. Aromas are blocked or linger for shorter times, and cold foods are not as flavorful so odd tastes are covered up. Also, the coolness numbs the tongue to some unpleasant tastes.

Suck on hard, sugar-free, sour, or mint candy, or, for younger children, lollipops. Candies like these can mask strange tastes any time of the day and even before a meal. These should be offered only to children older than four years of age, to avoid the possibility of choking.

Drink ginger ale or mint tea. Ginger ale and mint tea cover up metallic tastes and help with swallowing food.

Eat chicken and fish, and avoid red meat. Changes in taste buds may make red meat distasteful. People receiving chemotherapy often prefer chicken or fish, which retain their flavors.

Prevent an early feeling of fullness

Poor appetite can be caused by an early feeling of being full. Sometimes, medicines cause gas and the child feels bloated after eating very little. Following are six tactics you can take to deal with this.

Exercise between meals. Any exercise gets the intestinal tract moving and shakes up pockets of gas. Even stretching and bending the waist by getting out of chairs or off couches helps relieve gas and move stomach contents.

Walk around or sit up for awhile after meals, but avoid strenuous exercise immediately after eating. Any exercise stimulates the bowel muscles to move downward. This action helps to empty the stomach and break up any gas that adds to a sense of fullness.

Drink beverages between meals instead of with meals. Liquids at mealtime can make the stomach feel full. Drinking less while eating allows more room for food.

Eat small amounts 6 to 8 times a day. Small, frequent meals or snacks prevent early fullness.

Eat slowly and chew food well. Avoid certain vegetables and carbonation. Cut back on fatty foods and gas-producing foods such as beans, cucumbers, green peppers, onions, broccoli, brussels sprouts, corn, cauliflower, sauerkraut, turnips, cabbage, chewing gum, milk, rutabagas, or carbonated beverages. Some vegetables naturally create stomach and intestinal gas and can keep your child feeling full as the food is slowly digested. Avoid these, as well as carbonated sodas or waters. Relieve the carbonation by opening cans and bottles early and letting the fizz evaporate while the sodas turn flat.

Use over-the-counter medicines to help break up gas. Many of these contain herbs or drugs that break up gas. One particular ingredient, simethicone, is very helpful with attacking gas and breaking up air trapped in the intestines. Check with the doctor and nurse before buying these over-the-counter medicines because they shouldn't be used with some other medicines.

Add more proteins and calories to food

Rapid weight loss often can be slowed down by increasing the nutritional value of food that is eaten, especially with calories and proteins. The next two pages contain 16 suggestions for how you can make the food count more.

Offer small, frequent snacks (six per day) even if your child is not hungry, and encourage eating as much as wanted. Smaller meals and snacks may add up to higher protein and calorie intake.

Choose nutritious carbohydrates and high-protein options, such as fish, chicken, turkey, eggs, cheeses, milk, ice cream, tofu, nuts, peanut butter, yogurt, beans, and peas. Try to get as much protein and carbohydrates as possible from each food item served. This is called 'power-packing' foods.

Add butter or margarine to vegetables, soups, pasta, cooked cereal, and rice. These add fat and calories. Add sugar, syrup, honey, and jelly to vegetables, meats, cereals, waffles, and rolls. Sweet sauces add calories. Use sour cream or cream cheese on baked potatoes, vegetables, or crackers. Creams are fattening and nutritious and easy to swallow.

Add whipped cream to hot chocolate, ice cream, pies, puddings, gelatin, and other desserts. Add sugar to whipped cream, boosting calories and fat. Add powdered coffee creamers or powdered milk to gravy, sauces, soups, and hot cereals. These are good sources of calcium. Use milk instead of water to dilute condensed soups or cooked cereals. If a recipe calls for water, use whole milk instead.

For children who take bottles, feed high-calorie formulas. Ask your nurse or dietitian about these products, which are available in stores or pharmacies.

Use mayonnaise instead of salad dressing and light cream for all or part of milk in recipes. Mayonnaise contains more fat than salad dressing and is high in calories. Light cream has more fat and calories than milk.

Add ice cream to milk drinks. Ice cream increases the fat and calorie content to milk.

Add nonfat dry milk (1 cup) to one quart of whole milk for drinking and use in recipes. You can more than double the protein and calorie content of regular (4%) milk if you add powdered dry milk. Use half-and-half or evaporated milk instead of water in recipes. Half cream and half milk or evaporated milk are much higher in fat, protein, and calories than water, and they provide vital minerals and nutrients. Also, many people with cancer drink "Instant Breakfast" mixes for their extra calories. These are sold in grocery stores.

Use peanut butter on crackers, bread, waffles, apple wedges, or celery sticks. Peanut butter is an excellent source of protein and calories.

Offer crushed granola, nuts, seeds, or wheat germ in shakes or on desserts. Use nutritional supplements in between meals or with snacks, such as Isocal Ensure, Sustacal, Resource, or Citrotein. These powders or liquids are loaded with nutrients and can be purchased in most drug stores. Ask the nurse or pharmacist for information about buying them and ask for recipes. Also, in some states, the American Cancer Society will help with purchasing these supplements. Avoid diets designed to "purge the system" or restrict certain foods or food groups. Certain diets are designed to purge the intestinal tract. Unfortunately, they also promote looser stools and remove important vitamins and minerals and fluids from the body. The child with cancer needs these nutrients, so such diets should be avoided. Ask your child's nurse or doctor about using vitamin supplements. Vitamins replace some of those that are lost because of a smaller appetite and lower intake of food. A daily multivitamin and iron can be important supplements to the diet. However, some vitamins counteract certain chemotherapy medicines, so you should check with the doctor or nurse first before taking vitamins. For example, B vitamins counteract methotrexate, which is often taken by children undergoing treatments for leukemia. A health-care professional such as a doctor, nurse, or dietitian can recommend brands of vitamins that would be acceptable.

Possible Obstacles

Think about what will stop you from carrying out your plan and how you will deal with it. Here is an obstacle that other people have faced.

- "He says he's just not interested in food. He's not hungry at all."
Response: Lack of interest in food cannot be easily changed. Try to offer small snacks or meals in the company of people he or she enjoys. Try the other tips in this homecare plan but don't focus on eating so much that it's the only topic you ask about or talk about.

Carrying Out and Adjusting Your Plan

Keep track of the amount of food your child is eating and his or her weight. If you see a problem, check [When To Get Professional Help](#) to see if you need professional help. Try to determine whether your child's eating is being hindered by bothersome tastes and smells, dry or sore mouth, or an early feeling of fullness.

If your plan doesn't work

If you are dissatisfied with progress towards meeting these goals and easing the problem with loss of appetite, review the list of appetite problems in this homecare plan and select those that stand in the way of solving this problem. Then review the suggestions underneath that heading and ask yourself what steps you can add to your plan. Another helpful booklet is "Eating Hints," available free from the National Cancer Institute. Ask your nurse or dietitian for a copy.

If you or your child are discouraged with progress, voice your concern to your doctor or nurse. They may refer you to a dietitian, who may be able to give you new ideas and who can analyze whether the diet is adequate. The doctor may also make other suggestions to help you deal with this problem.

Mouth Problems

The information in this homecare plan fits most situations, but yours may be different. If your child's doctor or nurse tells you to do something else, follow those instructions.

Understanding the Problem

Chemotherapy can interrupt the growth of healthy cells in the mouth. Problems with the mouth are an occasional side effect of treatment because the tissue inside the mouth is composed of rapidly growing cells. Some chemotherapy drugs do not allow them to mature. When the mouth tissues are weakened, mouth sores are more likely to happen and take longer to heal.

In addition, cancer and cancer treatments can reduce the ability of a person's immune system to fight infection. When the immune system cannot protect the body from normal bacteria or outside germs, weakened or inflamed tissues in the mouth can become infected. The body's basic defenses are lowered temporarily. Therefore, an occasional side effect of cancer treatments is the presence of mouth sores or a very sore mouth, throat and esophagus.

Pain in the mouth or throat can cause children to avoid eating and drinking. If the child drinks little for 24 hours or more, he can become dehydrated. This is a serious problem, especially in young children. If sore mouth occurs repeatedly, your child may be unable to take in enough nutrients to fight infections and allow for normal growth and development.

Your goals are to:

- prevent mouth problems,
- call for help when it is needed,
- treat mouth sores, blisters, or infections, and
- maintain hydration and nutrition.

When To Get Professional Help

The first question you should ask is whether your child needs help from medical professionals. Then you'll need to find out how urgently he or she needs that help. Report the signs and symptoms below to help the health care staff decide whether an infection is brewing in the mouth, tongue, throat, or esophagus (the tube leading to the stomach). Sometimes, these problems can become so severe that the child is hospitalized for antibiotic therapy or pain medication.

You should call the clinic, doctor or nurse immediately if any of the following are true:

- Temperature is over 101 degree F. (Refer to "How to Take Temperature" section.) Fever can indicate a mouth infection. If the temperature goes up suddenly, report it. However, a mouth infection can occur before the temperature goes up, so fever is not the only thing to watch for.
- So much difficulty swallowing that your child isn't taking medicine as often as it's been prescribed. When the throat is sore or swollen, swallowing becomes more difficult. Call if your child skips medicines because of this.
- So much difficulty swallowing that your child eats or drinks very little. (Refer to fluids chart, which your doctor or nurse will fill in for your child's situation.) The child may be eating or drinking less because of a sore or painful throat. Going without nutrition or fluid causes weakness and possibly dehydration. How soon to become concerned over this varies from infants through adolescents, so ask your doctor or nurse.

You should call the clinic, doctor, or nurse during office hours if any of the following are true:

- A light redness on tongue grows much redder. Redness comes before a mouth sore. You will need a light to tell if the mouth, gums, or tongue are redder than usual. If your child is taking little by mouth or complains of pain, use a small flashlight to look into the mouth and find any sores. Check the mouth twice a day, morning and night, until the sores have healed. Look at the roof of the mouth and all of the lining. Look under the tongue and gums.
- Redness on tongue turns to white patches, or white patches appear in mouth or on gums. White patches may indicate an infection. Usually, it's a thrush infection (*Candida albicans*). This infection happens when the mouth lining is unable to fight off normal organisms. *Candida* increases in number and becomes a problem.
- Sore or blister on the lips or in the mouth. If the normal skin lining the mouth is affected by chemotherapy, mouth soreness and sometimes mouth sores or blisters follow. If a cold sore or herpes blister appears, antiviral medication can be prescribed to hasten healing.
- Sore throat or painful throat. The lining of the throat is the same as the lining of the mouth. These areas are just as likely to get red and sore. Sores can also occur down to the stomach and result in heartburn.
- If your child needs stronger pain medications. A wide range of pain relief products is available. Maintaining comfort is a priority, so don't hesitate to ask about other options if your child's pain is not well controlled.

When you call the doctor or nurse, they may ask you the following questions:

1. When did the mouth problems start?
2. Is the mouth, tongue, or throat redder than usual? Have any white patches or blisters appear around or in the mouth?
3. What did your child eat or drink in the last 24 hours? For infants, have you found any changes in the daily patterns of wet diapers? For children or adolescents, has there been any change in the amount of urination?
4. How are the mouth and teeth cleaned? Are any rinses used?
5. How is your child's level of activity?
6. Is there a change in chewing or swallowing?
7. Has any medicine been ordered for the mouth or throat? How often is it taken?
8. Does your child have any problems, such as gagging or nausea, in taking medicines? Does this keep him or her from taking medicines as often as they're prescribed?
9. When was the last chemotherapy or radiation treatment?
10. Does your child have a fever?

Here is an example of what a parent might say when calling:

"I am Joan Smith, Billy Smith's mother. Billy is Dr. Neely's patient. He is being treated for lymphoma. The homecare plan says I should call if he's not able to drink well for 24 hours."

What You Can Do To Help

If you decided that the mouth problem is not an emergency, here are four things you can do to solve problems with mouth sores or a sore mouth.

- Soothe a sore mouth and ease swallowing
- Prevent dehydration
- Treat mouth sores, blisters, or infections
- Moisten a dry mouth

- Prevent mouth problems

Soothe a sore mouth and ease swallowing

- Encourage your child to rinse the mouth, after eating, with a solution of salt water or half-strength Peridex. Baking soda soothes the mouth and helps it heal. Rinsing after eating removes food particles that could irritate the gums, but does so more gently than commercial mouthwashes, many of which contain alcohol. Avoid these, because they dry out the mouth.
- Offer plenty of liquids and suck on ice chips or Popsicles.
- Moisten food with cream, milk, gravy, and sauces. Moist food is easy to swallow, especially when the mouth and throat are tender.
- Offer soft, moist, bland foods, such as soups, eggs, pastas, quiches, baby foods, cheese dishes, tuna fish, applesauce, custards, pudding, canned fruit, cooked cereals, bananas, gelatin, yogurt, ice cream, sherbet, frozen fruit bars, Popsicles, or shakes. Bland foods are those that are not spicy or salty. Examples are bread, pudding, Jello custard, rice, and tapioca. All are soft, moist, and easier to swallow than most food.

Prevent dehydration

Remember that the child's mouth may be too sensitive for extreme temperatures. In this case, cool (not cold) or tepid (not hot) liquids may be best tolerated. These may be offered carefully via a straw or syringe.

Treat mouth sores, blisters, or infections

Use the following list at the very hint of a sore or infection to reduce the seriousness of mouth and throat complications.

- Rinse after eating or drinking with warm tap water or a solution of 1/2 tsp salt to 2 cups of water. Mouth rinses remove food particles, which may build up and cause bacteria to grow. Rinses also soothe sore tissues, which helps them heal more rapidly. See that your child's mouth is rinsed at least 4 times a day and as often as every two hours while he or she is awake. If the salt rinse causes a burning sensation, use less salt.
- Ask about giving your child a numbing liquid or lozenge as a "throat coat" before eating and swallowing. Many people swallow mouth gels or "throat coats" (a thick, jelly-like liquid) before meals and at bedtime, when the mouth is very sore because of the effects of chemotherapy. Another choice is Maximum Strength Sucrets an over-the-counter anesthetic that a child can easily suck on. These products numb the tongue and throat enough to let liquid and soft foods pass without much trouble. Many hospital pharmacies will also make a mixture that may contain Maalox and liquid Benadryl which heal and soothe the soreness and decrease swelling and inflammation, especially in the throat and esophagus. Ask about these "mouth gels" or mouth medicines if they haven't been prescribed as part of the chemotherapy.
- Use acetaminophen according to label instructions (acetaminophen tablets or Tempra liquid, which is alcohol-free and may be easiest to tolerate. If you need further help, contact your nurse or doctor.
- Ask about other prescription medications. During chemotherapy and a few weeks after treatments, many people use a prescription mouth rinse (Peridex) to swish and spit at least two times per day. This prevents infection and sores.
- Finish antibiotics when they are prescribed to treat an infection. The doctor also may order an oral antibiotic. If so, be sure that your child takes all of it until the bottle is

empty, or until a doctor or nurse instructs you to stop giving it. Antibiotics are intended to kill the infection in the mouth. If they are effective, your child's mouth should usually feel better, and eating and drinking should be easier.

- Ask about using other pain pills or liquids for pain relief. Pain pills or liquids could be taken about an hour before eating and drinking. This will help take the edge off biting, chewing, or swallowing when the mouth feels sore or when there are blisters.
- Avoid using hydrogen peroxide rinses. Peroxide kills bacteria, but it is very drying. Its use can lead to a mouth and throat infection known as thrush. It can also damage healing tissue.

Maintain nutrition and prevent dehydration by:

Serving soft foods that are easier to swallow.

MEATS AND PROTEINS-Include beef, pork, and chicken, fish, smooth peanut butter, eggs, cottage cheese, mild cheese, macaroni and cheese, yogurt, and bean casseroles. Always make sure that meat is well-cooked, tender, and easy to chew. Avoid sharp cheeses, crunchy peanut butter, and spicy foods.

VEGETABLES-Include well-cooked vegetables that are easy to chew, and baked or mashed potatoes. Avoid vegetables with a lot of acid, such as tomatoes or potato skins, or crunchy or raw vegetables, fried potatoes or vegetables, and tomato soups and sauces.

FRUITS-Include apple sauce, apple juice, grape juice, nectars, prune juice, soft cooked or fresh non-citrus fruit, and bananas. Avoid citrus fruits and juices, and fruit peels.

MILK-Include milk, milk shakes, cream soups, eggnog, buttermilk, custards, and puddings.

BREADS-Include all cooked or dry soft cereals, soft bread and rolls, and pasta with mild sauce. Avoid seeded breads, crusty breads, or granola bars.

- Softening breads and cereals with milk.
- Using a blender.
- Using gravy, butter, or cream sauces, which add liquid to food and make it easier to swallow.
- Eating foods at room temperature.
- Avoiding extremely hot or cold foods.
- Letting carbonation or fizz escape from sodas.
- Serving gelatin, pudding, and softened ice cream. These foods count as liquids. They are important to offer because the child with mouth sores needs many fluids to combat a dry, sore mouth and throat to prevent dehydration and electrolyte imbalances.
- Ask about high-calorie liquids, such as Ensure or Isocal or milk shake recipes.

Prevent mouth sores

If your child does not have mouth sores or blisters, follow this daily schedule to prevent such problems.

- Brush the teeth after meals and at bedtime. Brushing removes bacteria and food, and stimulates gums and the lining of the mouth.
- Use a soft toothbrush. However, if your child's gums are sensitive or bleeding, use a soft sponge applicator or a cotton-tipped applicator, until the problem resolves itself. Alternatively, a soft toothbrush can be further softened by soaking it in warm water

before use. Because the mouth is easily irritated, give your child a soft-bristle toothbrush to use. Soft bristles prevent cutting or scraping, reducing the likelihood of infection.

- If your child has been given a prescription for Peridex an antimicrobial mouthwash, you should swab or rinse the mouth twice a day. Peridex is a special bacteria-fighting mouthwash that will prevent infected mouth sores. If your child objects to the taste, you can mix it with a little water to dilute it. You also can avoid having your child eat right after using Peridex because its residual taste tends to change the flavor of foods.
- Keep your child's lips moist with petroleum jelly, mild lip balm, or cocoa butter. If swallowing is difficult, then the mouth and lips become very dry. Lip balms prevent chapping and infection.
- Notify your nurse or doctor if your child is prone to cold sores. Cold sores are caused by a herpes virus and may flare up with each round of treatment. In some cases, it is necessary to prescribe an antiviral medicine to be used preventatively with each cycle of chemotherapy.
- If you have been given other mouth care medications, use them until your doctor or nurse instructs you to stop. Until then, ask for refills.
- Avoid cigarettes, chewing tobacco, and alcoholic beverages. Younger children are unlikely to be using these substances, but teenagers may be doing so. Discourage their use, as they irritate the mouth.
- Offer your child plenty of liquids (refer to the fluids chart, which your doctor or nurse will fill out for your child's situation). Taking frequent sips of water helps prevent dehydration. Many people carry large plastic cups with straws attached, and drink from these frequently to keep the mouth moist.
- Encourage your child to use dental floss at bedtime, but stop the flossing if it causes bleeding or pain, or if mouth sores are present. Flossing removes food particles. Flossing also can cause very small cuts in the gum tissue, but these heal during the night because no food is eaten.
- Avoid commercial mouthwashes. Many commercial mouthwashes contain alcohol, which is very drying. Ask your nurse what works best, and what mouthwashes the medical center recommends.
- Braces may need to be removed. Being made of metal, braces may rub the gums or lining of the mouth, and may need to be removed until soreness passes.

Possible Obstacles

Think about ideas and attitudes that could prevent you from carrying out your plan to solve your child's mouth sore problems.

Here are some obstacles that have sometimes stopped others.

1. "My daughter didn't want to brush her teeth or floss before diagnosis. How can I get her to do this now?"
Response: It's important to stick with it and make it a routine. Food particles can build up and cause bacteria to grow. Don't wait until there's a problem to start your child on mouth care.
2. "My teenager doesn't want to quit smoking or drinking."
Response: Both of these habits irritate the mouth. If the adolescent on chemotherapy doesn't quit either habit, then that's all the more reason to take other measures to care for the mouth.
3. "My child will eat only one food when she has mouth sores."
Response: That's OK for a couple of days until the problem is resolved. It is most

important that she is able to drink the recommended amount of fluid each day to prevent dehydration.

Carrying Out and Adjusting Your Plan

Your child will tell you if his or her mouth is sore. Keep track of how frequently these episodes take place, so the doctor or nurse can recommend specific treatments if they are needed.

Also, stay alert to whether mouth problems are interfering with your child's regular patterns of drinking and urinating, because dehydration and weight loss can lead to other problems. Are you doing everything you can to treat and prevent these sores?

If your plan doesn't work

If problems with mouth soreness or swallowing are getting worse, review "When To Get Professional Help." Ask yourself if you are doing everything you can to encourage good oral hygiene and to protect your child's mouth and throat against soreness and infection. Tell the doctor or nurse what you did to deal with any mouth problems and discuss what else should be done.

Nausea/Vomiting

The information in this homecare plan fits most situations, but yours may be different. If the doctor or nurse tells you to do something else, follow those instructions.

Understanding the Problem

It's natural to be concerned about nausea and vomiting. In the last few years, we have learned a great deal about how to control both. As a result, most children or adolescents receiving treatments for cancer have much less nausea.

Some children and adolescents never experience any nausea or vomiting from cancer, its treatments, or other medicines. Others deal with one or both symptoms at different times in their illness, depending on which treatments they receive and how they react to them.

Your goals are to:

- prevent dehydration and electrolyte imbalances,
- call for help if it is needed,
- make the best use of anti-nausea medicines, and
- do what you can to ease the nausea and vomiting.

When To Get Professional Help

The first question you should ask is whether the patient needs help from medical professionals. You should call the clinic, doctor, or nurse immediately if any of the following are true:

If there is blood or material resembling coffee grounds in the vomit. Coffee ground material is actually old blood, and signals that some bleeding has occurred inside. This happens very rarely but it is important to report.

If vomiting occurs more frequently than you expect. Check the fluids chart. Ask the doctor or nurse about these times. For most children or adolescents, vomiting three times per hour for more than four hours is serious, but your situation may be different.

If the vomit shoots out for a distance (projectile vomiting). Projectile vomiting may mean that there are problems in the stomach or intestine that should be investigated by your doctor.

If your child skips taking two doses of any prescribed medicines or can't keep them down because of nausea or vomiting. Medicines will have to be given other ways until pills can stay down again.

If the child or adolescent takes a small amount of liquid and eats no solid food. (Check the fluids chart filled out by your doctor or nurse.) Also, check on urinary output. For a very young child, you should be concerned if there are no wet diapers in eight to 12 hours. For an older child, you should be concerned if he or she goes 12 to 16 hours without urinating. Ask the doctor or nurse about the number of cups of liquids. Without liquids, people become dehydrated after continued vomiting. Nutrition is needed to keep up your child's energy and to fight the illness. Most children or adolescents need to drink more than four cups in 24 hours. But your needs may be different, so check the fluids chart, which your doctor or nurse will fill out, to determine when to call about not eating or drinking.

If severe weakness or dizziness happen along with the nausea or vomiting. It is normal to feel a little weak or dizzy with nausea, but if a person can't get up, then you need to call a doctor or nurse.

If severe stomach pain happens while vomiting. Severe pain is always a reason to call the doctor.

If you are very worried and want information or advice immediately. If you're following this homecare plan and you're still worried, then call.

When you call, the doctor or nurse may ask you the following questions:

1. How long has nausea been a problem?
2. When does it begin and how long does it last?
3. How bad was the most recent nausea?
4. How much does the nausea interfere with normal activities?
5. Was medicine prescribed for nausea/vomiting? Name of medicine(s) How often should it be taken? How many doses at one time? How many doses were taken in the last two days? How much relief did it give? How long did the relief last?
6. In addition to nausea medicine, what did you do to help your child feel better and what were the results?
7. Was the nausea followed by vomiting?
8. What did the vomit look like? Was this vomit the same color as earlier vomit? If not, how was it different?
9. How often has vomiting happened in the past 24 hours?
10. What other symptoms are new since the nausea/vomiting began? (Answer questions below for each new symptom.)
SYMPTOM:
Where?
How bad?
When started?
When does it happen?
How long does it last?
What relieves it?
What doesn't help?
11. What and how much did your child eat in the past 24 hours?
12. What and how much liquid did your child take in the past 24 hours? Was his or her urine output normal?
13. How frequent were bowel movements in the past two days, and were they the same amount and color as usual?
14. What is the temperature of the child or adolescent with nausea?
15. When was the last cancer treatment?

Here is an example of what someone might say when calling:

"I am Eileen Dunn, Jennifer Dunn's mother. My daughter is Dr. Chang's patient. She is being treated for neuroblastoma. The homecare plan for nausea says that I should call if she vomited after taking the last two doses of her anti-nausea medicine."

What You Can Do To Help

There are three things you can do at home to deal with nausea or vomiting.

- Make the best use of nausea medicine
- Limit nausea and vomiting on your own

- Prevent dehydration

Make the best use of nausea medicine

Check to be sure you followed instructions on the label of the bottle and any instructions given by the nursing staff. Here are ways to get the most help from anti-nausea medicine, especially around the time of chemotherapy treatments.

- Give your son or daughter anti-nausea medicine on a consistent schedule. Give the prescribed anti-nausea medicine before chemotherapy treatment. Continue to give your child the medicine every four to six hours or as prescribed for at least 12-24 hours and continue as long as nausea or vomiting persists. The anti-nausea medicine must be taken on a consistent schedule to maintain adequate drug concentration in the blood.
- Give anti-nausea medicine before and after receiving chemotherapy treatments. For the medicine to be effective, your child needs to have enough of it in the bloodstream. That's why he or she should start taking it before chemotherapy and then keep taking it every four to six hours, or as directed by the doctor.
- Give anti-nausea medicines a half-hour before meals. Allow time for the medication to be absorbed before eating, usually 30 to 60 minutes. Liquids can be absorbed more quickly than pills. The anti-nausea medicine will ease a negative response to food and not let nausea get in the way of trying to eat.

Limit nausea and vomiting on your own

This is a list of ideas for what you can do on your own to help reduce nausea and vomiting. Start with those ideas that have helped in the past, but try new ideas, too. You can't be sure if an idea will help until you try.

Encourage the child or adolescent with cancer to do the following:

- Encourage him or her to eat three to four hours before treatment, but not just before treatment. This keeps something in the stomach and helps the body to get the nutrition it needs. Then serve frequent light meals throughout the day. Try to have your child's stomach empty just before treatments if you find that works best for you.
- Avoid serving fried foods, dairy products, and acids like fruit juices or vinegar salad dressings. These foods are hard to digest and may make nausea worse.
- Offer chewing gum or hard candy if your child is old enough to have them normally. Try peppermint or fruit flavors. These will cover up any unpleasant tastes during chemotherapy.
- Let fresh air into the house or, in good weather, have the child or adolescent go outside. Taking in more oxygen helps calm the feeling of nausea. Encourage mouth breathing for a few minutes, or open a window.
- Sleep through nausea. Some people find it helpful to lie down when they are nauseated. The anti-nausea medicine will sometimes make people sleepy, which helps them to sleep through their nausea.
- Offer sips of fluids or ice chips 30 minutes after vomiting. Let the vomiting pass and wait a while before offering food or liquids. For young children, try a teaspoon to a tablespoon of liquid. For older children or adolescents, try an ounce at a time. Let the fizz go out of sodas before drinking them because carbonation can upset the stomach again. Stir sodas vigorously with a spoon to release carbonation.
- Offer dry crackers. This often helps women who are pregnant and nauseated and helps many people with cancer, too.

- Avoid unpleasant or strong odors. Keep your child or adolescent away from the kitchen. Often breathing through the mouth can prevent nausea from odors.
- Encourage frequent mouth rinses (saltwater solution or tap water, not commercial mouthwashes). Frequent swishing and rinsing removes unpleasant tastes.
- Encourage rest. Allow short rest times between everyday activities like dressing or walking. Taking it easy can help to keep the nausea away.
- Distract your child's attention. Watching TV, reading, or playing games may help your child to not notice nausea as much. You can also ask the child life staff for suggestions.
- Encourage your child to relax. If the child or adolescent with cancer is tense, all physical symptoms seem more intense. Many people find that, by relaxing, the symptoms are not as bothersome. (See the home care plan for "Parents' Anxiety" for more explanation of how to practice relaxation.

Possible Obstacles

Think about ideas or attitudes that could stop you from carrying out your plan and how you will overcome them. Here is an obstacle that sometimes occurs.

- "Why should I give my child an anti-nausea medicine when she hasn't vomited yet?"
Response: Chemotherapy often makes people nauseous, and it's important for your child to take the medicine in advance, and keep on taking it, to allow it to build up in the bloodstream and be distributed throughout the body. For it to be effective, your child should take it as prescribed and continue to do so for 12 to 24 hours. Waiting until nausea starts only aggravates the problem, because then the child or adolescent may have difficulty keeping down the very medicine that is supposed to help.

Carrying Out and Adjusting Your Plan

You can check on how well this homecare plan is working by keeping track of the number of times your child vomited, by asking how severe the feelings of nausea are, and by paying attention to how much fluid he or she is able to keep down and whether urinary output is affected.

If your plan doesn't work

If your child's problems with nausea are getting worse, review "When To Get Professional Help," and ask yourself if you're doing everything you can to reduce this symptom. If the child or adolescent is becoming anxious about getting nauseated or if the nausea is harder and harder to control, ask the doctor about alternative anti-nausea medicines.

Constipation

The information in this homecare plan fits most situations, but yours may be different. If the doctor or nurse tell you to do something else, follow those instructions.

Understanding the Problem

Constipation is when bowel movements are occurring less often than usual and when stools are hard or difficult to move. Constipation can be caused by medicines used to treat cancer, or by narcotics, emotional stress, changes in diet, or decreases in activity. Even if the child or young person with cancer isn't eating much, the body still makes waste, and regular bowel movements are still necessary.

When people with cancer are constipated, they often have a decreased appetite and feel bloated. This adds to their discomfort.

Your goals are to:

- call for professional help when it is needed,
- help to relieve the constipation, and
- prevent it in the future.

When To Get Professional Help

The first question you should ask is whether the person who is constipated needs help from medical professionals.

Call the doctor or nurse during regular office hours if any of the following is true:

- Your child has not had a bowel movement in 3 or 4 days. Your child will be more uncomfortable as the constipation continues. If it is allowed to go on for more than a few days, it also will be more difficult to reverse. Reporting the usual bowel pattern and the day and type of the last movement helps the doctor or nurse to suggest medications and to advise you on other measures to take to help relieve the problem.
- Severe straining on the toilet or commode.
- Intermittent cramping with a full (rounded) abdomen. Reporting other symptoms and their severity alerts health care professionals to the need to assess whether other, more serious, problems are present. In these situations, constipation is a sign or side effect of these problems. Pain or vomiting can indicate an abdominal problem, such as a temporary blocking of a section of the bowel, or infection.

Call the doctor or nurse immediately if either of the following is true:

1. Severe abdominal pain or an abdomen that feels harder than usual, and very full.
2. Red blood around the outside of the stools. These symptoms can indicate that tearing has occurred in the tissue around the rectum, which can become the site of entry for a serious infection.

When you call, the doctor or nurse may ask you these questions:

1. How often are the usual bowel movements? The question assesses the degree of constipation.
2. When was the last bowel movement? What did it look like? Reporting what the last bowel movement looked like (watery or dry) tells the health care professional if food is being digested properly and if the stool has enough

water in it as it passes along the long digestive and intestinal tract. In addition, color is very important to report. Very dark black stools could indicate blood in the stool.

3. Does your child normally take medicines to help move the bowels, such as stool softeners, Colace, or Senokot? It is important to report what bowel-movement aids your child is taking so the doctor or nurse will know what is working and what isn't, and suggest alternatives.
4. Does feeling constipated interfere with normal activities, such as walking or eating? The degree to which constipation is interfering with your child's comfort and activities is very important to report, because it guides the health care professional to prescribe stronger or gentler medicines and actions to relieve the constipation.
5. What other symptoms are there?
 - distention or bloating of the abdomen
 - pressure or sense of fullness in the rectal area
 - small, frequent "smears" of stool
 - small amounts of loose stools or "leaking," or diarrhea
 - rectal pain with a bowel movement
 - constantly feeling the need to have a bowel movement but unable to pass stool

Answers to questions about other symptoms help describe the severity of the constipation. If there is no bowel movement for days but small amounts of diarrhea occur, then telling the health professionals about both problems may alert them to the possibility of impacted stool.

6. What medications did your child take in the past two or three days?
 - narcotics
 - stool softeners
 - chemotherapy

Some medicines can interrupt normal bowel activity, and the doctor or nurse will recognize which medicines might be contributing to constipation. Therefore, be sure to mention whether any medicines were started that week.

7. What and how much did your child eat or drink in the past 24 hours?

Finally, if health care professionals know about food and fluid intake, they can judge if the constipation is leading to an emergency and requires a clinic visit. If they decide that relieving constipation is not an emergency, they may suggest an increase in fluids as well as many of the actions that are listed on the following pages.

Here is an example of what someone might say when calling:

"I am Aaron Ramirez, Tiffany Ramirez's father. My daughter is Dr. Luckenbaugh's patient, and she has been diagnosed as having Wilm's tumor. The homecare plan for constipation says to call if she hasn't had a bowel movement for four days. She feels as if she should go, but nothing happens."

What You Can Do To Help

There are two things you can do to help solve a constipation problem.

- Relieve constipation
- Prevent it in the future

Relieve constipation

If being constipated is not an emergency and you don't need to call a doctor or nurse, the next step is to help relieve constipation and discomfort.

- Give oral stool softeners and use them every day: Start with a dose in the morning and one in the evening. If that doesn't provide relief, add a third daily dose. Continue this regimen until it is effective.

A stool softener draws water into the bowel and decreases the dryness of stools so that they can more easily move down the long intestinal tract. These can be tried if the child does not meet any of the "call right away" criteria. Tablets, syrups, or "sprinkles" can be bought at any pharmacy, there are many brands to choose, and Colace or Senokot tablets are frequently recommended for children or young people. If finances are a concern, ask the pharmacist about less-expensive options and ask clinic staff if they have samples.

- Give a mineral enema, Fleets enema, soap suds enema, or suppository for immediate relief, but only if directed by an oncology doctor or nurse. Enemas are the last step to try when relieving constipation. They evacuate the lower bowel, which helps the upper bowel move as well. If an enema is recommended, ask for specific instructions about how to do this for your child.

If blood counts are low or if the lining of the rectum is already inflamed, an enema or suppository can cause further breakdown and lead to a serious infection. Therefore, these should only be used at times specifically recommended by your oncology doctor or nurse.

Prevent constipation

There are many things you can do to prevent constipation. If your child has been constipated recently, you should use these tips to prevent it.

- Gradually add foods high in fiber to the diet, such as:
 - Whole grain cereals and breads
 - Dried fruits, such as prunes and raisins
 - Popcorn, nuts, and seeds
 - Beans and legumes
 - Raw fruits and vegetables

High fiber-foods draw water into the stools. They also provide bulk-that is, they are made of materials that do not break down as the food passes through the intestines. For example, skins and coverings on nuts, beans, grains, fruits, and vegetables are not easily broken down, and these help form stools that are easily passed out of the body. If raw fruits and vegetables are hard to chew, try grating or cooking them.

- Add unprocessed bran to the diet. Bran stimulates bowel activity. Sprinkle it on cereal. Start with two teaspoons per day and gradually increase this amount up to two tablespoons per day. Be careful. Adding large amounts of bran to the diet too quickly might cause diarrhea and discomfort. Also, be sure to read the next item.
- Encourage your child to drink plenty of liquid every day. (Consult your doctor or nurse for the correct quantity to insert in a table of fluids.) Fluids add water to the stools and prevent dry hard stools. It's necessary to do this step along with the step above. You can encourage fluid consumption alone, but if your child is eating bran, it must be accompanied by more liquids.
- Offer hot or warm liquids such as tea, or lemon water. Hot or warm liquids stimulate the bowels. People often say that coffee makes them go to the bathroom. It's the combination of caffeine and hot liquid that causes this. Hot tea or hot lemon water also can be effective.

- Serve prune juice, other fruit juices or nectars. Prune juice, whether warm or cold, stimulates the bowels to work.
- Exercise, such as walking every day, also helps. Even a small amount of movement, such as walking in the house, helps stimulate muscles like the bowel. Talk to the doctor about the amount and type of exercise that is right.
- Avoid regular use of laxatives or enemas. Laxatives-bowel stimulants or irritant-may cause cramping and prevent the intestines from finding a regular pattern. These are different from stool softeners.
- Give one or two stool softeners every day. Giving one or two stool softeners every day will help prevent constipation. If the person is eating or drinking less and not feeling well enough to get exercise then stool softeners should be tried.
- Try diet and exercise tips first, then medicines, and follow a daily schedule just as you do with other medicines. Following a schedule of diet, exercise, and medicines to prevent constipation should be considered as important as taking other medicines. Daily attention to eating helpful foods, drinking liquids, and taking preventive medicines will add up to successful prevention.

Possible Obstacles

Think about ideas and attitudes that could prevent you from carrying out your plan to solve your child's constipation problem.

"I saw some liquid B.M. How could he be constipated?"

Response: Sometimes a child can be constipated but small amounts of liquid bowel movement can leak around the harder stool that is lodged in the lower bowel. Report the absence of normal stools and mention the small amount of liquid diarrhea, too. Constipation can become very uncomfortable for the child if left untreated.

Carrying Out and Adjusting Your Plan

Prepare in advance for constipation, especially if Vincristine or narcotics are prescribed, or if the person is less active. Use this homecare plan as a reference and begin to change diet and food habits to prevent constipation.

Checking on results

After new medicines are started, determine whether your child's bowel habits are changing. Is the constipation happening less frequently? When it does happen, do you both know what to do to relieve it? Are your actions to prevent constipation taking effect?

If your plan doesn't work

If your plan doesn't seem to be working or your child's constipation is getting worse, you can take three actions. Consider them in this order.

1. Check the "When To Get Professional Help" section of this care plan. If you answer yes to any of those questions, call the doctor or nurse according to instructions.
2. Develop a new strategy using this homecare plan.
3. If constipation continues, ask the doctor or nurse for help. Describe what you have done and what the results have been.

Diarrhea

[The information in this homecare plan fits most people, but your child may be different. If the doctor or nurse tell you to do something else, follow what they say. If you think there may be a medical emergency, go directly to When to Get Professional Help]

Understanding the Problem

Diarrhea is defined as increased water in the stools. With diarrhea, bowel movements usually happen more frequently than usual and feel more urgent. Having diarrhea can be very upsetting to a toilet-trained child. Losing these fluids also adds to fatigue and feeling "washed out." Diarrhea can also cause dehydration, which can be a serious health problem. Therefore, controlling diarrhea is very important for comfort and for health.

Your goals are to:

- call for professional help when it is needed
- replace lost fluids and nutrients following diarrhea
- help the person with cancer avoid foods which could increase diarrhea
- do what you can to increase comfort

When To Get Professional Help

Call the doctor or nurse if any of the following are true:

- **Severe Diarrhea.** Ask the doctor or nurse when to call about diarrhea. Severe diarrhea means that a lot of fluid is being lost. With severe diarrhea, stools are very runny and frequent, and the person often complains of stomach cramps as well. The severity of the problem depends on many factors, such as the person's weight or previous state of fluid balance. Losing small, frequent amounts of fluid in the stool in diarrhea can be dangerous for a small child or for anyone who has been recently struggling with diarrhea or vomiting. In this situation, dehydration happens or worsens quickly. Reporting severe diarrhea early is important so that fluids are given to reverse or prevent the dehydration.
- **Diarrhea for more than one day.**
- **Blood in the diarrhea stool.**
- **Fever above 101 degree F with diarrhea.**

Know the following facts before you call:

1. How many bowel movements are usual each day?
2. How many bowel movements were there in the past 24 hours?
3. How runny were they?
4. Any other symptoms with the diarrhea? Information about other symptoms tells the doctor or nurse how serious the problem is. There can be a danger of other side effects, such as a rectal infection or dehydration. Rectal infections are caused by bacteria that invade the body when the skin is broken down from the acids and irritants in the diarrhea stool. This is uncomfortable and painful. Examples of other symptoms are:
 - stomach pain
 - stomach cramps
 - bloating (feeling very full in the stomach or abdomen)
 - nausea (sick to the stomach)
 - vomiting
 - decreased urine output
5. How much liquid was taken and how much as eaten in the past two days? Liquids and foods that were taken inform the health professionals if the

amount of liquid coming out of the body is being replaced by fluid intake. Dehydration is important to treat because it could lead to dangerously low blood pressure and chemical imbalance. Sometimes intravenous (IV) fluids are ordered to balance out the fluid loss. These IV fluids can contain other nutrients that are being lost in the diarrhea, such as glucose, potassium, and sodium.

6. What medicines were taken in the past two to three days?
 - chemotherapy (when)
 - stool softeners
 - antibiotics
7. Has weight been lost? How much?
8. Is there any history of other bowel problems?

Here is an example of what someone might say when calling for help:

"I am Joan Smith, Harry Smith's mother. My son is a patient of Dr. Ungar's with leukemia. The homecare plan on diarrhea says to call if he's had diarrhea for more than one day."

What You Can Do To Help

If you decide that this is not an emergency, then there are three things you can do to solve this problem. Consider them in this order:

1. Replace lost fluids and nutrients promptly
2. Avoid certain foods
3. Increase comfort

Replace lost fluids and nutrients

Important fluids and salts are lost with diarrheal stool. Replacing them is crucial. Here are several ways to do this.

- **Offer clear liquids, for example, Pedialyte, Ricelyte, and Gatorade.** Chicken broth, tea, flat ginger ale, and Popsicles; may be used in small quantities in addition to electrolyte supplements. If an infant is breast-fed, continue breast-feeding. Drinking clear liquids like chicken broth or juice provides nourishment but also lets the bowel rest. Clear liquids are easier for the intestines to absorb into the bloodstream, and they quickly replace the fluids being lost with diarrhea. Ricelyte, Pedialyte, and Gatorade have a balance of liquid and electrolytes (salts) which are easily absorbed and will maintain the proper balance in the body.
- **Serve fluids between meals.** Taking fluids between meals keeps a steady amount of water and other nutrients going into the body. Drinking between meals is also less likely to cramp a sore stomach or lower intestines.
- **After 24 hours of clear liquids, add low-fiber foods, for example, bananas, rice, applesauce, mashed potatoes, dry toast, crackers, eggs, fish, and poultry.** Low-fiber foods do not attract or pull water out of the body into the bowel. They are easier to digest than high-fiber vegetables.
- **Eat small meals throughout the day instead of three larger meals.** Smaller meals are easier to digest. The person will take in more fluid and food this way if served more frequently than three times a day.
- **Increase high-potassium foods in the diet, such as apricot or peach nectar, bananas, and mashed or baked potatoes.** People tend to lose potassium when they have diarrhea. This chemical is vital to the body and needs to be replaced.

Avoid certain foods

Some foods increase the action of the bowel and how quickly it pulls fluid out of body tissues into stool. Avoiding these foods will help reduce a problem with diarrhea.

- **Avoid serving foods that produce gas, for example beans, raw vegetables, raw fruits, broccoli, corn, cabbage, cauliflower, carbonated drinks, and chewing gum.** These foods make a person stop eating or drinking early. Gas also adds to discomfort. Chewing gum also should be avoided because it makes some people swallow air, which also adds to abdominal discomfort.
- **Avoid serving foods that contain acids, such as highly spiced food or citrus juices like orange or grapefruit.** These make the stomach and intestines churn and can create more discomfort as well as more diarrhea.
- **Avoid serving fat, such as fatty meats and greasy fried foods.** Fats are difficult to digest. If the person has diarrhea, then fats are pushed through without being digested, and their undigested presence adds to the diarrhea.
- **Cool down extremely hot food or hot drinks.** Hot foods and liquids stimulate the bowels. Avoid these until the diarrhea is solved.
- **Limit the person's caffeine, for example, coffee, strong teas, sodas with caffeine, and fruit juices.** Caffeine and fruit juices make the bowel work faster. If a person has diarrhea, you want to slow down their bowels because they are already overactive.
- **Avoid giving milk and milk products if they seem to make diarrhea worse. Milk can also make diarrhea worse.** Milk and dairy products should be resumed last-after diarrhea is resolved and the child is tolerating other foods and fluids.

Increase comfort

The lower abdomen can become quite sore from intestinal cramps that may accompany diarrhea. The person with cancer can also feel very worn out from bouts with diarrhea. Rectal skin or skin around a stoma can become very sore. Here are several ways to ease abdominal or skin soreness:

- **Put a warm hot water bottle wrapped in a towel on the abdomen.** Warmth on the stomach can relieve pain and discomfort caused by stomach tightness or cramps. However, do not use a heating pad. The skin may be very sensitive to heat, especially if the person is receiving chemotherapy or radiation therapy, and a heating pad could cause additional problems with the skin.
- **Cleanse anal area gently, but thoroughly, after each bowel movement.** After diarrhea, cleanse the outside of the anus very gently with warm water and then dry the skin to reduce redness and prevent infection. (You may need to pat the skin dry or dry with a hair dryer set on "cool"-no heat.
- **Soak in warm water. Use a tub or Sitz bath.** Sitz baths can be bought at most pharmacies or medical equipment stores. Sitz baths are plastic bowls that are placed over the toilet and the person can sit in the bowl of warm water while it flows into the bowl from above and spills into the toilet below. Sitting in a tub of warm water is also practical.
- **Apply soothing creams, ointments, or astringent pads to the rectal area, such as Tucks.** Creams prevent anal skin from chapping in the same way they prevent diaper rash or chapping on infant skin. Try Nupercainal, A&D, or Vaseline. Astringent pads also help to dry the area and soothe irritated skin.
- **Protect the rectal skin with a barrier ointment such as Desitin, Balmex, or Criticaid.** If the diarrhea continues and the anal area becomes very sore and red (or to prevent redness and breakdown), apply an ointment, such as Desitin, Balmex, or Criticaid to cover the skin. Fluids will be less likely to burn the skin since this type of

ointment covers the skin with a protective layer. These ointments must be thoroughly cleaned away and then reapplied after each bowel movement.

Possible Obstacles

Think about what ideas or attitudes could prevent you from carrying out your plan and reaching the goal of controlling or preventing diarrhea.

Here are some obstacles that other people have faced.

"He's had nothing to eat or drink for days so this diarrhea can't last much longer."

Response: The body can keep removing fluid for much longer than you think. The fluid is drawn from body tissues and diarrhea can continue even if the person stops eating or drinking. It's very important to replace the fluids that are lost even if the person thinks that these will be washed out instantly.

Carrying Out and Adjusting Your Plan

Be aware of the frequency and severity of diarrhea. Are you able to stop the diarrhea on your own whenever it starts? Is the anal skin or skin around a stoma as well cared for and protected as it can be? Are other precautions with fluids and diet being followed to prevent diarrhea?

If your plan doesn't work

If problems with diarrhea are getting worse or the person with cancer is becoming very worn out, review When to get professional help. When calling, tell the doctor or nurse what was done to deal with diarrhea and discuss what else should be done. If you don't think that you need to talk with a doctor or nurse about this problem, then ask yourself if you are doing every-thing you can to protect the skin against soreness and to encourage plenty of fluid intake to prevent dehydration. If diarrhea problems continue, ask the doctor or nurse for help. Tell them what you have done and what the results have been.

Skin Problems

Understanding the Problem

Many people experience changes in their skin during cancer treatments. Sometimes chemotherapy causes this. Symptoms may include dry skin, itch, rashes, sores, sweating, darkening of skin, veins, or fingernails. Chemotherapy also may make the person with cancer more prone to sunburn.

Radiation therapy causes skin problems that can last several weeks after treatments end. Symptoms include dryness, itching, and redness around areas where the radiation beam enters or exits the body. Most of these reactions will go away a few weeks after treatment is finished.

When to Get Professional Help

Call the doctor or nurse if:

- **Skin gets very rough, red, or painful.** This may be a reaction (possibly allergic) to a new chemotherapy drug. A doctor may be able to substitute another drug.
- **A cut becomes red, sore or swollen, or doesn't heal.** Act early to prevent skin infection.
- **A rash or hives start;** this may signal a reaction to food, liquid, or a new drug.
- **Severe itching lasts more than three days.** This may be a reaction to a drug, or the body may be processing materials by pushing excess substances through the pores of the skin.
- **Skin is scratched open and looks red.** Red and open skin can become infected.
- **Pus comes out of an opening or cut,** usually indicating a skin infection.
- **Skin turns yellow.** This means that a major organ, such as the liver, is not working well.
- **Urine becomes the color of tea.** This is another signal that a major organ is not working well or that bleeding is occurring higher up in the urinary system.
- **Bowel movements are clay-colored** (more white than orange).
- **A bruise does not improve in a week.** Slow bleeding may be occurring.

When you call, you will need to be ready to answer questions that the doctor or nurse may ask:

1. When did the problem start? What do you think brought it on?
2. How bad or embarrassing is it? What helps it feel or look better?
3. What is the person's temperature?
4. What causes a bruise or a rash, and what makes either one go away?
5. Are any cuts not healing? If there is itching, where is it and what relieves it?
6. When was the last chemotherapy treatment? What other medicines are being taken?

What You Can Do To Help

If the skin problem is not an emergency, below are some things to help you deal with the problem.

1. Relieve itching
2. Prevent dryness and itching
3. Conceal dark skin, veins, or discolored fingernails
4. Treat acne
5. Limit sweating
6. Decrease sun sensitivity

7. Take care of skin during and after radiation therapy
8. Take care of the diaper area

Relieve itching

- **Suggest bathing with cool water** and using gentle soap. Try an oatmeal or oil soap. Alpha Keri; may be added to bath water; it eliminates the need for soap while it softens skin.
- **Add baking soda to bath water.** It soothes sensitive skin and reduces itching.
- **Remind the person to rinse skin thoroughly** and pat dry.
- **Apply cool, moist compresses** to itchy areas.
- **Suggest keeping nails short and clean.** They are less likely to scratch open the skin.
- **Encourage the person to wear clean white gloves** if he or she is scratching.
- **Change bed sheets daily.** This removes flaked dry skin and bacteria, which cause itchiness.
- **Wash sheets and towels in gentle laundry soap**, such as Dreft; or Ivory Snow.
- **Avoid harsh laundry detergents**, such as those that contain chemicals to attack oil and dirt.
- **Keep room cool** at 65-75 degrees F. When the body sweats more, itchiness increases.
- **Encourage rest.** Too much activity makes the skin sweaty and prone to itch and irritation.
- **Avoid extreme cold or heat.**
- **Suggest covering up in the sun.** Use a lotion with at least a SPF #15 sunblock.

Prevent dryness and itching

- **Add mineral oil or baby oil to bath water.** Oil will soak in and prevent skin dryness.
- **Take sponge baths**, which are cooler.
- **Avoid full baths or showers**, which expose skin to heat for a longer time.
- **Use warm water**, not hot water.
- **Do not scrub skin.** Scrubbing pulls on delicate tissues and removes important moisture.
- **Pat skin dry.** This is more gentle than rubbing and helps lock in needed moisture.
- **Apply a mild water-based moisturizing cream** to skin just after a bath.
- **Limit bathing** to once a day.
- **Encourage drinking** two quarts of fluids every day unless instructed otherwise.
- **Avoid extreme heat, cold, or wind**, which chafe the skin.
- **Avoid colognes**, after-shaves, or lotions that contain alcohol, which dries out skin.
- **Remind the person to use an electric razor** rather than a straight or blade razor.
- **Avoid opening or popping blisters.**
- **Put dry clean gauze** on any open areas.

Conceal dark skin, veins, or discolored fingernails

- **Wear long sleeves** to hide dark veins and provide some protection against bruising.
- **Women may want to wear nail polish** or a thin layer of make-up foundation.
- **Keep nails clean**, short, and filed smoothly.

Treat acne

- **Keep skin clean with mild soap** and warm water. Harsh soaps inflame blemishes.

- **Pat skin dry.** Gentle drying allows new skin to heal.
- **Avoid astringents.** Although they dry out blemishes, they dry the whole face and remove too much moisture. Keeping skin clean is the best treatment for acne caused by chemotherapy.

Limit sweating

- **Dress in two light layers of clothing.** Wear cotton closest to the skin. The outer layer should be light, to allow air to pass through.
- **Change wet clothing as soon as possible.** It can lead to chills and discomfort.
- **Use a thin layer of corn starch** (which absorbs sweat) in skin folds. However, when the white cells are low (often after chemotherapy), do not use corn starch because it can cause a skin fungus or yeast infection to develop.

Decrease sun sensitivity

- **Cover legs and arms** by wearing long sleeves and pants. Chemotherapy makes the skin tissue extra sensitive to the sun's rays, and sunburn occurs rapidly.
- **Wear lightweight fabrics.** They allow more air to pass through to the skin and keep it dry.
- **Wear a wide-brim hat** and sunglasses.
- **Use a suntan lotion** with a sunblock SPF rating of 15 or higher.
- **Apply sunscreen to any newly exposed scalp.**
- **Stay in the sun for only a short time.**
- **Stay out of the sun from 11:00 a.m. to 3:00 p.m.,** when it is hottest and most dangerous.
- **Cover all skin appropriately when outdoors.** Reapply sunblock at least every hour if hot and sweaty. Sunburn can occur in as short a time as 15 minutes of direct sunlight. Remember that ultraviolet rays penetrate clouds, so use these tips on overcast days as well.

Take care of skin during and after radiation therapy

- **Wash with lukewarm water** and mild soap. Avoid scrubbing.
- **Keep the treatment area clean and dry.** Take a daily sponge bath or lukewarm shower.
- **Avoid using scented or medicated lotions,** rubbing alcohol, creams, body oils, talcs, perfumes, or antiperspirants. All of these skin will irritate the skin.
- **Avoid using corn starch to control perspiration,** or in areas that are moist or wet. If you have difficulty keeping an area of skin dry, consult the medical staff.
- **Avoid ice packs.** Ice irritates skin and may constrict blood vessels, inhibiting healing.
- **Avoid hot water bottles and heating pads.** Heat irritates skin and can further dry it out.
- **Avoid direct sunlight to treated skin** for at least one year after radiation treatment.
- **Wear loose clothing**
- **Avoid scratching treated skin.** It can lead to infection, irritation, or soreness.

Take care of the diaper area

- **Change diapers often** - every two to three hours during the day.
- **Change diapers first thing in the morning.**

Possible Obstacles

- "It's only the skin and not the body."
Response: Skin problems need to be treated early to prevent infection and to decrease discomfort. If you notice changes, talk them over with the nurse or doctor. Don't wait until an infection or severe discomfort occurs.
- "No one seems to know what to do about itching. I guess we'll just have to live with it."
Response: Itching is a very difficult problem to heal. Try a combination of strategies to relieve constant itching. Keep experimenting, and visit a dermatologist if necessary.
- "I'm so afraid I'll get fried by radiation therapy."
Response: Radiation therapy does cause skin changes, but the intent is not to 'fry' the skin. Although it does get red and sensitive, skin will heal. Be sure to call for help, especially if skin gets moist or wet and becomes sore. Clinic staff will keep a close eye on the skin, and the radiation therapist can stop the treatment and give the skin a rest.

Carrying Out and Adjusting Your Plan

Have you called for professional help when it was needed? Have you been able to relieve itching, prevent dryness, conceal dark skin, veins or nails? Have you treated acne when it occurred, limited heavy sweating, and decreased sun sensitivity?

If your plan doesn't work

If your plan does not seem to be working, or the skin problem seems to be getting worse, review "When To Get Professional Help." If you answer yes to any of those questions, call the doctor or nurse immediately and ask for help. Describe what you've done and what the results have been. If the skin problem is not an emergency, select those symptoms that are of most concern, and develop a new approach using this homecare plan.

Bleeding

[The information in this homecare plan fits most situations, but yours might be different. If the doctor or nurse tell you something else, follow what they say. If you think there may be a medical emergency go directly to When to Get Professional Help. Good problem solving requires a calm, positive attitude. If you are very upset or discouraged about bleeding then get a friend, neighbor or family member to help you with this plan.]

Understanding the Problem

Bleeding can be very upsetting. It can happen at different times but especially when a person is receiving treatments for cancer. Chemotherapy decreases the number of platelets which clot the blood. When this happens, the person is at a higher risk of bleeding, especially from the mouth, the nose, and in the long gastrointestinal (GI) tract. Family caregivers should know when to sound the alarm and to catch bleeding in its early stages.

Your goals are to:

- call for help when it is needed
- to control bleeding if it starts
- to prevent future bleeding

When To Get Professional Help

The first question you should ask is whether or not the young person with a bleeding problem needs help from medical professionals.

You should call the doctor or nurse if any of the following are true.

- **Any unusual bleeding that last more than 10 minutes**, such as bleeding from the nose, gums, or skin.
- **Vomiting of blood or coffee ground material.**
- **Blood in the urine.** Look for red, pink or dark brown urine.
- **Blood in the stools.** Look for red, dark red or black colored stools.
- **Little red or purple spots underneath the skin or in the mouth or on the trunk, stomach, or back**, which appear within a few hours.
- **More bruises on different parts of the body**, such as on the chest, waist, abdomen, or head rather than the more normal places, such as elbows and knees.
- **Severe headaches that happens suddenly.**
- **Very sleepy or unable to wake up.**
- **Your child is injured, especially if he bumps his head hard.**

When you call you will need the following facts to answer questions which the doctor or nurse may ask you.

1. When did this sign of bleeding start?
2. How long did it last?
3. How much was there?
4. What do you think caused it to happen?
5. Has the person coughed up blood?
6. For menstruating females: Is there vaginal bleeding? How heavy is the flow?
7. What medications were taken recently?
 - Aspirin
 - Ibuprofen-Motrin, Advil

- Iron
 - Any suppositories
 - Chemotherapy (when)
8. Is the person receiving radiation therapy? If yes, where on the body?

Here's an example of what someone might say when calling:

"I am Jane Smith, the mother of John Smith. My child sees Dr. Jones at the oncology clinic for neuroblastoma. The homecare plan on bleeding says to call if he had bleeding from the gums. He just ate some cereal and started bleeding around the front teeth. He also just started chemotherapy two weeks ago and I was worried that this caused the bleeding."

What You Can Do To Help

If you decide that the bleeding problem is not an emergency at this time, here are two things you can do on your own to control bleeding if it happens.

Control Bleeding

Platelets are the elements in the blood that clot the blood. When these are low, blood does not clot and bleeding does not stop by itself.

Low platelet counts mean that bleeding can happen more easily and last longer than normal usually. Some chemotherapies cause platelet counts to drop. Therefore, when a person is receiving chemotherapy, you should be on the lookout for any bleeding or rapid bruising. Stop it if you can, and report it to the physician or nurse early.

When bleeding starts, it often flows from tiny capillaries that are very near the skin surface, such as from the nose or gums. These capillaries open easily but they also close easily.

- **Press on areas of bleeding skin.** Pressing on the skin gives the blood in the little blood vessels more time to clot up. Apply pressure for about five minutes to the skin site to maintain the pressure. If you can get an ice-filled cloth or very cold cloth, do so, but don't let go of pressing the skin. Ice helps the bleeding to stop. If the bleeding doesn't stop completely, do this again for 10 minutes.
- **Apply a cold cloth or ice pack to the area of bleeding.** Again, pressing helps stop the bleeding. For a nose bleed, pinch the nose with a handkerchief or put ice wrapped in a soft cloth over the bridge of the nose and pinch for several minutes.

If bleeding is from the nose:

- **Put a cold cloth on the nose and pinch the nose.**
- **Do not lie down.** Lying down keeps blood flowing more easily to the head. If the young person sits up or stands, then blood does not flow quite as quickly and the bleeding is more likely to stop.
- **Tilt the head forward.** This prevents blood from dripping in the back of the throat, which can cause gagging and be very uncomfortable.

Prevent bleeding in the future

There are many ways to prevent bleeding and bruising if the platelet count is low.

- **Do not use ibuprofen, which is the same as Motrin or Advil or Nuprin, among others.** Ibuprofen decreases the blood's ability to clot. Avoid giving these at all times.

- **Do not use aspirin or aspirin-containing products.** At the drug store, read the fine print on the label of any analgesic or pain relief pill. It will list aspirin or "acetyl salicylic acid" as part of the ingredients. This means the pill has aspirin in it. Aspirin makes one bleed more easily, especially if platelets are low.
- **Use a very soft toothbrush or a sponge-type toothbrush.** Gums bleed easily when irritated or scraped. A soft toothbrush treats the gums much more gently, and they are less likely to bleed.
- **Do not floss your teeth if this causes oozing from the gums.** This can cut the gums and bleeding may be hard to stop. Resume flossing when the counts go up again and the doctor or nurse says it's OK to go off of bleeding-type precautions.
- **Rinse and brush the teeth after eating.** Rinsing helps remove any leftover food which can build up and start an abscess or sore and make the gums bleed.
- **Serve a soft diet, such as soup, mashed potatoes, custards, Jello, or puddings if there is mouth soreness.** Avoid foods that are sharp or crunchy or hot, spicy, or acidic foods. Soft foods are the least likely to create a cut or scrape in the mouth. Non-spicy foods also are less likely to cause bleeding. Think back to when you burned the top of your mouth on pizza or a grilled cheese sandwich. The skin tore. When platelets are low, the skin also will bleed if it tears because it was burnt.
- **Avoid blowing the nose forcefully.** Discourage nose-picking or vigorous nose-wiping. There are many tiny blood vessels in and near the nose which can open up if the nose is blown too forcefully.
- **Apply petroleum jelly or lip balms often.**
- **Avoid straining to move bowels and avoid constipation.** Stool should be kept soft so it's easy to have regular bowel movements and go to the bathroom. Straining can break open the delicate tissue near and around the rectal opening and bleeding can start. Constipation can be avoided by drinking water and fluids and by taking a daily stool softener, such as Colace or Senokot. If constipation does occur, offer a mild laxative after checking with the doctor or nurse.
- **Shave with an electric razor, not razor blades.**
- **Supervise use of sharp objects such as knives, scissors or tools.**
- **Avoid contact sports.** Examples of contact sports are football, soccer, basketball, wrestling, and tug of war. Anything that involves rough playing should be discouraged, too.
- **Avoid heavy lifting and strenuous activities.**
- **Protect the child from injuries such as falling off furniture, down stairs, etc.** Use a bed rail and pad it with soft blankets. If you don't want to use a bed rail, push the bed up against a wall and line up chairs on the open side, or place soft pillows on the floor around the bed. Another idea is to take the bed off its frame and place the mattress on the floor. Discourage climbing on furniture, trees, etc.
- **Supervise outdoor play in order to avoid falls, injuries, etc.**
- **Do not use rectal thermometers, suppositories or enemas.** Anything put into the rectum can tear very delicate tissue and bleeding can start easily.
- **Ask about the blood counts.** Ask staff to explain about platelets, what makes them go up and down, and what happens to a person with cancer as platelets rise and fall. Then you can ask what the blood counts are each time they are drawn.

Possible Obstacles

Think about attitudes or ideas that could prevent you from carrying out your plan to control or prevent bleeding.

Here are some obstacles that other people have faced.

- "When my children have fevers, I always give them PediaProfen; and it works."
Response: When one is under treatment for cancer and getting chemotherapy, it's important not to take any aspirin or ibuprofen products even though these drugs bring a fever down. The risk of bleeding from these drugs is too great. You also don't want to mask the fever by giving a medicine to lower the temperature before you are told to do so by the doctor or nurse. Mask-ing means that the fever goes down to normal for a short time so you don't think that there's anything really wrong. The doctor and nurse want to know how high the fever is, so call and report it.
- "My toddler is always climbing on things and falling down. It's impossible to prevent this."
Response: The key with toddlers is to prevent serious falls (down stairs, off furniture, etc.) and to prevent head injuries.
 - Close doors to stairways securely or install a gate.
 - Do not leave your child unsupervised, even for a minute, or on a couch, chair, or bed unless there are siderails or the tray table is securely fastened.
 - Move furniture with sharp edges or corners from your child's environment. Also move heavy or sharp objects that your child could pull or knock down onto himself.
 - Ask about your child's platelet count so that you will know when to monitor very closely (low platelets) and when you can allow more liberal activities (normal platelets).

Carrying Out and Adjusting Your Plan

Go over the goals of this homecare plan and compare the situation now to when you started. Are you able to stop the bleeding on your own whenever it starts? Are the skin and mouth as well cared for and protected as they can be? Are other precautions to prevent bleeding being followed?

If you answer yes to these types of questions, you are meeting your goals and preventing or solving problems with bleeding and bruising. Keep a close eye on this situation in case it changes. However, if you answered no to any of these questions, then you need to continue to attack the problem with bleeding and adjust your plan.

If your plan doesn't work

If problems with bleeding are getting worse, review When to get professional help When calling, tell the doctor or nurse what was done to deal with bleeding and discuss what else could be done. If you don't think that you need to talk with a doctor or nurse about bleeding, then ask yourself if you are doing everything you can to protect the skin against bruises, bumps, or cuts and to encourage good oral hygiene.

Tiredness and Fatigue

[The information in this homecare plan fits most situations, but yours may be different. If you think there may be a medical emergency, go directly to When to Get Professional Help]

Understanding the Problem

Children and adolescents with cancer can feel very worn out and tired because of the disease itself or from the treatments. It may be because of anemia, which means there are fewer red cells circulating oxygen to the body. Other causes are malnutrition (not eating enough) or a temporary increase in waste products as cancer cells are destroyed by radiation therapy or chemotherapy.

Sometimes people feel tired after each course of treatment for their cancer. They complain of not having enough energy or not feeling as if they can get going.

Tiredness also may happen because normal resting and sleep habits are disrupted. It may happen because the person with cancer is feeling depressed.

You should not "push" your child into doing more than what he or she feels is reasonable. On the other hand, let your child be the guide as to how much he or she can do. Don't excessively restrict activity. If other symptoms occur with increased fatigue, then it's important to talk with the doctor or nurse.

Your goals are for the person with cancer to:

- experience as little tiredness as possible
- use energy as effectively as possible
- keep regular schedules of sleep and rest

When To Get Professional Help

The first question you should ask is whether help from medical professionals is needed because of an emergency that goes along with feeling tired. The problems that need immediate help are ones that indicate an unexpected physical problem.

You should call the clinic, doctor, or nurse immediately if any of the following are true:

- **Dizziness.** Dizziness and feeling a loss of balance can happen when walking or getting out of bed or going from a standing to a sitting position. Dizziness can also happen without moving or changing one's position. This symptom can happen to anyone occasionally. When it is severe and frequent, you should get medical help.
- **Falling, followed by an injury, bleeding, mental confusion or unconsciousness.** Report all bad falls so the doctor or nurse can judge what caused the falling, and what follow-up is needed. Sometimes they'll recommend using other measures for prevention.
- **Unable to wake up.** This is a sudden and unexpected change in level of consciousness or alertness. You should call right away if you cannot awaken your child. You will probably have to take him or her to a medical facility for tests to determine the cause of this problem.
- **Feeling out of breath, breathing rapidly while at rest, or rapid heartbeat while at rest; also, sudden severe headache.** Breathlessness usually happens because the body is not getting the right amount of air and oxygen because of anemia (low red blood cell count). Less commonly, this can be caused by some problem with the lungs and respiratory system.

You should call the clinic, doctor, or nurse during regular office hours if any of the following are true:

- **Persistent ringing in the ears.** This can be caused by a reaction to medication, a change in blood flow to the brain or other physical changes. Medical tests are usually required to determine its cause.
- **Recurrent headache.** Recurrent headaches can also signal anemia or infection.
- **Excessive sleepiness.** When a child or adolescent is more interested in sleep than in normal activities such as eating or playing, it signals a lack of energy that can be due to anemia or depression.
- **Extreme pallor.** Indicates anemia.

The doctor or nurse may ask the following questions when you call:

1. How clear are your child's thoughts?
2. Has any confusion appeared or increased since fatigue increased?
3. Is your child feeling depressed or "blue"?
4. Has any new medicine been started, such as pain medicine or sleep medicine?
5. How is the child's activity level? Is the child sleeping instead of participating in normal waking-hours activities?
6. Have you noticed any change in sleep and nap duration?
7. Any fever?
8. How is the child's color?

Here is an example of what someone might say when calling:

"I am Karen Anderson, Christopher Anderson's mother. My son is Dr. Bhat's patient, and he has been diagnosed with ALL. The home care plan for fatigue says that I should call if he takes naps so much that he's skipping meals and playtime."

What You Can Do To Help

If you decide that tiredness is not an emergency, you can try the following strategies to help solve this problem.

- Help the person get the most out of the day
- Promote rest and sleep

Help the person get the most out of the day

- **Plan the day so social activities or trips happen when he or she feels most refreshed and awake.** Plan activities during the time of day or evening when your child feels best. Allow time for rest between events so the day and evening are not packed with people and events.
- **Rest between bathing, dressing, and walking.**
- **Conserve energy by doing things only for a short time.** When fun or distracting events are planned, encourage resting ahead of time.
- **Agree on what's most important to do.** Discuss what brings the most enjoyment or what is necessary to do. Encourage doing the things at the top of this list.
- **Avoid dizziness or falls by getting up or moving very slowly.** Dizziness can result from fatigue. When your child is getting up from lying down, remind him or her to sit on the bedside and dangle the feet and legs for a few minutes before

standing up. If this problem happens often, ask about safety equipment. Also see Safety Measures in the homecare plan section on Bleeding.

- **Plan regular exercise to reduce fatigue.** Plan activities to do every day despite the fatigue, even if it's something as small as getting dressed or walking out to sit on the porch. Short walks also are very helpful.
- **Serve regular snacks and meals.** Serve a well-balanced diet from the four food groups. Meat and dairy products provide needed protein. If finances are a concern, ask your dietician or social worker about nutrition programs such as WIC, which can help provide high protein foods. Another important food group is nutritious carbohydrates, which will give the most energy. Serve pasta, bread, fruit, and potatoes.

Promote rest and sleep

- **Keep as active as possible during the day so that normal fatigue sets in at night.** If your child remains active throughout the day, then sleep may be easier at night.
- **Resume usual patterns of rest and sleep as much as possible.** A regular schedule of naps and bedtime helps the child's body, because it comes to expect a routine. Regular habits help sleep.
- **Read the homecare plan on Parents' Anxiety if nervousness or anxiety interrupt sleep.** Anxiety interrupts rest and sleep. The homecare plan has some good ideas on handling anxiety. Talking to, touching, and listening to the child or adolescent also help manage anxiety.
- **Encourage rest when tired by going to bed earlier, sleeping later, and taking naps during the day.** If naps are a habit, then longer ones allow more rest and help to reduce fatigue.
- **Play relaxing music before sleep.** Use whatever helped to promote sleep before. Music can be very soothing. So can the voice of the television or of someone reading.
- **Drink warm milk at bedtime.** Milk contains tryptophan, an amino acid, which naturally promotes sleep.
- **Give a warm bath or back rub at bedtime.**

Possible Obstacles

Think of ideas or attitudes that might stop you from trying to solve a problem with tiredness and fatigue.

1. "The fatigue comes with the treatments. There's nothing we can do to help it."

Response: Cancer treatments often do result in fatigue, but you can control how tiredness affects your child's life. Showing this homecare plan to others will remind them that rest and sleep are very important now. You can try many techniques to help your child reduce a feeling of fatigue.

2. "There are many things to worry about. No wonder I can't sleep."

Response: Although this is less common in children than adults, sleep will help to reduce some of the anxiety in the long run because physical fatigue can add to feeling anxious and jumpy. Set a goal of better rest as one of your child's top priorities.

Carrying Out and Adjusting Your Plan

Keep track of how much of the day your child spends in bed. Ask him or her to assign priorities to activities and choose those that are important and rewarding. Check on whether current patterns of sleep and rest are similar to those before the illness.

If your plan doesn't work

If your plan does not seem to be working or the tiredness is getting worse, you can do several things. Ask yourself if you are expecting change too fast. It usually takes time for tiredness to go away. You can also develop a new plan by repeating the steps in this homecare plan.

If tiredness is increasing and of major concern to your child, ask the doctor or nurse for help. Tell them what you have done and what the results have been.

Hair Loss

[The information in this homecare plan fits most situations, but yours may be different. If the doctor or nurse tell you to do something else follow what they say.]

Understanding the Problem

Keeping a good appearance, even when one is suffering from a disease like cancer, can be very important to the young person with cancer. Some treatments cause hair loss seven to 14 days after treatment begins. Hair may not grow back for six to 12 months after chemotherapy; radiation to the head causes permanent hair loss. Hair that does grow back may have a different color or texture. You can limit the amount of hair loss and help the person live a normal life during this time.

What You Can Do To Help

Caring for the scalp is very important to decrease itchiness and dryness.

- Brush and wash away hair that is falling out.
- Gently clean hair and scalp with a mild protein shampoo twice a week, and massage the scalp.
- Use a protein conditioner, which adds body to fine or limp hair.
- Avoid harsh, damaging products containing bleach, peroxide, ammonia, alcohol, or lacquer.
- Avoid heat, curling irons, and hot rollers. Use the coolest setting on a blow dryer.
- Keep hair short and easy to style.
- To avoid breaking hair strands, avoid braids or ponytails, and use a wide-tooth comb.
- Ask the hair stylist about getting a permanent wave for thin hair during chemotherapy, to make it look fuller. (Avoid using a home permanent kit, however.)
- Postpone a permanent on new hair until after three haircuts or trims.
- Protect the head from sun with a hat and sunblock having SPF of at least #15.
- Use a satin pillow or a hair net while sleeping.
- Wear a hat or a head scarf to retain heat (and prevent dried-out skin) during cold weather.
- Wear sunglasses to protect eyelashes.
- Gently wash loose hair from arms, underarms, pubic areas; men should also wash hair from chest and face.

Getting a wig or head cover can preserve the person with cancer dignity and self-esteem.

- Ask a hair stylist about buying a wig. Some will come to your home or to the hospital.
- Call a wig shop in the phone book, and talk with professionals about wigs.
- Match a small lock of the person's hair with a wig color before starting chemotherapy.
- If you can't buy a wig, ask about borrowing one from the American Cancer Society.
- Before all the person's hair is lost, take the wig to a hair stylist to have it styled so that it looks like the person's hair.
- Practice wearing the wig at home.
- Return the wig to the hairstylist for repair or restyling.
- Wear turbans, scarves, or hats.

Possible Obstacles

1. "I can't afford a wig."

Response: Some medical insurance will cover part or all of the cost of a wig because it is needed after a medical problem. You might need a prescription; the doctor should write "wig for alopecia" or "full cranial prosthesis." Also, the American Cancer Society may be able to help with the cost of a wig. Local hair stylists may have free wig services.

2. "People say that he'll just have to live with being bald or having patches of hair on his head."

Response: Appearance can be very important to the young person with cancer. Don't try to second-guess your family member or friend on how he or she reacts to losing hair. Helping him or her look his or her best during a difficult time in life can boost spirits and confidence.

Carrying Out and Adjusting Your Plan

If possible, decide in advance whether the person with cancer wants a wig (many do not) and what kind, and order it as early as possible. Consider alternatives, such as hats, scarves, and baseball caps. Meanwhile, follow the steps in this plan to slow or minimize hair loss. If your plan doesn't seem to be working and hair loss is getting worse and you both feel badly about it, get help from a social worker, nurse, or hair stylist.

Promoting Independence

[The information in this homecare plan fits most situations, but yours may be different. If the doctor or nurse tell you something else, follow what they say.]

Understanding the Problem

When a child is diagnosed with cancer or any serious disease, it means changes and new routines will be entering his or her life. Visits to hospitals and treatment clinics will become part of the child's schedule.

A child frightened by these changes may "regress," or slip back to an earlier stage of development. Examples: A toddler who was recently toilet-trained may go back to needing diapers. A child who gave up bottle feeding may demand it again. A preschooler may resume thumb-sucking. A school-age child may resume bed-wetting. A polite teenager may grow demanding and hostile.

This is a normal phase that children will, in time, grow out of. In the meantime, it can take time for them to learn to be comfortable in a hospital or clinic.

You as a parent face a challenge. At a time when your normal instinct is to protect and nurture your sick child, you need to guard against letting him or her become too reliant.

This is a hard thing for many parents, because in the midst of a very upsetting time, caring for a child represents one of the few things over which you still have control. You can't control the cancer, or the cancer treatment, but you can control caring for your daughter or son.

You'll need to walk a fine line between giving and giving in. It's important to give a child options and choices, which promotes independence, yet resist the temptation to give in to every whim or demand, which emotionally hinders him or her.

Teenagers require special sensitivity, because this is a time of life when they're starting to exert their independence. While you naturally view your teenager as the infant you reared from birth and so your protective instinct is powerful, you may need to remind yourself to back off and give him or her time and space.

Your goals are to:

- call for help if it is needed
- prevent children from becoming over-dependent on you
- encourage children to develop a healthy independence as they work their way through treatment.

When To Get Professional Help

You should seek help from the doctor, nurse, hospital social worker, or counselor if any of the following is true:

- **If a child becomes uncooperative with treatment.** Usually, you or the medical staff will notice signs that a child is growing more reluctant. If your child is having a harder and harder time accepting something, ask the medical staff if some other

method or medicine can be substituted. If you're beyond that point, however, and your child refuses to cooperate, you need to tell the doctor or nurse right away.

- **If you see a sharp change in the child's personality and he or she doesn't snap out of this change.** If a child who is usually outgoing and friendly becomes withdrawn, or if a child who is usually quiet becomes angry and lashes out, that's no cause for immediate alarm. If the change persists, however, and the child seems to be unable to shake off that change, talk to the doctor or nurse.
- **If you as the caregiver feel as if you've lost control or lost the support you need.** If you or your child are extremely upset, get help now before it grows into a pattern. One way you can tell if you're at this point is if something that always worked before in dealing with your child no longer works. If you let the situation go, you'll be frazzled and burnt out, and will be unable to give the child your best care. The homecare plan for Parents' Anxiety contains some ideas on how to deal with stress, both for you and for your child.

What You Can Do To Help

- Preventing problems of over-dependency
- Dealing with dependency

Preventing problems of over-dependency

You can take several steps to promote independence and avoid a child's becoming too reliant on you.

- **Treat your child as normally as possible under the circumstances.** This is the single most effective way to foster a healthy attitude and self-image in a child undergoing cancer treatment. Of course, it's impossible to go back to the way things were before the diagnosis or the treatments, but maintaining a kind of normalcy isn't out of reach. If you suddenly change all the rules, your child may ask why and conclude that you know something very serious. He or she may think: "Why don't I have to do the dishes anymore? If they're being so nice to me, I must be going to die." If there's no physical reason a child can't keep doing chores around the house, insist that he or she continue to do them. If the child physically can't do so, find an alternative task.

Keep this phrase in mind: Independence equals hope. If you encourage your child to keep doing the same things as before, it inspires hope. You are sending a message that life will go on, that treatment does end at a certain time-whether the child is "well" or just well for a period of time followed by a relapse-and that there's reason for hope.

This issue extends to scheduling and daily routines as well. At certain times, children with cancer are vulnerable to viruses and it's advisable to limit exposure to other children or large groups of the public. But don't carry this to an extreme-if the doctor says it's OK for your child to return to school, don't hold him or her back out of misplaced fears over any cough, cold or flu that might come along. Being with friends and continuing or resuming a normal school routine promotes not only educational progress, but emotional and social development as well. If you're in doubt, ask the doctor.

Another reason is simply a quality-of-life issue-children who are spoiled really do not enjoy it.

- **Set limits on behavior.** Closely related to treating a child normally is setting or maintaining limits on behavior. If it wasn't OK for your child to hit her baby brother before she was diagnosed with cancer, it shouldn't be OK now. Impose the same consequences for unacceptable behavior as before. Ask yourself: How would I respond in this situation to my child if my child didn't have cancer? And then respond in that way.
- **Stay calm and avoid imposing your frustrations on your child.** At all costs, avoid threatening your child, such as by saying, "If you don't take this medicine, I'm going to leave," or worse, "If you don't take this medicine, you know you could die." The child may already be upset (for example, about taking an unpleasant medicine or sitting still for a painful procedure), so it's pointless to frighten him or her by introducing a new fear. A child can't focus on more than one crisis at a time. Reassure your child that your love doesn't depend on behavior.
- **Be honest.** It's very difficult for a parent to have to tell a child that he or she will undergo a painful procedure. But it's worse to deceive the child by pretending you don't know, or by saying it won't hurt much when you know (and the child will find out) that it hurts a lot. If you don't know the answer to a child's question about, for example, what's going to happen at the hospital today, say so. Or promise that as soon as you find out, you'll tell him or her. Broken promises and dishonesty will only increase a child's sense of frustration and feeling alone. Trust and confidence, on the other hand, will help a child mature far beyond his or her years in emotional and mental development.
- **Give choices.** Both at home and in the hospital setting, negotiating for a child to do something he or she hates to do can be a trying experience. Be creative by setting up choices rather than throwing down orders or ultimatums. Try some of these approaches, which have been used by parents and medical staff:

"You have to take the medicine. I know you don't like to do it this way, so what about another way? Can we coat the pill with applesauce or chocolate syrup? If you don't like taking a pill, how about a liquid?"

"We need to take this medicine by 2 o'clock-do you want to do it now or five minutes from now?" Or give the child a timer and say, "By the time this rings, you need to take the pills." Or: "By the time your favorite cartoon is over, you need to take these pills."

"Here are the three pills you need to take. Which one do you want to take first?"

This is true for older children and teenagers, as well. If your 17-year-old son wants to rearrange his chemotherapy treatment schedule to allow him to spend a long weekend at the beach with friends, there's nothing wrong with that.

- **Be liberal with praise.** It's easy to focus on the negative things, so make sure your child hears praise and positive comments as well. If a child has handled a couple of difficult procedures particularly well, make sure you say that you noticed. It will set the tone for helping your child cope with the same or other procedures later. Also, praise them for doing the normal things that have nothing to do with cancer treatment, as in, for example, "You did a good job helping with the dishes. Thank you."
- **Carefully plan a hospital stay.** Especially for younger children, a stay in a hospital can be scary. It may be the first time he or she is separated from parents. Try to ease into it by bringing familiar things from home, and photos of the family.

Get children involved with other activities in the hospital and establish a routine so

they know what's going to happen and when. Some children have difficulty being apart from parents, so if it's necessary, you can gradually increase your time away from the child, building up to an overnight separation. Remind your child that he or she can call you on the phone. Arranging for other relatives or friends to visit when you can't will help provide some security. Teenagers, on the other hand, take a different approach. They won't want you to hover (see "Give Teenagers Space and Time," next page).

- **Phrase requests positively.** Some treatment procedures will be unpleasant or painful. You may need to help get your child to do something he or she doesn't want to do. Rather than threaten by saying: "If you don't hold still, I'm going to have to hold you down," rephrase the identical message in a kinder way: "You need to hold still and if you can't hold still, I'll help you."
- **Recall what worked in the past.** Try to recall how your child coped with stressful events in the past—a school play or sports competition, for example, or a previous hospitalization. If medical staff members haven't already asked, let them know how your child normally handles stress or new situations, so they know what to expect and how to best talk with your child.
- **Encourage your child, especially a teenager, to learn about his or her condition and participate in decisions about care and treatment.** Make your child a central part of the planning and decision-making for treatment and care. When the doctor comes in, encourage your child to ask the questions rather than you posing them for him or her. Instead of saying, "This is what Michael wanted to know," say: "Michael, what did you want to ask the doctor?" Encouraging the child to respond directly and take part will help restore his or her sense of control.

For older children—that is, from school age on, and especially for teenagers—encourage them to learn about their disease and to talk with others their age who have cancer, so that they hear how others have dealt with it. Ask the staff if any other current patient in the clinic or hospital has had a similar problem, and find out if a meeting can be arranged.

It's common for teenagers to withdraw and feel that they're facing this all alone. In addition, they understand more than young children and have a concept of the finality of death.

In any case, this principle holds true: A child who is better informed will respond to treatment better.

- **Give teenagers space and time to be alone, and encourage them to maintain friendships.** Don't suffocate your teenager with 24-hour round-the-clock vigils. He or she needs time alone. Before the diagnosis, you didn't spend every single moment with your teenager, so it's unnatural to do so now.

Cancer and cancer treatments represent an intrusion into a teenager's life. Just at the point when they're preparing to take greater control and become independent by growing toward adulthood, a cancer diagnosis rips control from them. This is why it's helpful to keep conditions as normal as possible.

Encourage friends to visit. Consider rounding up your teenager's friends (especially those who can't yet drive) and driving them to the hospital for a day-long Saturday visit. While they spend time together in the lounge, for example, you and a spouse, family member, or friend might visit in the room, in the cafeteria, or in another area. This achieves several goals—you're keeping a presence without intruding; you're demonstrating to your teenager that you take seriously his or her need for friends

and are willing to help, and you're also serving your own need to be near (if not right beside) your teenager. Keep things in perspective-you can visit one-on-one on another day; your teenager's friends, who, unless it's summer, probably have school obligations, may not have that opportunity.

Dealing With Dependency

If your child has already slipped into a type of dependency, or his or her behavior shows backsliding to an earlier period of development, you can take steps to steer the child back toward independence.

- **Be patient.** Understand that this is a normal pattern and that putting added pressure or stress on yourself or your child may only prolong the behavior. Try to hold reasonable expectations of the child. If a child has just gotten off bottle feeding and has to begin the unfamiliar routine of cancer treatment, he or she may want the bottle again. That's OK-in time, the child will get back on track and resume normal feeding.
- **Maintain routines.** As much as you might be tempted to feel sorry for your child and relieve him or her of household chores, you'll promote a sense of normalcy by keeping the same routine as before. If a child is physically unable to continue some task, such as washing dishes or taking out the trash, find a substitute activity, such as doing light dusting or sorting and opening the mail.
- **Offer choices where possible.** If your child is feeling no control over anything, try to give control back by offering choices, even in small things such as what to wear, when to eat, and when to exercise.
- **Phrase requests in a positive way.** Some treatment procedures will be unpleasant or painful. To gain ideas on how to deal with this, observe staff members who are successful in getting children to comply with their requests without being threatening. At home or in the hospital or clinic, you may be called upon to get your child to do something he or she doesn't want to do. Rather than threaten by saying: "If you don't hold still, I'm going to have to hold you down," rephrase the identical message in a kinder way: "You need to hold still and if you can't hold still, I'll help you."
- **Praise a child for positive or constructive behavior.** Just as with prevention, this technique can help you guide a child out of dependency by reinforcing good or acceptable behavior. If a child handles a procedure well, make a point of noticing it and telling him or her about it.
- **Stay attuned to your child's emotional state.** If your child isn't talking about what he or she is feeling, it may help for you to talk about it, such as by saying: "You're really scared about these things, and that's normal, you would react this way, being in the hospital is very scary, and it is upsetting." If you hit the nail right on the head, your child's probably going to think: "Oh, that's right, I do feel this way," and may go even further by explaining it. It also shows your child that you understand him or her.
- **Recall what worked in the past.** Try to recall how your child coped with stressful events before the cancer diagnosis or treatment, or with other hospitalizations. That may give you clues for how to get him or her to handle this situation.
- **Remain open to staff members' advice, even if it is blunt.** Parents usually know what's best for their children, but the blur of events surrounding a crisis illness can sometimes cloud their judgment. Don't be offended if a doctor, nurse, or hospital social worker takes you aside and says, "If you don't stop giving Jennifer everything she demands, she's going to become a spoiled brat." This observation very likely is based on years of experience with hundreds of parent-child relationships. If a staff member says this to you, chances are good that it's true.

- **Understand that teenagers may seesaw back and forth between dependency and independence.** For teenagers, before the diagnosis and treatment, they were increasingly making decisions themselves and becoming more independent. Now their parents may be giving them directions and orders, as if they were little children again, perhaps telling them they have to go to the clinic at a certain day and time. You may find that your teenager, seeking security, wants to be nurtured and comforted, or that he or she swings back and forth between wanting nurturing and wanting independence. Through all of this, your instinct will probably be to play nursemaid, but don't smother him or her. Encourage as much independence as you find is healthy for both of you. Remember that going back and forth is OK as long as your teenager doesn't get stuck in an attitude of dependency.
- **Make sure you're meeting your own needs.** It's so easy to get wrapped up in your child's situation that you neglect your own needs. Make sure you're getting time to rest and recover. Also, ask the medical staff about support groups or coffee hours, which some hospitals or clinics offer on a weekly or monthly basis. Some include participation by "veteran" parents whose children have undergone a regimen of medical care and are now off treatment.

Possible Obstacles

1. "In our family we've never told children about things like this. I just can't bear the thought of breaking the news to my daughter that she'll have to go through a very painful set of treatments."
Response: Honesty is still the best course. Children will grow and mature emotionally and mentally if you treat them honestly. Care seems to go more easily and produce better results when a child knows in advance what's going to happen. If your family background, culture, or religion hasn't traditionally encouraged openness, talk it over with medical staff members. They may be able to direct you to a family with a similar background who has experienced this situation and could share how they handled it.
2. "My son may not make it and so I want to spend the time I have with him, and I don't want to feel guilty for having disciplined him."
Response: Your son may indeed survive and if you spoil him now, you'll have far more work undoing this behavior in the future.
3. "I'm keeping things under control, but Melissa's grand-parents seem to want to give in to her all the time."
Response: If you can't seem to get your relatives to treat your daughter normally, ask the staff to speak privately with the relatives to explain why giving in to your child's demands isn't healthy for her emotional growth. Hearing it from someone in authority may make an impact.

Carrying Out and Adjusting Your Plan

Is your child learning to do without your constant presence? If you've noticed behavior from an earlier age returning, is he or she gradually easing back to normal?

Consider medical staff members to be a resource, because they see children with cancer and parents interacting every day. The variety of personalities is endless, but they will have a good idea of what your child might need to help grow into a healthy state of emotional independence.

If your plan doesn't work

Review the sections When to get professional help and Dealing With Dependency to make sure you haven't overlooked anything. If your child still insists on behaving in a younger way, or if you feel that you've reached the end of your rope, call a doctor, nurse, hospital social worker, or counselor and get help.

School

[The information in this homecare plan fits most situations, but yours may be different. If the doctor or nurse tell you to do something else, follow what they say.]

Understanding the Problem

School is an essential part of a child's life and well-being. It's important to maintain the continuity of education even if the type of schooling varies. To promote a sense of normalcy, you as a parent should see that education continues as smoothly as possible, both for learning and for social reasons such as maintaining friendships.

Cancer treatments almost always disrupt schooling. Depending on the severity of the disease and the schedule of treatments, a child could be out of the classroom for a week, or for many months. A child may return to school but need frequent absences to go to a clinic for continuing treatments. Or a child's physical condition and energy may fluctuate, meaning that he or she may be in school only intermittently.

If your child is too weak to attend school, or if he or she is especially vulnerable to virus and infection, homebound instruction may be needed. Finally, if a child is hospitalized for an extended time, an in-house teacher may be available to continue his or her lessons in the hospital.

As soon as your child's condition is known, you should get a note from the doctor explaining the diagnosis and the need for being off school so that teachers and school administrators can, as soon as possible, begin to prepare for sending work home or arrange for tutoring.

The best situation is if a child can return to his or her own classroom, and you should work toward this as soon as the doctor says it's medically feasible.

Not all of the changes that a child undergoes as a result of getting cancer are negative. By getting support from parents, teachers, and classmates, by facing and overcoming obstacles, and by learning to accept and process difficult news, many children can grow and mature socially and emotionally far beyond their years. Sometimes children even choose careers in health care as a result of undergoing cancer treatment.

Your goals are to:

- call for help if it is needed
- maintain as much normalcy as possible in your child's school life
- avoid problems at home
- get help from educators when it is needed

When To Get Professional Help

You should seek help from the hospital social worker or counselor if any of the following is true:

- **Your child resists going to school.** If your doctor has cleared it for your child to return to school and the child resists but won't talk about it, you may need to find the underlying reasons. A hospital social worker may be able to talk with your child and find out if he or she is upset about feeling different, about looking different, about losing friends because he or she has been away for so long, or a host of other reasons.

- **If your child is having problems at school.** If your child is having problems at school that he or she didn't have before getting cancer, you'll need to learn more about them to resolve them. Your child may be upset about missing so much school and feel that it's hopeless to catch up in the curriculum, or he or she may be facing annoying reactions to physical changes in their appearance from other students. A hospital social worker, the school nurse or guidance counselor, or a combination of several of them may be able to work out a solution, either for issues like arranging tutoring or for personal issues. Social workers, for example, can suggest responses that are appropriate to give to someone who makes fun of a child's appearance. See Prepare your child emotionally upon returning to school
- **If the school system's bureaucracy is overwhelming and you can't seem to make any progress in getting what your child needs.** Members of medical staff, as health-care professionals, are your best allies to accomplish something for your child if the school bureaucracy is an obstacle. Most educators are eager to accommodate your child's needs and, in fact, want them to be educated either in the classroom or through tutoring. While most children can resume learning in their regular classroom setting, keep in mind that federal law-Public Law 94-142-protects a child's right to an alternative education. While it is written primarily for handicapped individuals, its provisions mandating the development of Individualized Education Plans (special education) include health-impaired students, such as anyone with cancer. If you encounter attitudinal obstacles, persist until you find someone who can help. As an extreme and last resort, if you've run out of options, consider (by yourself or with a medical staff professional) going outside the administration and seeking help from an elected school-board member. An inquiry from a board member sometimes carries weight that one from a parent or taxpayer does not.

What You Can Do To Help

- Making arrangements with schools
- Avoiding problems at home
- Getting practical help from the school upon your child's return
- Prepare your child emotionally upon returning to school

Making arrangements with schools

- **Make certain that school continues to be an important part of your child's life.** If a child's disease requires extended hospital stays or frequent absences from school, it's easy for parents to give up, figuring that it will be impossible for the child to keep up with the rest of the class. It's also easy to fall into a negative trap of thinking, "If my child has cancer, she has no future, so why should I worry about school?" However, for both educational and social reasons, it's vital that children maintain contact with their school, teachers, and friends. It's also important because the routine promotes a child's sense of life being normal, or as normal as it can be under the circumstances. School is a child's equivalent of a "job" or "work." Without it, most children will feel as if they are lost or don't fit in, or are academically and socially inferior. One way to prevent uncertainty in your child's mind is to simply state, as early as possible and as early as you know details, that he or she will definitely be going back to school. If your hospital has in-house teachers who help children while they're staying there as an inpatient, make sure you let the child know about that and tell him or her what to expect.
- **Establish a working relationship with school officials early.** It's important to work together early on with teachers and administrators, letting them know what they can expect in terms of attendance and absences, and the child's general health.

This is especially true if a child is having difficulty at school, either educationally or socially. One step you can take to help create the right attitude among school staff is to practice using and promoting the term student to refer to your child, rather than patient. This simple shift of terminology underscores what your child can do, not what he or she can't do. It also casts members of the school staff in their intended role as educators, rather than as teachers trying to play part-time nurse.

- **When your child misses school, make sure that a hospital social worker contacts the school to arrange both continuity of schoolwork and continuity of social contact with the child's classmates.** Hospital social workers, in particular, are trained in coordinating school needs and schedules with a child's medical treatments and serving as intermediaries. Social workers also can help arrange for a child to make a social visit to his or her school, even if it's not yet possible to return full-time. In addition, they can talk with not only teachers and administrators but also other students to explain the child's condition, what to expect of him or her, and what they can do to help the child and preserve the link between child and school. This might include arranging for your child's class to send cards, send videotaped personal greetings (and arranging a return video greeting from the child to the class), or even having the teacher visit your child in the hospital. Especially if your child will be in and out of classes over an entire school year, it's important to maintain that connection.
- **If you need help from the medical staff in dealing with school rules, ask for it.** Some school districts may have regulations that were written for situations other than chronic illness, and you may need help seeking flexibility. For example, some districts require a child to be out of school for two weeks before they will authorize tutoring or homebound instruction. You child may not be off school for two weeks at one stretch, but instead may miss two days here, four days there, accumulating much more than two weeks of absences in the course of treatment over a school year. The hospital or clinic staff can help explain this to school administrators, who usually are understanding and flexible. If a child is in and out of school, some districts even provide in-school remedial support to help him or her through the disruption.

Avoiding problems at home

- **Pay attention to the doctor's recommendation on returning to school.** Many families are cautious and want to protect the child who has cancer. When a doctor says it's OK for the child to go back to school, that doesn't usually mean it's optional—the meaning usually is that the child **should** go back to school for both educational growth and emotional well-being.
- **If you have a job and have taken time off to care for your child, you should go back to work.** Even if it's on a part-time basis, go back to work to demonstrate to your child that life goes on. If you stay home and keep your child home when he or she is capable of returning to school, it's unhealthy emotionally for both of you.
- **Be sensitive to the needs of your child's siblings who may be in school.** Make sure that teachers of your other children know what's going on with the child who has cancer, because it can affect both their classroom performance and their emotions. For example, if the child is having a hard time with treatment, is undergoing surgery, or suffers a relapse, teachers of the siblings should know. Also, siblings who attend the same school may grow weary of other students continually asking them about the sick child, never about them. They also may resent being constantly reminded of the situation. Siblings also may feel the loss of their identity if teachers rely on them to ferry books and homework assignments back and forth. One way to turn this around is to praise them, thank them, and remind them what

an important job they are doing in helping the child with cancer.

Some siblings have chosen to express their thoughts and feelings about a brother's or sister's cancer by doing a science report or project on the disease and treatment. You might consider suggesting this to a sibling, but gently, and with plenty of other alternatives. For more detail, see the homecare plan for Brothers and Sisters of Children with Cancer.

Getting practical help from school upon your child's return

- **Prepare your child, and school officials, for the practical side of returning to school.** If the child needs minor medical assistance at school (for example, in taking medications or maintaining a catheter), meet with the school nurse or other officials to see that someone at school can help handle these situations. Officials also should be alerted that a child with cancer is especially vulnerable to infection from common childhood diseases such as chicken pox. If your child can't move or walk as easily as before, make sure he or she can leave class five minutes early to get to the next class on time. If your child tires easily, make sure he or she knows it's OK to lie down in the nurse's office to rest. On the other hand, make sure school officials don't let the child abuse this privilege and skip out of class or work when he or she isn't tired. Similarly, school officials shouldn't be afraid and oversensitive by, for example, insisting on sending the child home immediately if he or she is running a slightly elevated temperature of 99 F. Try to get the school to treat your child normally, as a student, and not as a patient.
- **Pay special attention to maintaining continuity of learning for an adolescent.** Children of any age benefit best from uninterrupted learning, but a practical aspect of attendance is that an older child stands to lose more from absences or missed homework than a younger child. An adolescent who is inadequately educated in 11th and 12th grades will be a poor candidate for college or a poor prospect for the job market. Ask educators to remember this as you seek their help in easing your adolescent back into the school routine.

Prepare your child emotionally upon returning to school

- **Coach your child to be prepared for the reactions of others on his or her return to school.** Things won't be the same when your child returns to school and he or she needs to understand that others may react unpleasantly to physical changes caused by treatment or surgery. Students or even teachers or school staff members may stare without saying anything. Other reactions might be pointing, or snickering. You should tell your child that when this happens, one of two things can occur. If your child feels comfortable talking about it, he or she could be ready to explain the reason for the changes. One opening might be: "I bet you're wondering why my hair is gone," or "Are you wondering why I don't have any hair?" A follow-up response might simply be: "I have cancer. I take medicine for it, and the medicine makes my hair fall out. My hair will come back when I'm finished with the medicine." On the other hand, if your child doesn't want to talk about it, such as might be the case if a stranger walks up on the street and asks about the lack of hair, he or she may simply wish to say: "I'd rather not talk about that." Either of these is better than a nasty retort, such as "None of your business" or "Buzz off."

Physical changes may not be restricted to hair loss, which is the most widely known side effect of cancer treatment, but also can include puffiness from being on steroids, a gain or loss in weight, bruises, scars or amputations, limping, or a loss of energy. Also, these changes may mean the child will have to live with restrictions on

activities like gym class, or contact sports or other outside activities. If you haven't already done so, ask a hospital social worker to coach your child in how to explain these physical changes to other students so they understand.

- **Make sure your child doesn't use the disease as an excuse to take it easy or not work up to potential.** Some children can be tempted to use the fact that they have cancer as an excuse to take it easy, to not work up to their potential, or to stay home from school. One good clue for you, as a parent, is whether your child tended to do this before the cancer diagnosis and treatment. Sometimes a child asks to stay home from school, saying that he or she just doesn't feel good but without identifying a specific pain or problem. You, the parent, have to make the call, but be aware that nothing may be wrong. Also, be aware that your child may be embarrassed to go to school for the reasons noted above-physical changes and a fear of others' reactions. If this is the case, consider asking the hospital social worker to arrange a school visit to explain the disease and its treatment and effects.

Possible Obstacles

1. "I'm so afraid of losing my child, I don't want to send her back to school. My highest calling as a parent is to stay home and take care of her."
Response: If the doctor says a child is well enough to return to school, you should follow his or her directions. Emotionally as well as educationally, the most healthy situation is for a child to be learning among peers.
2. "The cafeteria aides at my child's school are saying that cancer is contagious and that other students shouldn't eat with him."
Response: Misinformation and rumors can really disrupt a child's successful re-entry into school. A one-time comment is nothing to become alarmed over, but if this pattern persists and your child is being affected by it, try to arrange a school visit from the hospital staff.
3. "Kids at school are making fun of my child's bald head."
Response: Re-read the section on preparing your child emotionally for returning to school and review the responses with your child to make sure he or she understands what to say to counter or soften attitudes.

Carrying Out and Adjusting Your Plan

Is your child's education going forward as well as can be expected under the circumstances? Are you successfully working with the school staff and hospital staff to make the transitions as easy as possible? Is your child readily going back to school, or reluctant? Is your child getting class work and homework completed? Are his or her grades about what they were before the diagnosis and treatment? If they're not, is it because of absence only, or because your child is discouraged?

If your plan doesn't work

Review the section When to Get Professional Help to make sure you haven't overlooked anything. Otherwise, call the hospital social worker and explain what you have done and why it seems not to be working.

Helping Brothers & Sisters Cope

Understanding the Problem

Brothers and sisters of a child with cancer go through a big adjustment of their own while their sibling is diagnosed, treated, hospitalized, and brought home again.

The times that are most upsetting to the young child with cancer may not be the most upsetting times for siblings. For example, the first days of a diagnosis are very upsetting to children with cancer. They undergo many types of tests, some of them painful or scary, and they go to new places and meet many different people. Brothers and sisters, on the other hand, may have difficulties that worsen over time as they adjust to their sibling's illness.

The many reasons for this include:

- The household stays on a different schedule and doesn't seem to return to normal.
- Everyone (parents, relatives, friends, teachers, etc.) focuses attention on the child with cancer.
- As a result, parents spend less time with other children in the home.
- Siblings may see their parents in a new and disturbingly very sad, frightened, and confused.
- Brothers and sisters often believe that they will also get cancer.
- As the illness progresses, parents hope things at home will get better. However, the behavior of the siblings may not improve. They may do things to shift attention back to themselves, express their feelings, or start acting like they did when they were younger. These changes can take parents by surprise.

Some common reactions of children when a sibling has a serious illness such as cancer:

- **Acting younger.** Brothers and sisters may act younger than usual. Most children, especially those between 3 and 6 years old, won't talk about their feelings but they will show their feelings in their actions. You can expect to see changes in their behavior. Children who were potty trained may wet their pants again. They might become more active and jump around more than usual. They may be uncooperative and less obedient.
- **Problem behaviors.** Not all changes in behavior come as a result of a sibling being treated for cancer. Still, you may find increased fighting, yelling, or staying away from other family members and friends. These problems may occur outside the home, such as at school or church. Children may break things, or they may abandon former activities, sports, or hobbies; come home late; or refuse to help with chores. These attitudes may be more likely when the sick child is staying in the hospital.
- **Emotions.** New and confusing emotions may arise. Old feelings, such as jealousy or anger, can also show up more strongly or more often because the siblings are getting less attention than before, their normal routines are disrupted, and many of their usual ties to family and friends are changed. Resentment is common. Parents and other adults focus more attention on the sick sister or brother. For example, brothers and sisters find that classmates, playmates, and teachers always ask how the sick child is getting along, but don't ask how the sibling is doing. It's only natural for them to feel left out and resentful. Another reaction is sadness. Brothers and sisters may feel sad or depressed and may withdraw from family, friends, or favorite activities.
- **Complaints of illness.** They may complain more about physical illness, but you may have trouble finding evidence that something's really wrong. If you take a temperature or look for a red sore throat or runny nose, you may not see an actual sign of illness-the child just says he or she doesn't "feel well." He or she may not

want to go to school that day, or may not want you to leave to go to the hospital or a clinic appointment. Examples of common complaints are headaches, stomach aches, disrupted sleep, or a lack of appetite. If these were common before, there may be an increase in complaints or in their severity. Illness complaints are one way for a child to ask for attention.

- **Self-blame.** Siblings sometimes blame themselves for the problem of cancer and then feel guilty. Children often blame themselves for family problems such as divorce and separations, and it's true for illnesses as well. Brothers or sisters might think that something they did caused the cancer. They may also feel guilty about bad feelings they have about their sister or brother with cancer.
- **New fears.** Your children may develop a new fear, thinking that they are also going to get cancer. Actually, this happens rarely. Reassure them but remind them to tell you about any new problems, such as trouble sleeping or headaches or not feeling well, so you can help them when they need you.
- **Trying to act "grown up."** Sometimes children who see their parents under a lot of stress will try to be "grown up" so their parents don't have to worry about them. If this goes on for a long time, they may miss important parts of their childhoods.

You will be better able to deal with these problems if you understand and appreciate why your children behave as they do.

Your goals are to:

- seek information and support with problems with your other children
- know when to seek professional help
- to be prepared to cope with behavioral problems, emotional upheaval, and physical complaints

When To Get Professional Help

If the brother or sister has any of the following symptoms or behavior problems, you should get help from a professional experienced in helping children and families under stress.

- **The brother or sister's behavior changes markedly, including become self-destructive.** Children who are depressed often show it rather than talk about it. Self-destructive behavior is one way to say, "I'm so sad and depressed that I don't care." Hurting themselves by doing very dangerous things, or getting into serious trouble at school, or even staying in bed all day and forgetting all their responsibilities can be signs that they are giving up.
- **The brother or sister begins to harm someone else.** Sometimes children learn ways of seeking attention or distracting themselves that may hurt others. An example is becoming hostile or aggressive toward the sibling with cancer, or taking out their feelings on the family pet. Since someone (or the pet) is at risk for being hurt, seeking help is very important.
- **The brother or sister becomes very destructive.** Although a few tantrums can be expected when children are feeling confused or frightened, extreme acts of destruction, such as continued breaking of items, or any incidence of fire setting, should be a signal to seek professional help.
- **Severe physical problems develop, such as nausea, vomiting, or fever.** Physical problems should be treated by a physician at once.
- **The brother or sister asks for professional help.** If your child wants to "talk to someone just for me," or says, "I can't stand this anymore," or "when do I get to have special attention," he or she may need individual help. Talking privately with your child may be the first step in finding out that they would benefit from some brief professional help.

- **The brother or sister talks about suicide or wanting to die.** Thinking about suicide is always a serious problem that needs a professional opinion. Psychologists, social workers, and child life specialists are trained to identify serious depression and suicide risk in children.

When you have tried everything you can, including suggestions in this Homecare plan and strategies that have worked in the past, and you still feel helpless or hopeless about your ability to cope with these family problems. After all, you are the "expert" on your family. You are the one who will know when you have tried as many helpful suggestions as you can, or when your child's emotions are out of control.

How to get professional help

Asking for professional help. Getting help for family problems is like getting help for physical problems. Some parents hesitate to ask for professional help for their children's emotional problems. They may think that seeing a psychologist, psychiatrist, or social worker means they are weak or strange, or that they have failed as a parent. Being upset during a major illness is normal. So is getting help for these problems. Professionals, such as social workers, nurse counselors, clergy, psychologists, psychiatrists, and child life specialists are skilled and experienced in helping people deal with emotionally stressful experiences, just as your family doctor is there to help with physical problems.

Ask for help from professionals such as social workers on the pediatric oncology team who know how to help families deal with the stresses of the illness. Other sources include child psychologists or psychiatrists, social workers who specialize in family problems, or school counselors. These professionals have worked out many solutions that might help. A good person to ask for contacts would be the social worker or nurse that you feel most comfortable with.

Helping children deal with stressful feelings takes time. It will usually take several sessions with a counselor or therapist before problems seem to get better. Some people get worried when a sibling starts to talk about feelings of fear, anger, or resentment because it sounds like worsening of the problem. It is important to remember that bringing a problem out is often the first step in solving it.

What You Can Do To Help

- Seek help in understanding your other children
- Anticipate behavior problems, emotionally upheaval, and physical complaints
- Prevent sibling problems from becoming severe
- Help siblings deal with their feelings

Seek help in understanding your other children

- **Talk with a child life specialist, social worker or nurse, or a child psychologist, about how to understand the behaviors and feelings of your other children.** Get to know the other health professionals where your child receives care. Don't wait until a doctor or nurse recommends that you see them because of some problem. Seek them out yourselves.

Pediatric oncology social workers and pediatric oncology nurses, and child life specialists can help you understand sibling behavior problems. For example, a young father described an event that upset the whole family during what should have been

a happy day. His 7-year-old son with cancer had just returned home from the hospital. Within minutes, the boy's 12-year-old sister refused to help with dinner for visiting relatives. This was a big change as she used to be obedient and cheerful. Feeling left out, she was resentful and angry. The parents took a photo of her brother-but not her-at the front door. A favorite neighbor played ball with him, but ignored talking with her. When the daughter was asked to feed the cat and help with dinner, she refused. Her parents became angry and sent her to her room. The father was relieved when a social worker told him that many siblings react this way.

- **Ask if the hospital or clinic has a special program for siblings.** Most children with cancer are treated at special childhood cancer treatment centers. Many siblings confide in the health professionals who they feel most comfortable with. Staff members at these centers understand the problems of the family, and also realize that this time is especially hard on siblings, so most offer special group meetings for sisters and brothers. An example might be a day-long workshop to learn about cancer, its treatment, and its problems. Siblings get to talk about their own family experiences and share their thoughts about coping with all of the changes in the family. Programs like these help siblings feel less alone, get ideas on how to handle change, and get to know hospital staff whom they could turn to when they are having trouble coping.
- **Meet and talk with other parents of a child with cancer who also have other children.**
- **Find or start a support group in your local community or county for parents of children with chronic illness.** Support groups are usually held monthly somewhere near you, even if you live in a rural area. If you live in a city, the support group can be just for parents of children with cancer. In a rural area, the group could include parents of children with many different types of illnesses, such as cystic fibrosis, respiratory disease, deafness, blindness, or diabetes. These groups can really help. Information is given on local transportation help, help in the home, or financial assistance. These groups also deal with family problems, including helping siblings cope. Along with education, the social time and sharing time with other parents can be very supportive. Through this group, many people have become lifelong friends.

In a few cases, some parents have found these support groups to be unhelpful. Parents can be constructive in a group or not help at all. It really depends on who is leading the group and what the person's intentions are. You are the best judge of what helps you, but meeting and talking with other parents at a group will allow you to find support and information that won't come to you any other way. Some of these parents may have other children who are the same age as your own, and getting them together can be a great way to help all of your other children cope.

Anticipate behavior problems, emotional upheaval, and physical complaints

- **Write short instruction sheets on how you want relatives and teachers to help with any problems.** Many relatives and friends will naturally give their attention to the sick child. It often helps to write instructions for them stating the problems you are having with the sibling and what you want them to do when they witness problem behaviors or emotions. This saves you a re-explanation every time you see relatives and friends and the problem is routinely treated the same way.
- **Hold a family meeting to create an atmosphere where everyone gets to talk about how they feel.** Explaining what is happening with the disease and treatment, allows family members to express worries or complaints about household affairs. Have some ground rules such as no punishing during the meetings and that everyone will get equal time to talk.

- **Prevent sibling problems from becoming severe**
- **Encourage the child with cancer to share toys and gifts and let the parents spend time with siblings.** The child with cancer is still a family member and needs to feel like one. Being asked to share possessions and events and time with parents puts this child back into the family. This reminds the child that rules still apply.
- **Explain to your other children why you can't spend as much time with them.** Be honest with your children and tell them that the next few days (or weeks) will be very hard for their sister or brother so parents have to be away from home to help the child with cancer get through a tough time. Because children feel most secure when life follows a predictable course, he or she will also want to know when you'll be back home and when life will be more normal.
- **Schedule special time on the calendar with other children to do fun things.** Get a calendar for your children and mark off days and times that you will do things with them. If there is a special show or public event that they want to see, try to go with them or have a favorite relative go with them. Keep your appointments with them even if you have to change plans to do something closer to home or near the hospital. A child who is feeling lonely or left out will remember every broken promise.
- **Explain and leave notes about who will be at home, when others will be at home, whom to call with problems, and what to eat for snacks if hungry.** A list reassures the children about the next week's schedule. They can refer to it when in doubt. The best place to put the list is on the refrigerator or a kitchen cabinet. Even older children, such as teenagers and young adults, need these guidelines because they may not remember what you told them and they do not want to shoulder all the responsibility of running the household when you are away.
- **Continue setting limits.** You may feel guilty about the fact that your child has cancer, and find yourself thinking, "If only I had done something different, he or she wouldn't be sick." Such feelings and thoughts are normal, but they are intensified when you feel that you can't handle your other children well. So to adapt, you change the rules. If you were strict, you get softer. If you decide that you weren't strict enough, you double the number of rules. Find a balance among basic guidelines for their day and set rules about bedtime, mealtime, homework, and recreation. Your children will appreciate the boundaries if you stick to them consistently.
- **Take siblings into the hospital and clinic so they can learn about the disease and what it's like to have cancer.** Take siblings to hospitals and clinics so they can see the child with cancer get through the appointments and tests. They can also see that having cancer is not all fun and games. After attending clinic evaluations, tests, and medical "play" sessions with child life staff, they might better understand the problems the child is going through and be less jealous of the attention the illness brings the child. They also might be able to ask better questions about what is happening after they see the inside of the hospital, doctor's office, and waiting rooms.
- **Ask grandparents and family members and friends not to forget the other children.** Relatives may focus their conversation and lavish gifts only on the child with cancer. Remind them about how hard it is for the other children at this time and that these children need to be remembered too, through conversations, cards, and small gifts. Ask school nurses and teachers to help. Explain what is going on at home to the school staff. School nurses will then understand if your child keeps showing up in the clinic with headaches or other complaints. If they know you want them to be involved, teachers will watch for problems.

Help siblings deal with their feelings

- **If the sisters or brothers of the child with cancer are young, have them make a "feeling bag" or other art project as a way of telling you about their emotions.** Young children can create a "feeling bag" by decorating the outside of a paper bag with pictures from magazines and pasting on the outside of the bag all the parts of themselves they show to others. You can help them put inside the bag pictures that represent the feelings they "keep inside." This simple activity often helps children express and understand their feelings.
- **Catch children doing good things and compliment them on good behavior or handling difficult emotions or situations.** If you set up a reward system for good behavior, you'll watch the good things and focus on their positive side. For every thing you criticize them for, find other things to compliment, such as bringing dinner dishes to the sink, or entering a room without interrupting an adult conversation. This will help them feel good about them-selves and about their relationship with you. Focusing on negative things makes everyone feel discouraged and less hopeful that you can cope with the new changes.
- **Teach children who are old enough specific ways to cope with the challenges of the illness.** Children can practice stress management just like adults do. You could help them learn to take a deep breath and relax when they feel the pressure mounting. Encourage outdoor exercise, or exercise with them.

You can also try to help them cope by teaching basic problem solving steps: collect facts before jumping to a conclusion or before giving up, plan what to do to deal with a problem, try different ways to solve the problem, and decide how well these actions worked. Parents could sit down and map out a plan with the child about changing problem behaviors.

Possible Obstacles

Think about attitudes or ideas that could prevent you from following the ideas in this plan to help siblings cope.

1. "I feel embarrassed that I can't deal with my other children."
Response: You should not feel embarrassed because the whole family is under stress and not all of the problems with your other children are solely your fault. You will find that almost everyone will be very understanding about this.

It would help to talk to other parents of children with cancer. You'll realize that they've asked for help from child life specialists, social workers, teachers, school nurses, and other relatives, and that they were helpful.

2. "Cancer is such a dreaded disease, and my child could die. I need to spend my energy on helping my sick child."
Response: The doctor and nurses will give your sick child all the medical help needed to fight the cancer. Depending on prognosis, the child may or may not survive. But you must remember that no matter what, you are still a family. Withdrawing from the sick child's brothers and sisters will only make an already tense time more difficult.

Carrying Out and Adjusting Your Plan

1. Plan in advance how you will deal with problems that may arise.
2. Keep alert to signs that the illness is affecting other children in the family.
3. Put yourself in their shoes and try to understand why they are feeling or acting this way.

4. Review this homecare plan for ideas for helping them deal with this illness. Ask other parents for suggestions. Think back to similar situations in the past and try to recall what worked then.
5. Be realistic in your expectations. It's normal for children and for parents to have problems coping with this illness. Don't expect to eliminate problems. But you can notice them early, which is when they are the easiest to deal with. Also, progress may be slow, so be patient. Even if the problem persists, your efforts may be preventing it from getting worse.

If your plan doesn't work

If you feel that you've run out of ideas, or if the problems seem so great that you can't deal with them, you should get help from other people.

Social workers, child life specialists, or nurses who are experienced working with children with cancer and their families are a good source of ideas and guidance. Mental health professionals such as psychologists or social workers who specialize in family and children can also be helpful. Clergy, teachers or school counselors often have wide experience with families under stress and can be helpful in providing guidance.

Problems Paying Expenses

[Good problem solving requires a calm, positive attitude. If you are very upset or discouraged, ask a friend, neighbor or family member to help you.]

Understanding the Problem

Financial problems can cause considerable concern and add to the burdens of dealing with this illness. People are often embarrassed when they have financial problems and so don't seek the help they need or else they wait until their financial problems are overwhelming before seeking help-which makes them even more difficult to solve.

Medical treatment for cancer is very expensive. It is common for families to have large expenses, especially if their insurance is limited. If you are worried about paying your medical bills, you are not unusual. However, there are important options for you to know about. Don't wait until you are overwhelmed. Remember that your child is a pediatric oncology patient at Hershey Medical Center and that there is special funding for medical treatment. You may be eligible for it just as so many other families are.

Your goal is to:

- get whatever help you need to pay the expenses associated with this illness.

What You Can Do To Help

It is important that you deal with financial problems early-before they become a crisis. Don't put it off. The earlier you start working on this problem, the easier it will be to solve. If you talk to the people you owe money to before it becomes a crisis, they are usually willing to work with you. Following is a list of things that you can do to help solve this problem.

- **Apply to Four Diamonds Fund** The Four Diamonds Fund helps families of young persons with cancer pay their hospital and medical bills incurred at the Hershey Medical Center. The young person must be diagnosed before age 21 and be a dependent. He or she remains eligible for this funding until age 25. After you complete the application, a financial counselor will review the information and determine if you are eligible to receive this funding.
 - **Talk with the social worker about submitting your application to the Four Diamonds Fund.** Social workers are the best source of information about how to get help with medical expenses and who qualifies for help. They will give you an application form and explain the program.
 - **Family Financial Participation (FFP)** means that you have enough income and assets to help to cover the costs of the medical and hospital expenses. If you are assessed as eligible for Family Financial Participation, then you will need to pay that portion before the Four Diamonds Fund takes over and pays the remainder of the bills.
 - **If you are not assessed as eligible** for Family Financial Participation, then the Four Diamonds Fund will cover bills not paid by insurance.
 - **Hospital bills will be submitted automatically to the Four Diamonds Fund** by the Patient Accounts Department. If you have major medical coverage, then you yourself must submit physician bills to collect your insurance benefits.

Get help with insurance billing forms Many insurance forms can be confusing and difficult to complete. Putting them aside can add to your stress. Here are two helpful suggestions on completing these important forms.

- **Meet with financial counselors at the hospital** who will help you answer questions about bills or about what is covered by your medical and hospital insurance. Turn in your Four Diamonds application and a wage verification from to a financial counselor at the hospital. You will receive a letter within 30 days telling you whether or not you are eligible to receive Four Diamonds coverage.
- **Ask a friend or family member** who is confident with medical bills and accounts to be responsible for billing.

Apply for medical assistance

- **Talk with the Insurance Verification Department** at Hershey Medical Center who can help you apply for Medical Assistance if your child is in the hospital. The Insurance Verification Department is located on the first floor of the hospital near the gift shop. You can make an appointment or walk in and visit them.
- **Contact your County Board of Assistance** who can help you apply for Medical Assistance if your child is not in the hospital. Every county has a Board of Assistance that is open five days a week. Look up their number in the blue pages of the telephone book under "County Government." If transportation to their office is a problem, let them know this and ask for help in getting a ride there.

Find out if Social Security Benefits are an option Contact the Social Security Office toll free number 1-800-772-1213 to ask about your eligibility and then to apply for monthly payments from Supplemental Social Insurance (SSI) benefits.

Learn what community resources will help with finances Following is a list of resources that you can explore yourself. They usually have guidelines to decide if you are eligible for help from their funds.

- **Ask the American Cancer Society for help** with transportation and gas mileage reimbursements. Help with transportation and medication costs is sometimes available for a short time from the American Cancer Society (ACS). Call your local ACS office. Their number is in the white or blue pages of your telephone book. Some of their offices also run volunteer driver programs which can help offset the expense of gas and the wear and tear of driving. Otherwise, they can offer a small amount of money towards mileage and gas.
- **Ask the Leukemia Society of America for help** with gas mileage reimbursements. The Leukemia Society has special financial help programs. The social worker at the hospital will give you their forms and help you submit them.
- **Ask the local chapter of the American Red Cross** what they can offer, such as financial assistance during emergencies or paying home heating and electric bills. The Red Cross has many different programs for families in times of crisis or financial need. Their number is also in the telephone book.
- **Use the Blue Pages section of your telephone book**, which is usually labeled "A Guide to Human Resources," and call local transportation programs or the county Board of Assistance. The blue pages in your phone book have a section called A Guide to Human Resources. Look through the headings and locate the list of services under Transportation. Call and ask if you and your family are eligible for help with the costs of driving to treatments or paying for buses, cabs, trains, or planes. Some of these services may offer transport that you did not know was available.

Your county's Board of Assistance can also tell you about your eligibility for help through programs such as food stamps, medical assistance cards, or cash assistance.

- **Ask social workers, family members, and friends about community groups or churches** who help people in financial need because of illness. Some community groups have funds to help members, but others, especially religious groups, have

funds to help anyone in need. Talk to members of community organizations about your needs or ask your friends and family to speak to them about what they can offer.

- **Ask the social worker about financial review programs for drugs or supplies.** If you have home IV supplies by Caremark and are having difficulties with payment, inquire about their financial review program.
- **Gather unpaid household bills to show your immediate financial needs** to social workers or case workers at any of the above offices. Gather any unpaid household bills to prepare a brief financial statement to report to any of the above organizations. These include unpaid telephone bills, electric bills, rent, and utilities. Each organization offers help that is slightly different and it's wise to reveal an unmet need, such as the need for help with heating expenses in winter when you want to keep the house especially warm for the young person with cancer.
- **Meet with social workers about immediate household expenses.** Social workers also know how to help you with immediate financial needs, such as unpaid electric or telephone bills. Many times, they can restore these services by describing why you need heat and electricity because of your child's medical conditions.
- **Talk with all creditors about rearranging financial contracts** before collection notices are sent.
- **Negotiate worktime with employer**
 - **Ask social workers to talk with employers.** You may find that you need to take quite a bit of time off from work. This challenges the whole family household, especially if you are a two-wage earner family. Many employers are very understanding at this time and help you make arrangements to be away from the job. The social worker can call your employer and verify the difficulties of the situation and speak on your behalf if you are having trouble negotiating time off from work.
 - **Weigh the pros and cons of different worktime options.** Many parents and family members use a mix of strategies to spend time with the young person with cancer at home or in the hospital and still juggle time at work. List your options and look at pros and cons of each possible decision so you can make the best decision for the whole family. For example, you might have to wrestle with whether or not to go part-time or take a leave of absence from work.
 - **Accept offers of help with worktime and employee benefits** from other employees. Don't underestimate how family and coworkers are willing to help. Other people understand many sides of your dilemma about work and are willing to help out. For example, coworkers could donate their laved time so you can continue to receive pay without working.

Possible Obstacles

Think about attitudes or ideas that could prevent you from getting help with medical, hospital, or household expenses.

1. "I feel embarrassed and humiliated to not to be able to pay my bills."
Response: Many people, just like yourself, have been in the same situation. Household expenses have also risen and yours are no exception. Medical expenses are so large nowadays that it is becoming common for many people to have problems paying. You should not feel embarrassed since the problem is not your fault. You will find that almost everyone will be very understanding.

It would help to talk to other parents of young persons with cancer. You'll realize

that they've asked for help and overcame any shyness or guilt or embarrassment about needing financial help at this time in their lives.

2. "I didn't handle money in our family-other people did. So I don't know what to do."

Response: If money matters are new to you, then get help from someone who is familiar with budgets, with paying bills, and with asking for financial assistance.

Don't let things drift because then expenses can get out of hand and you will have a greater financial crisis to deal with.

Carrying Out and Adjusting Your Plan

Don't wait! Get started as soon as possible. If you have trouble getting started, ask someone to help you. Talk to a social worker and to financial counselors at the hospital. They have had a great deal of experience with these problems and can often be creative in helping you to deal with them.

If you have problems with insurance or medical forms, ask staff in the doctor's office, or a social worker at the hospital or home-care agency for help.

If your plan doesn't work

If you are having some success, but not as much as you would like, you may be expecting too much progress too soon. Be patient and keep trying. It will often take time to turn things around financially.

If you are feeling worn down by financial problems, ask someone else to help you work out a solution. Sometimes people who are not directly involved can see new ways to deal with the problem.

Social workers are the professionals who have the most experience with these problems. If the social worker whom you talked to was not helpful, ask to talk to another.

Parents' Anxiety

What is anxiety?

Anxiety is a common and normal response to new or stressful situations. Everyone has felt worried at various times in day-to-day life. For example, some people feel anxious or nervous before they interview for a new job, before talking to a group of people, or when they are worried about someone they love. Here are some different ways that people experience anxiety:

- Nervousness
- Tension
- Panicky feelings
- Fear
- Feeling something bad is going to happen
- Feeling like "I'm losing control"

When you are anxious you may also have physical symptoms like:

- Sweaty palms
- Upset stomach
- Tight feelings in your stomach
- Shaking or tremors
- Difficulty breathing
- Racing pulse
- Hot and flushed in your face

Sometimes these feelings come and go fairly quickly. Other times these feelings last a long time.

Tension can help people to do something well. For example, many actors say that they have "butterflies in their stomach," or anxious moments, before they perform. Sometimes people actually enjoy the feelings of anxiety, like when they are watching a horse race or riding a roller coaster.

However, when these feelings are very strong and contain fearful thoughts, they get in the way of everyday living. When they last a long time, they can prevent people from doing the things that are important to them. This is when people need to learn to manage anxiety better.

Recognizing when a person is anxious

One of the difficult things about anxiety is that people may not know when they're experiencing it. They may think that they are just worried. But then, before they realize what is happening, they are experiencing serious anxiety symptoms.

Sometimes the parents of young persons with cancer don't realize how anxious they are becoming, but family and friends do. Family and friends can help by pointing out what is happening early, and they can help the parents of the young person with cancer control the anxiety before it gets out of hand.

Anxiety related to cancer

When parents are told their child has cancer, it often makes them feel anxious. Some feel afraid, nervous, and even overwhelmed. Others may feel panicky, as if they have lost

control of their lives. These are normal reactions.

Many parents experience anxiety during their child's illness. Anxiety can be caused by:

- Worries about medical procedures
- Fear of pain and discomfort in the young person with cancer
- Fear of the illness getting worse

Although some anxiety is normal, it can become so severe that it interferes with your ability to cope with the young person's illness.

What you can do to help yourself

Controlling anxiety is primarily in your hands. You should not feel guilty if, in spite of your best efforts, you are very anxious. If the anxiety is severe, a professional may be needed who can use special techniques such as anti-anxiety medicines or stress management techniques.

Family and friends caring for someone with cancer can become quite anxious. Sometimes it is because they worry about the person's illness and their own ability to cope effectively with all the stress involved. Sometimes it is because the anxiety of the young person with cancer makes them anxious. Poor communication between the person with cancer and family and friends can also be a source of anxiety for everyone.

Therefore, you should read this home care plan to help yourself.

Your goals are to:

- accept that some anxiety is both normal and understandable
- get professional help for anxiety when that is necessary
- learn about your anxiety and manage it as much as possible
- use this home care plan if anxiety is interfering with your ability to help your loved one.

When To Get Professional Help

The first question you should ask is whether professional help is needed. You should call the doctor, nurse, psychologist, or social worker for anxiety if you:

1. Have a history of severe anxiety requiring professional help or therapy and are feeling very anxious now.
2. Have a much lower quality of life because of anxiety symptoms.

Professional help is needed if anxiety symptoms are interfering with daily activities or are very upsetting.

Some people are hesitant to ask for help with emotional problems because they don't want to appear "crazy." They should understand that being upset during a major illness is normal, and so is getting help for these problems.

It is best to start with your family physician. Ask for an evaluation of possible causes of the anxiety and recommendations for treatment or referral.

Physicians can evaluate whether to prescribe anti-anxiety medicines. Physicians can also make referrals to mental health professionals such as psychologists, psychiatrists, social

workers, and nurse counselors.

If you are not sure whether professional help is needed, ask a nurse or social worker for guidance.

Call the doctor, nurse, or social worker if any of the following symptoms persist for several days

- Severe problems falling or staying asleep several days in a row
- Feelings of dread and serious apprehension for several days
- Trembling, twitching, and feeling "shaky"
- Fluttering stomach with nausea and diarrhea
- Increased heart rate or feeling a rapid pulse
- Wide mood swings that you cannot control
- Shortness of breath

What You Can Do To Control Anxiety

If it's not an emergency, here are six things you can do:

- find out what thoughts are causing the anxiety
- talk to someone who has been through the situation causing the anxiety
- increase pleasant, distracting activities
- increase companionship
- encourage use of relaxation techniques
- ask a physician for an evaluation

Always start with the first one-being sure about what thoughts are causing the anxiety.

- Try to find out exactly what thoughts are causing anxiety. Understanding the thoughts that are causing the anxiety is the key to controlling it.

Anxiety has two parts: thoughts and feelings. Worried thoughts lead to nervous feelings. Nervous feelings can lead to more worried thoughts and so on. To stop this cycle, you first need to find out what thoughts are causing the anxiety and why those thoughts are making you nervous.

For example, admitting the young person to the hospital may be upsetting, but, when you ask yourself what it is about the hospital that makes it upsetting, you may decide that you are primarily concerned about paying the bills. On the other hand, you may be anxious about having to work with new staff and explaining your child's needs again. Sometimes you won't be able to find an exact reason; this is when professional help may be useful.

If you are anxious about medical procedures your child must undergo, try to find out exactly what it is about the procedure that is upsetting. Is it needles, pain, leaving the child alone? If you cannot explain it, ask: "How would you change the procedures so that they don't make you and the young person with cancer so upset?"

If you are anxious about receiving medical information, try to find out exactly what kind of news would likely cause you to be upset. Is it being told the young person needs more treatments? Has to go into the hospital? The prospect of being unable to do certain things in the future?

Getting the facts can help you feel less anxious. For example, if you are worried about whether the doctor will say that the disease has progressed, you may learn that the doctor will not know whether the cancer is responding to treatment for another 8 weeks. Or, if you are upset by needles, you may learn that the test the doctor has ordered does not use needles.

When you get the facts, you may also discover that there are ways to "get around" a problem that is making you anxious. For example, if the anxiety is about needle sticks in the veins, blood could be drawn with a small prick on the finger. Or, if you are worried about the young person being alone during a test, you can plan to be with him or her during that time.

- Talk to someone who has been through a similar situation. It is often reassuring to hear about what happened to other parents and how they reacted during a stressful experience. It helps parents to know that they are not alone and that someone else got through it. This can make the future seem more manageable, even if the experience was difficult for the other parents.

You should choose the parents you talk to carefully since some people can be more reassuring than others. In general, though, most people find that talking to someone who has been through the same experience reduces worry and anxiety.

Most people who have made it through scary experiences are happy to talk to others about their experiences. The treatment team may be able to refer you to parents or to a support group where you can find others who have had similar experiences.

- Increase pleasant, distracting activities. Think about and do things that are pleasant and relaxing can help reduce anxiety.

There are three types of enjoyable activities: activities with other people, activities that give a sense of accomplishment, and activities that are especially involving so as to displace thoughts about the situations that are making you anxious.

- Increase companionship and time spent with friends and family who care. Being with family and friends whom you know and enjoy is an excellent way to take attention away from what is causing the anxiety. It can also give family and friends the opportunity to express caring and love for you.

Knowing that other people care and are available to help when needed gives people strength and confidence in facing frightening experiences.

- Use relaxation techniques. Relaxation is a skill which can be used to counteract anxiety. You can't be anxious and relaxed at the same time. When you do things that make you feel relaxed, anxiety decreases.

There are many ways to feel more relaxed. Choose a way that is comfortable. Prayer or meditation helps many people when they are in tense situations. Many people are relaxed by certain kinds of music. Walking or mild exercise can reduce anxiety, too.

There are also special relaxation exercises and tapes which are available commercially. These programs teach relaxation as a skill. With practice, people can learn to relax their muscles more than they usually would. They can then learn to use this skill when they are in tense situations. Oncology nurses, doctors, psychologists, and social workers are often familiar with relaxation techniques and may be able to recommend a program, book, or audio-cassette tape.

The last section of this home care plan explains how to use and practice relaxation techniques. It is important to practice these skills because the better you are at becoming relaxed, the better you will be able to control anxiety.

Ask a physician for an evaluation and treatment recommendations. If anxiety does not improve in spite of your efforts, you can discuss the problem with a physician. Contact a family physician who knows you and the medical situation of your child.

Physicians can help in two ways:

1. They can assess whether anti-anxiety medicines should be prescribed. You should only take anti-anxiety medicine after consulting with a physician who is familiar with your medical history. These medicines may cause problems when combined with other medicines.
2. They can assess whether referral to a mental health professional is needed. If so, they can help with a referral.

Possible Obstacles

Here are some obstacles that other people like you have faced in dealing with anxiety

1. "My problems are real. I have to face them even if they make me anxious."
Response: Your problems are real. A certain amount of anxiety about them is normal and understandable. However, research and experience shows that severe anxiety interferes with the ability to solve problems. Managing anxiety makes problem solving easier. This home care plan will help to prevent anxiety from becoming severe.
2. "I can't stop the thoughts that make me anxious. They keep coming back and racing around my head."
Response: It's scary to feel like you can't control your thoughts. However, there are some techniques to try which may reduce or even stop them.
3. "I'm anxious because my child is anxious."
Response: Spending a lot of time with someone who is very anxious can be stressful and can even make you anxious, too. You need to take time for yourself-to take a break from caregiving and rebuild your emotional strength. You should also involve as many people as possible in carrying out this home care plan. Their support will help you take breaks and to know that you don't face these problems alone.

Think of other obstacles that could interfere with carrying out your plan:

- o What additional road blocks could get in the way of doing the things recommended in this home care plan? For example, will other people help? How will you explain your needs to other people? Do you have the time and energy to carry out the plan?
- o You need to develop plans for getting around these road blocks. Use the four COPE ideas (creativity, optimism, planning, and expert information) in developing your plans. See the chapter on Solving Problems Using the Home Care Guide at the beginning of the book for a discussion of how to use the four COPE ideas in overcoming your obstacles.

Carrying Out and Adjusting Your Plan

Your first step is to talk this plan over with someone you trust. If you think that anxiety is likely at certain times, make plans for what to do at these times to prevent anxiety from

building up. It is always easier to manage anxiety before it is serious and before you feel overwhelmed by it.

Stay alert to the possibility that professional help may be needed. Review regularly the questions in the When To Get Professional Help section of this plan. Seek help if the anxiety seriously interferes with your ability to give care and your quality of life.

Checking on results

Talk regularly about emotional feelings. Some people find it helpful to rate their anxiety on a 10-point scale, with zero being "no anxiety" and 10 being "the worst anxiety ever experienced." Keeping a daily log of anxiety levels takes a little extra effort, but by keeping track of it, you can deal with it before it gets serious, and it can save a lot of energy later.

If your plan doesn't work

Ask if you are expecting change too fast. It usually takes time to change someone's anxiety level. Look for small improvements at first. Remember: Your efforts may be successful even if they just stop the anxiety from getting worse.

If these techniques do not seem to be helping and you have been feeling anxious for several weeks, then you should get professional help.

A Relaxation Technique

Many parents of young persons with cancer have found relaxation techniques helpful. These techniques can be used anytime-even for short periods of time. Try this exercise yourself to see how it feels and works for you.

Relaxation should be practiced once a day, but not within an hour after a meal since digestion may interfere with the ability to relax certain muscles.

1. Sit quietly in a comfortable position (such as in an easy chair or sofa) and practice this exercise when you are not feeling rushed.
2. Close your eyes.

Deeply relax your muscles, beginning with the face and going throughout the entire body (shoulders, chest, arms, hands, stomach, legs) and ending with the feet. Allow the tension to "flow out through your feet."

Now concentrate your attention on your head, and relax your head even further by thinking, "I'm going to let all the tension flow out of my head. I'm letting go of the tension, and I'm letting warm feelings of relaxation smooth out the muscles in my head and face. I'm becoming more relaxed."

Repeat these same steps for different parts of your body: your shoulders, arms, hands, chest, abdomen, legs, and feet. Do this slowly-spend enough time to feel more relaxed before going on to the next part of the body.

3. When the body feels very relaxed, concentrate on your breathing. Become aware of how rhythmic and deep your breathing has become. Breathe slowly and deeply. Breathe through your nose. As you breathe out, say the word "calm" silently to yourself. Slowly take a breath in. Now slowly let it out and silently say "calm" to yourself. Repeat this with every breath. It helps you to relax more if you concentrate on just this one word "calm." Continue breathing deeply, becoming more and more relaxed.

4. Continue this exercise for 10 to 15 minutes more. Remain relaxed and breathing slowly. At the end of the exercise, open your eyes slowly to become adjusted to the light in the room, and sit quietly for a few minutes.

When it is over, ask yourself how relaxed you became and if there were any problems. One problem can be drifting and distracting thoughts. If this happens at the next session, think to yourself, "Let relaxation happen at its own pace." If a distracting thought occurs, let it pass. Let it fly away like a bird. Don't fight it. Concentrate more on the word "calm." Let the thought drift by and repeat "calm" over and over again as your breathing gets slower and deeper-as you relax more and more.

5. Do these exercises regularly-once a day is best. In the beginning, it may help to have someone else give you the instructions. You can record these instructions on an inexpensive tape recorder and play them when you are relaxing. If you prefer, you can record yourself giving the instructions and use that.
6. When practicing, choose a time when you will not be disturbed. Tell the other people in your household what you are doing and ask them to be quiet during the exercise.
7. After you become skilled at this exercise, you will find that it is easy to apply when you are getting tense. For example, if you are feeling tense while waiting to see the doctor or for a treatment, you can easily close your eyes for a few minutes and use this exercise to relax and feel calm.
8. It's a good idea to learn this relaxation technique early-before anxiety becomes severe. It can then help to keep severe anxiety from happening.

Parents' Depression

The information in this homecare plan fits most situations, but yours may be different. If the doctor or nurse tells you to do something else, follow what they say.

Understanding the Problem

The stress of caring for a child with cancer can cause many uncomfortable feelings such as depression. Sometimes we are able to get over "the blues" after a short time. But sometimes these feelings last a long time and can severely hurt the quality of your life. When someone is sad, discouraged, pessimistic, or despairing for several weeks or months, and when these feelings interfere with being able to manage day-to-day affairs, we say that he or she is suffering from depression. Depression can last a long time if you don't do something to stop it.

In addition to feelings of sadness, the symptoms sometimes include problems with appetite, sleeping, having the energy to do things, and problems paying attention to things. Alcohol abuse, especially if it is new or worse since the illness, may be a sign of depression. Sometimes a depressed person also thinks about suicide as a way out.

Depression works like a downward spiral. You feel down, so you don't put energy into solving problems. When the problems get worse, they can cause you to feel worse. And so on and so on. Somehow this has to be interrupted. Some kind of change has to happen, or you will have these feelings for a long time.

In this home care plan, we discuss some ways to tell when to seek medical help. We also discuss some ways that you can help limit or manage depression.

Some depression is a normal response to the stresses and uncertainties of caring for a child with a serious illness. **Don't expect to get rid of all of these feelings. However, you can help to limit the length and severity of depression.**

It is important to pay attention to your own emotional health if you are to do your best as a caregiver.

Your goals are to:

- keep an eye out for early depressive symptoms and manage depression early before the symptoms become severe.

When To Get Professional Help

Symptoms that indicate that professional help is needed

If any of the following is occurring, you should get assistance from a health professional.

- **You have been depressed before this illness and have had at least two of the following symptoms consistently during the past 2 weeks:**
 1. Feeling sad most of the day
 2. Loss of interest in almost all daily activities
 3. Difficulty paying attention to what you are doing and trouble making choices.

If you have a history of serious depression before your child's illness, you are vulnerable to depression. Having a child with a serious illness like cancer may trigger your depression, in which case, professional help will be needed.

- **You notice wide mood swings from periods of depression to periods of agitation and high energy.** Some people who have wide, uncontrollable swings in mood may have a "manic-depressive" illness. They cycle between being depressed with low energy and having a great deal of energy with feelings of agitation or feeling "high." The moods often don't seem connected to what is going on around the person. This requires professional help to determine if medication is necessary.
- **Nothing you do seems to help, even those strategies that have worked for you in the past.**

How To Get Professional Help

Getting help for depression is just like getting help for physical problems. Asking for help doesn't mean you are crazy. The problem could be caused by the stress related to caregiving, which is an understandable reaction to the serious issues you must face.

Some people are hesitant to ask for professional help with their emotional problems because they are embarrassed. They may think that seeing a psychologist, psychiatrist, or social worker means that they are weak or strange. Being upset when caring for a child with a major illness is normal. So is getting help for these problems. Professionals such as social workers, nurse counselors, clergy, psychologists, and psychiatrists are skilled and experienced in helping people deal with emotionally stressful experiences. **They are there to help you with this kind of problem just like your family doctor is there to help with physical problems.**

- **Ask for help from a family doctor or another physician who is familiar with you and your child's illness.** Physicians can evaluate whether anti-depression medications may help and can prescribe them if necessary.
- **Ask a mental health professional such as a social worker, psychologist, or psychiatrist for help.** Mental health professionals are experienced in helping people with many types of emotional problems. They can be especially helpful when there is a history of depression before the illness. Many psychologists, social workers, and other mental health professionals have experience working with parents of young people with cancer. They can be very helpful when depression is a reaction to the stress of the illness.

Changing depressed feelings takes time. It usually takes at least several sessions with a counselor or therapist before depressed people begin to feel better. It also takes time for medicines to work, and the doctor may need to adjust the doses before the medicines are helpful.

What You Can Do To Help

Caregiving can be stressful. To do your best in this difficult role, you need to find ways to stay emotionally well yourself. Here are some things that you can do for your own emotional health:

How to prevent or decrease depression

Much of the work here has to come from yourself. Following are methods that you can use to prevent or decrease depression. These techniques work for most people.

1. **Act before depression becomes severe** If you ignore the early signs of depression, it is more likely to get out of hand, to seriously affect your quality of life, and to require professional help.

2. **Schedule positive experiences for yourself** Keep doing things that make you feel good. Don't become so involved in your caring responsibilities that you neglect your own emotional health. Don't feel guilty about taking care of yourself. **If you become overwhelmed, you won't be able to provide care and support.** You will be a better caregiver if you take time to do things that you enjoy outside of your caring responsibilities. If you start feeling overwhelmed, take time off to do the things you enjoy. Do this early. This can help prevent your becoming seriously depressed and give you the strength to carry on.
3. **Help increase the number of activities that you do with other people Being with people you know and enjoy is an excellent way to take attention away from negative thoughts and feelings.** It provides opportunities to think about one's own life in comparison to others and to recognize the good things in one's life. It provides opportunities to give as well as to receive help, to share experiences and perspectives, and to get help in dealing with problems that are making you depressed. Most important is that other people can express caring and love. Knowing that other people care and are available to help when needed gives people strength and confidence when facing an uncertain future.

Three types of people can be especially helpful. Make a list of friends and family members using the following categories.

1. People who are sympathetic and understanding
2. People who give good advice and who can help solve problems
3. People who can turn route attention away from problems and toward pleasant experiences.
 - o **Set reasonable, attainable goals** Depressed people tend to set goals that are too high, and when they don't reach their goals, they tend to become even more depressed. When you plan positive experiences, be sure that your goals are reasonable. **It is better to set a low goal and accomplish more than you expected than to set too high a goal and fail.**
 - o **Control repetitive, negative thoughts and substitute positive experiences and thoughts**
Five techniques for controlling negative thoughts are explained at the end of this home care plan. They are:
 1. Thought stopping-to control repetitive negative thinking
 2. Arranging a plan and time for negative thinking-to control and limit negative thoughts
 3. Distraction-to take attention away from negative thoughts
 4. Arguing against negative thinking-to show yourself how unreasonable your negative thoughts are
 5. Solving day-to-day stressful problems that can be a cause of negative thoughts.

Possible Obstacles

Think about obstacles that could stop you from carrying out your plan and about how you will deal with them.

Here are some obstacles that other people, like yourself, have faced in dealing with depression

1. "My problems are real! It's normal to be depressed in my situation."
Response: Your problems are real and some depression is normal. But getting stuck in the feeling of depression can interfere with dealing with the problems that are causing the depression. The goal is to keep a balance between positive and negative thoughts. **The problems are real, but many of the good things in life are also real and should get equal attention.**

2. "Nothing will help, so it's no use trying."

Response: Give it a try! There is nothing to lose and a good deal to gain. **Start with things that are easiest to do. Then judge if these ideas are helpful.** If you are so depressed that you can't even try, then professional help is probably needed.

Think of other obstacles that could interfere with carrying out your plan

What additional road blocks could get in the way of doing the things recommended in this home care plan? For example, will other people help? Do you have the time and energy to carry out the plan?

You need to develop plans for getting around these road blocks. Use the four COPE ideas (creativity, optimism, planning, and expert information) in developing your plans. See the chapter on Solving Problems Using the Home Care Guide for Young Persons With Cancer at the beginning of the book for a discussion of how to use the four COPE ideas in overcoming your obstacles.

Carrying Out and Adjusting Your Plan

- **Talk this plan over with someone you trust.** Together you should agree on what you can do together to manage depression. It is important to work as a team when dealing with these problems. Sometimes the support and the feeling of being on a team is in itself helpful.
- **Use these techniques early.** Look for beginning signs of depression and put your plan into action then—don't wait until depression is severe. The techniques discussed in this plan have helped severely depressed persons, but usually as part of professional treatment.
- **Plan in advance what you will do to manage depression.** If you know that you are likely to be depressed at certain times based on past experience, then make plans for what you will do to prevent depression from building up.
- **Persist.** Even if you continue to feel depressed, don't give up. You are probably preventing the depression from getting worse. **Keep working cooperatively with someone you trust.** If you are working together, these ideas can only help.

Checking on results

- **Talk regularly about your feelings.** Although it may be difficult for you at first, talk about your feelings. It may seem scary at first to talk about what is upsetting. But it's important to do this because it helps you to control depressed thoughts and feelings.
- **Watch for indications that professional help is needed.**

If your plan doesn't work

Ask if you are expecting change too fast. It usually takes time to manage depression. Look for a small improvement at first. Remember: Your efforts may be successful even if they just keep the depression from getting worse.

If these techniques do not seem to be helping and you have been feeling very depressed for several weeks, review this home care plan to be sure you have tried all of the ideas. If so, you should seek professional help.

Techniques for Controlling Negative Thoughts

- Thought Stopping
- Arranging a time and a place for negative thinking
- Distraction
- Arguing against negative thoughts
- Solving day-to-day problems that are causing you stress

Thought stopping

One of the hard things about depression is that it's so easy to get stuck in a whirlwind of negative thinking. Suddenly you may find depressing thoughts going around and around in your head. It doesn't take long for this to make you feel bad; and then it may seem like you can't stop it. But you can!

The thought-stopping technique helps you to "snap out of it" when that whirlwind of negative thoughts first starts. If you catch it early, you can keep it from getting you too upset. The trick is to do this when you first notice a negative thought.

When you first feel yourself in the negative-thinking whirlwind, try one of these techniques:

- **Yell "STOP" really loudly in your mind.** Yell STOP when you scream STOP in your mind; pretend it is very loud. The idea is to wake you up, to make you aware that you're in danger of getting stuck in negative thoughts. You might start this by going to a place by yourself and shouting STOP out loud. Practice it this way until you can do it in your mind alone.
- **Visualize a big red STOP sign.** Try to see it clearly, and then get your mind on something else. Think of what a STOP sign looks like. Make sure you see it as a red sign. Practice seeing it in your mind so that you can bring it to mind easily. Now whenever you catch yourself starting negative thoughts, think of this image and stop yourself.
- **Slap yourself on the wrist with a rubber band.** Another way to remind yourself to stop is to gently slap your wrist with a rubber band. This isn't to punish yourself. It's to give you a physical reminder to stop the thoughts.
- **Splash some water on your face.** Splashing water in your face is another way to wake yourself up from the negative thinking. Pay attention to how the water makes you feel. And stop your negative thoughts.
- **Get up and move to a new spot.** Getting up and moving to a new spot gives you a change of scenery. You can use the new surroundings to help you think about other things.

You have to fight the negative thoughts. Maybe several of these techniques together will work for you. When you're depressed, you may look at techniques for stopping these thoughts and say, "That's silly. It could never work." Actually, research has shown that they can work. Give them a try!

Arranging a time and a place for negative thinking

This technique allows you to think about negative things, but puts you in control of when and where you do this thinking.

- **Find a negative-thinking "office."** This can be a room, a chair, or just a certain window. Make this the only place you let yourself think about all of the negative things.

Your "office" space can be any place you choose. Don't, however, make it your bed or your seat where you eat. These need to be "safe zones." Now you should try to only think your negative thoughts in this one place.

- **Schedule a time each day when you plan to think your negative thoughts.** Scheduling a time to think about your negative thoughts helps you to take control of them. You might not be able to control all negative thinking, especially in the beginning. But this technique will gradually help you to get control over your negative thinking.

Don't make this time around mealtimes, just before you go to sleep, or just before you expect to see people. These should be relaxing times. Make this time no more than 15 minutes. At the end of 15 minutes, stop. You can continue tomorrow.

Distraction

You can't think two things at once. When you start thinking negative thoughts, get your mind involved in another activity which "pushes out" or replaces the negative thinking. Try one of these ideas:

- **Take a vacation in your mind.** Close your eyes and think about your favorite spot. Spend a couple minutes there on a mental vacation. Relax and enjoy it.
- **Mental time travel into the future.** Think of something that you are looking forward to. Imagine that it is happening. Think of how nice it is to be there.

When you take your mental vacation or time travel to something you're looking forward to, really try to work your imagination. Think about as many details as possible.

What does it feel like? Is it a warm breeze? Imagine how it feels on your skin.

What does it sound like? Are there waves gently crashing on the beach? Are people laughing, or is music playing? Imagine it as clearly and vividly as you can.

What does it look like? Is the sky clear and blue? Or are you in a room? Imagine what the room looks like. Try to see it as completely as you can.

What does it smell like? Is it the salty smell of the ocean? Maybe you smell the fragrances of a garden or a big dinner. Make it as clear as you can.

What does it taste like? Are you drinking a nice cool drink? Feel it in your mouth. Taste it.

Use these exercises to fill your mind with as many pleasant details as you can. Think of as many as you can. This exercise is also helpful when you are feeling anxious and need help falling asleep.

- **Tension busting.** Use the relaxation exercises in the home care plan for Parents' Anxiety. Being relaxed helps you to think about pleasant things.
- **Do something you like.** Really get yourself involved in an activity you like.

The idea of this exercise is to fill your mind up with positive thoughts and to have them crowd out the negative ones.

Arguing against negative thoughts

The idea of this exercise is to make yourself see both sides of the picture. Things aren't usually as bad as they first seem when you're depressed. But the only way to see the other side is to actively argue against it.

You can fight your negative thoughts. Challenge their accuracy. **Every situation has at least two sides to it.** When you're depressed, you probably only see the bad side. If you weren't depressed, you would usually think of both sides. This exercise forces you to actively take the other side. **It is like having a debate with yourself.**

- **Is your negative thought really true?** Make yourself be clear about what evidence supports it.
- **Now take the other side. Argue the exact opposite.** Think of every reason why your thought may not be true or may be exaggerated. Don't give up too easily. Really argue as if you were arguing with someone else.

When you're arguing with your negative thoughts, try to be as complete as possible. You may want to write down the answers to the following questions:

What is the evidence against my negative thought?

Are there any "facts" in my thinking which are really just assumptions? Is my argument an example of "black and white" thinking? Are there shades of gray that I'm ignoring?

Is the negative side taking things out of context? Am I looking at the whole picture or just one small part of it?

Am I trying to predict the future, when I really know that I can't?

Try to punch as many holes in your "negative sides" argument as you can. Don't accept any illogical thinking at all.

Solve day-to-day problems that are causing you stress

Use a problem-solving approach to solving some of the day-to-day problems that are contributing to your feelings of depression, such as finding enough time to do housework, problems with family members, and so on.

The home care plan on Solving Problems Using the Home Care Guide for Young Persons with Cancer at the beginning of this book explains how to use four problem-solving steps to deal with problems that are not included in this workbook. The four steps are:

- Get information from cancer care experts about the problem and what you can do (the kind of information that is in the home care plans)
- Develop your plan in an orderly way, including reviewing the facts, setting reasonable goals, and choosing the strategies that are the best balance between risk and benefit. When you encounter obstacles, you should:
- Keep a positive outlook
- Be creative by seeing the problem from someone else's perspective, asking other people for ideas, and rethinking your expectations.

You can remember these ideas with the word COPE:

C for being Creative
O for being Optimistic
P for Planning
E for using Expert information

Fluid Chart (In and Out)

Your Child Must Drink Everyday

Use the following chart to determine the minimum amount of fluid your child needs to take every day during normal waking hours:

Age	Number of Ounces (oz)
Up to 1 year old	3 to 4 oz. every 2 hours
1 year to 5 years old	4 oz. every 2 hours
6 years old and older	6 to 8 oz. every 2 hours

Your Child Must Urinate Every Day

Your child should not wait too long to urinate. If so, he or she may be dehydrated. If your child urinates less frequently than the hours listed below, contact your physician promptly. For example, if your 6-month-old child has not wet his pants or urinated for 9 hours, you should call because 9 hours is longer than 8 hours.

Age	When to Call
Up to 1 year old	Call if no urine for 8 hours or longer
Over 1 year old	Call if no urine for 12 hours or longer