2007

Pediatric oncology: parent education handbook

Lindsey Anderson
University of North Dakota

Lacey Harrington
University of North Dakota

Follow this and additional works at: http://commons.und.edu/ot-grad

Part of the Occupational Therapy Commons

Recommended Citation
http://commons.und.edu/ot-grad/6

This Scholarly Project is brought to you for free and open access by UND Scholarly Commons. It has been accepted for inclusion in Occupational Therapy Scholarly Projects by an authorized administrator of UND Scholarly Commons. For more information, please contact zeineb.yousif@library.und.edu.
Lindsey Anderson, MOTS & Lacey Harrington, MOTS

Advisor: Gail Bass, Ph.D., OTR/L

A Scholarly Project
Submitted to the Occupational Therapy Department
of the
University of North Dakota
In partial fulfillment of the requirements

for the degree of
Master’s of Occupational Therapy

Grand Forks, North Dakota

May 12, 2006
This Scholarly Project Paper, submitted by Lindsey Anderson and Lacey Harrington in partial fulfillment of the requirement for the Degree of Master’s of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

___________________________
Faculty Advisor

___________________________
Date
PERMISSION

Title Pediatric Oncology: Parent Education Handbook

Department Occupational Therapy

Degree Master’s of Occupational Therapy

In presenting this Scholarly Project/Independent Study in partial fulfillment of the requirements for a graduate degree from the University of North Dakota, I/we agree that the Department of Occupational Therapy shall make it freely available for inspection. I/we further agree that permission for extensive copying for scholarly purposes may be granted by the professor who supervised our work or, in his/her absence, by the Chairperson of the Department. It is understood that any copying or publication or other use of this Scholarly Project/Independent Study or part thereof for financial gain shall not be allowed without my/our written permission. It is also understood that due recognition shall be given to me/us and the University of North Dakota in any scholarly use which may be made of any material in our Scholarly Project/Independent Study Report.

Signature________________________ Date_________

Signature________________________ Date_________
# TABLE OF CONTENTS

ACKNOWLEDGEMENTS ................................................................. v

ABSTRACT ............................................................................. vi

CHAPTER

I. INTRODUCTION. ................................................................. 1

II. REVIEW OF LITERATURE. .................................................. 4
   Overview of Childhood Cancer. ............................................ 4
   Treatment Team and Interventions. ....................................... 15
   The Role of Occupational Therapy. ....................................... 16
   Effects of Pediatric Cancer on Family. ................................. 17
   Conclusion. ................................................................. 21

III. ACTIVITIES/METHODOLOGY ........................................... 23

IV. PRODUCT. ............................................................... 25

V. SUMMARY ................................................................. 78

REFERENCES ......................................................................... 81
ACKNOWLEDGEMENTS

The authors wish to thank Dr. Gail Bass for her dedication, hard work, and support through the development of this scholarly project.
ABSTRACT

In America, approximately 12,400 children and adolescents are diagnosed with cancer each year (Harris, 2004). The number of newly diagnosed children is on a steady increase. With this steady increase it is important to ensure that parents of the child diagnosed with cancer have resources about cancer and the treatment process as well as support. A review of current literature, research, and resources was conducted in order to locate the gaps within pediatric oncology. The literature helped identify areas of concern related to pediatric oncology. The areas identified consist of the parents having minimal knowledge while under emotional stress when receiving the unexpected news. Another problem is the lack of user friendly resources for parents. The current resources include medical jargon, are lengthy, and contain in-depth information about cancer. The product of this scholarly project is a handbook for parents written in family friendly language. The handbook has it’s foundation from current research and literature and is based on the Occupational Adaptation Theory (Schkade & Schults, 2003). It is designed by occupational therapist to be distributed by health professionals diagnosing the child to parents and caregivers.

The Pediatric Oncology: Parent Education Handbook was developed to provide parents and caregivers with information about how to cope, handle, and survive when their child is diagnosed with cancer. When a child is diagnosed with cancer, things may seem overwhelming; this handbook outlines what to expect and in order to assist the parent/caregiver in becoming an advocate and supporter for the child.
CHAPTER I

INTRODUCTION

The *Pediatric Oncology: Parent Education Handbook* was developed by the authors because of personal experience and interest in this area. The authors both had friends who were diagnosed with the cancer or had friends with siblings diagnosed with cancer. The lack of resources and support available to these individuals and their families helped provide the authors with the idea to develop the parent education handbook.

In America, approximately 12,400 children and adolescents are diagnosed with cancer each year (Harris, 2004), and the number of newly diagnosed children is on a steady increase. Pediatric cancer patients and their families can become overwhelmed with the vast amount of information related to the diagnosis, treatment, and prognosis.

Educating parents and children about the physical and psychosocial challenges of pediatric cancer is of utmost importance. The problem identified by the authors after an extensive literature review was conducted, is that there is a mismatch of available user-friendly resources for parents. Two educational handbooks were found for parents whose child had been diagnosed with cancer. One was from the National Cancer Institute and the other from People Living with Cancer. These handbooks are not user friendly because they are extremely lengthy, provide in-depth information, and contain medical jargon. At this time of chaos, it is important that parents have a quick and easy to read resource that they can resort to for information.
With increased survival rates of cancer patients, occupational therapists can help manage the effects caused by chemotherapy, surgery, and radiation. Occupational therapists can play a role in a patient’s life by building strength and endurance and addressing psychosocial skills in order to reach a desired level of functioning (Strzelecki, 2006). Other areas they can address include: ways to deal with the illness, symptom management methods, educational handouts about tests, holding educational workshops, field visits, and in home procedure training. Occupational therapists can also address equipment options, self care issues, individualized care, home evaluations, and meaningful occupations with the patients.

The occupational therapy theory that was used to guide the development of the product was Occupation Adaptation. This theory requires that a person engage in the therapeutic process rather than listening to the therapist/parent. Occupational Adaptation theory assists the parents with developing relative mastery in order to provide the child with creative and personal ways to begin the internal adaptation process. The client is also the agent of change in the Occupational Adaptation model; therefore the target of therapy is to increase and capitalize on the client’s adaptive capacity with the client as the primary actor in this effort. With the client’s ability to utilize adaptive capacity, the goal of intervention is that the client can participate in life and societal activities to the extent that the health condition permits. The components of the internal adaptation process include adaptive energy, adaptive response modes, and adaptive response behaviors. Through these components, an individual can incorporate energy conservation techniques, coping skills, as well as maintaining self care. The adaptive response behavior illustrates that the illness or other event must be dealt with through corporative
participation. Occupational Adaptation results as the individual encounters occupational challenges resulting from the person/environment interactions. When an individual is faced with different occupational challenges this model allows the individual to respond adaptively and masterfully. (Schkade & Schults, 2003)

This project is divided into five chapters. Chapter I includes the reason why the authors chose the topic of pediatric oncology, an overview of the problem and product, and a summary of the theory behind the product. Chapter II is a review of current research and literature and includes sections on the types of pediatric cancer, treatment issues, and the role of the parents and occupational therapy. Chapter III addresses methodology and activities; this chapter is a description of the process used in designing the product. In addition, the specific plan of how data was gathered as well as how it was used in developing the product is described. Chapter IV is where the product of this scholarly project in its entirety. Chapter V contains conclusions and summarizes the purpose and key information found throughout the process. Recommendations for implementation of this product along with limitations are included.
CHAPTER II
LITERATURE REVIEW

The purpose of this project is to develop a parent education handbook covering the topic of cancer in the pediatric population. This product will be distributed by occupational therapists supporting the role that they can play in treating childhood cancer. To provide creditability, the information provided in the parent education handbook is based on current research and literature. This chapter is divided into three sections. The first section will provide an overview of childhood cancer including a description of cancer, types of pediatric cancers, common signs and symptoms, and an introduction to treatment options. The second section gives information regarding the team approach to treating cancer along possible treatment interventions. The final section addresses the effects of childhood cancer on families and outlines effective communication styles. The chapter will conclude with information supporting the need for an educational handbook for parents dealing with their child’s diagnosis of cancer.

Overview of Childhood Cancer

Childhood cancer is the leading cause of non-violent death in children under the age of 15. In America, approximately 12,400 children and adolescents are diagnosed with cancer each year (Harris, 2004). According to the American Cancer Society (2004), cancer is described as a cluster of related diseases that develops in cells, the body’s building blocks of life. Cancer results from the abnormal growth of cells in different parts of the body. Cancer cells have a longer lifespan than normal cells; they continue to grow
and divide at a rapid rate replacing normal tissue. The main formation of cancer is a tumor, but it can also develop in the blood and the blood forming organs. Often, cancer cells travel to different parts of the body, this process is called metastasis, spreading the disease quickly. Deoxyribonucleic acid (DNA) is located in every human cell and is responsible for the cells function. When the DNA in the cell is damaged cancer cells form. Damaged DNA can be inherited or can be caused by exposure to environmental toxins. (American Cancer Society, 2004)

One way to acquire cancer is through inheriting damaged cells; this happens because damaged DNA is unable to repair itself. This damaged DNA can be passed on from generation to generation. Damage to cells occurs because of exposure to environmental toxins such as radiation or chemicals. Environmental factors are not as prevalent for children as they are in adults diagnosed with cancer. (American Cancer Society, 2006)

Types of Pediatric Cancer

Children can develop cancer in many of the same areas as adults, but some types of cancer are more prevalent in children. The three most common types of childhood cancer are acute lymphoblastic leukemia (also known as acute lymphocytic leukemia), central nervous system (brain and spinal cord), and non-Hodgkin lymphoma, respectively (American Cancer Society, 2006). Childhood cancers range in age of onset from birth to twenty-one years. Other common cancers found in children include Wilms’ tumors, retinoblastoma, rhabdomyosarcoma, bone cancer, osteosarcoma, Ewing sarcoma, and Hodgkin Lymphoma.
According to the American Cancer Society (2006), 3,970 new cases of acute lymphoblastic leukemia will be diagnosed in 2006. Of these, about two thirds of the cases will occur in children. The average age of onset for acute lymphoblastic leukemia is four years old (Clark & Fletcher, 2003). Acute lymphoblastic leukemia is found in the bone marrow and formed by white blood cells; white blood cells are an important defense mechanism that protects the body from infection. Lymphocytes (B-lymphocytes and T-lymphocytes) are a type of white blood cell, and monocytes, neutrophils, basophils, and eosinophils are other types of white blood cells. Leukemia cells develop from these types of cells in the bone marrow. Due to an accumulation of these cells, leukemia quickly infects the blood stream and spreads throughout other parts of the body, causing these parts of the body to not function properly. (American Cancer Society, 2006)

The National Cancer Institute (2006) identified the only proven risk factor for developing acute lymphoblastic leukemia is exposure to radiation. There are other hypotheses regarding risk factors such as exposure to electromagnetic fields. The prognosis for this disease is also dependent upon many factors; some of these factors include: gender, race, severity, lymphocytes, and a previous diagnosis of Down’s syndrome (National Cancer Institute, 2006). Survival rate for children with acute lymphoblastic leukemia has increased dramatically over the last 35 years. In the 1960’s less than five percent of children survived acute lymphoblastic leukemia whereas today approximately 85% will live for five or more years (National Cancer Institute, 2002).

17% of childhood cancers result from involvement of the central nervous system (CNS); this type of cancer is the second most prevalent after acute lymphoblastic leukemia (Grouse, 2005). CNS cancers can develop in different areas, within the brain
and spinal cord, and develop from different cell types. The treatment options vary depending on the location and type of cancer. The etiology of CNS cancer is unknown, though progress is being made toward understanding chemical changes in the brain that could potentially cause brain tumors. Other possible risk factors for CNS cancer include cigarette smoking, exposure to radiation, and exposure to environmental toxins (American Cancer Society, 2005). The prognosis for brain tumors is dependent on many different factors; the most important factors are: location, behavior, and appearance of the tumor. Additional factors include child’s age, spread of the cancer, surgical removal, and functional level.

The third leading type of childhood cancer is non-Hodgkin lymphoma. Non-Hodgkin lymphoma (also known as lymphoma) is cancer of lymphoid tissue. Immune system cells form the make up of lymphoid tissue which is found throughout the body. The causes and risk factor are unknown, though immune system problems or immune deficiencies are possible suggestions to why children develop non-Hodgkin lymphoma. Chemotherapy is given to the entire body of someone with this type of cancer because by the time it is diagnosed it has already spread to other organs. (American Cancer Society, 2006)

_Treatment Symptoms/Complications_

The signs and symptoms of cancer vary from person to person depending on the specific type of cancer and treatment. According to Harris (2004), 35% of patients experienced a significant difference in energy, pain, nausea, and psychological symptoms. The most common signs and symptoms experienced with cancer are fatigue,
pain, weight loss, difficulty swallowing, weakness, nausea, bruising, constipation, and fever.

Fatigue is one of the most difficult symptoms to manage and treat in childhood cancers. Davies, Whitsett, Bruce, and McCarthy (2002) identified three types of fatigue experienced by children with cancer: (a) typical tiredness, (b) treatment fatigue, and (c) shutdown fatigue. Typical tiredness is identified by loss of energy that can easily be replenished. This type of fatigue is indicated through drooping eye lids, sluggish behavior, quietness, or grumpy behavior. This type of tiredness is related to cause and effect relationships therefore it can be anticipated and expected. Treatment fatigue is energy that is lost and replaced at a slower rate which is typically unanticipated by patients. Treatment fatigue is difficult to identify and predict though it often follows hospitalizations, chemotherapy, radiation, and surgeries. Shutdown fatigue is described as energy that is used faster than it can be replaced. Shutdown fatigue is identified by its intensity, duration, and immobilizing effects. Children characterize this type of fatigue as an enormous loss of energy, or as one parent noted a hibernating phase. Davies, et al. (2002) suggest that shutdown fatigue and treatment fatigue are negative factors contributing to child’s perceived quality of life.

Pain is a common symptom that causes distress in children receiving cancer treatment, and albumin levels are the best predictor of pain in cancer patients. Pain is the best understood of all the cancer related symptoms, although it is often difficult to maintain comfort levels. The pain experienced by children is often a result of modifying factors related to the disease and treatment. Helping children identify their pain assists in possible diagnosis and treatment of this symptom. The modifying factors are separated
into three categories: cognitive, behavioral, and emotional. Cognitive factors include understanding, control, expectation, and pain control strategies. Behavioral factors that help in treating and diagnosing pain symptoms include physical activities, social activities, and overt action. The last category of factors is emotional which includes anxiety, fear, frustration, anger, depression, guilt, and isolation. All of these identified factors should be taken into consideration along with the pharmacological drugs used to treat pain in cancer patients. (Harris, 2004)

The interaction between the parent and the child receiving treatment can have an impact on the perceived level of pain. In their study, Cline, et al. (2006) identified four communication behaviors between parent and child during treatment: (a) normalizing, (b) invalidating, (c) supportive, and (d) distancing. Normalizing communication is a manner in which coping is a relational task. The parents act as a support but imply the child should cope through routine behaviors. Invalidating communication places the child alone in the situation. Parents actively deny their child’s responses to the distressing situations and they deny the need for their child to cope. Supportive communication is described as parents who engage actively to offer support and coping strategies to their child. Lastly, distancing communication is when parents avoid the emotional and physical connection with their child, placing the child alone to cope independently. The authors noted that the data analysis indicated that children of distancing parents experienced higher levels of pain or distress when compared to other the communication behaviors. Worse treatment reactions were experienced by the children whose parents demonstrated invalidating behaviors during the treatment process.
In a study conducted by Harris (2004) 35% of pediatric patients experienced psychological effects in relation to cancer. During the treatment process, lifestyle changes of pediatric patients had a profound psychological affect. Moody, Meyer, Mancuso, Charlson, and Robins (2006) reported that children diagnosed with cancer often felt lonely, isolated, and lacked a normal childhood experience. Patients were often not able to participate in activities with other children due to neutropenia, an abnormally low number of neutrophils (type of white blood cell), and disconnection from their peers. Along with the disconnection from peers, hospitalization and its confinement increased the patient’s loneliness and isolated feelings. The children, in the study, suggested the hospital provide a more social environment with a variety of activities. They also requested better tasting medicine and an elimination of needle sticks. The children understood the need for these medical treatments but would have liked less evasive procedures.

Adolescents and children identified stress related issues when coping with cancer. Children felt angry about their cancer but seemed aware of the seriousness of the disease. Cancer diagnosis also produced fear for adolescent patients; the fear resulted from feelings of vulnerability and thoughts of death and its impact on family members. One patient suggested, “Doctors should provide more detailed anticipatory guidance of the treatment experience. They should tell ya’ your gonna’ look like you might be dyin’; weak, bald, skinny.” (Moody, et al., 2006, p.964). Educating the patient about illness, self concept, and gaining a sense of autonomy and control is an essential component in managing psychosocial stressors.
Types of Treatment

The treatment of cancer is dependent upon each individual’s unique situation. Having knowledge about the child’s type of cancer is essential when determining a course of treatment because the various types of cancers respond differently to treatment options. The most common types of treatment for cancer include: surgery, radiation, chemotherapy, and biologic therapies (American Cancer Society, 2004). Surgery is often a first treatment choice for patients with cancer because it has fewer side effects and has the greatest chance of a cure for some cancers. Surgery is most affective for cancers that appear to be localized (contained in a specific area). Radiation therapy can be used in conjunction to surgery or chemotherapy although it can also be used alone. Radiation therapy damages or destroys the cells that are cancerous thus hindering them from multiplying. Chemotherapy is used to cure, to slow the growth, to decrease spreading, and to relieve symptoms caused by cancer that has spread to other sections of the body (metastasized) through the blood stream. This treatment is often given intravenously or orally in cycles that last approximately six months. Biologic therapies utilize the body’s natural defense system (immune system) to stop or slow cancer cell growth. Many different biologic therapies are used today and can be used in combination with chemotherapy and radiation. (American Cancer Society, 2004).

Nutrition

Children diagnosed with cancer need a special diet when going through treatment. Nutritional needs change throughout the course of the treatment. Some of the changes include a need to increase the amounts of protein, carbohydrates, fat, water, vitamins, and minerals in the child’s diet. After a child receives treatment, an increased need for protein
is essential to help heal tissues and fight off infections. Protein needs can increase by as much as 50% compared to a healthy child of similar age (American Cancer Society, 2006). An increase of approximately of 20% of calories from carbohydrates and fats is needed for energy to promote healing of the tissue (American Cancer Society, 2006). Vitamins and minerals are essential for growth and development and provide the body with the needed components to obtain nutrients from food. Water is needed to prevent dehydration; consultation with a dietician is recommended to learn about proper amounts of water to stay hydrated. Meeting the recommended nutritional needs for patients with cancer can be difficult to meet because of altered food intake and taste perceptions.

Limited food choices, changes in taste and smell, chemotherapy, and poor appetite are reasons identified by children that resulted in decreased pleasure from food (Moody, et al., 2006). Skolin, Wahlin, Broman, Hursti, Larsson, and Hernell (2006) interviewed children, parents, and nurses and identified two categories related to food problems after the start of chemotherapy: causes of eating problems and altered food choice. Patients along with their parents identified change in taste of food as the reason for decreased food intake. Children identified learned food aversions as the second leading cause of eating problems. Another common complaint among children was the smell of food; this resulted in children refusing food trays and wanting roommates who also refused food trays (Moody, et al., 2006). Skolin, et al. (2006) noted that important causes of decreased food intake were nausea, vomiting, and pain caused by blisters in the mouth and abdomen; vomiting and bad tasting food were reasons children did not meet the nutritional requirements. In order to avoid bad tasting food, patients requested spicy and strong flavored foods to avoid the enhanced bitter taste in common foods.
**Energy Conservation**

Fatigue has been identified as a frequent and distressing problem related to cancer and its treatment. Cancer related fatigue interferes with a patient’s ability to function and fulfill daily roles and activities, therefore decreasing their quality of life. Cancer related fatigue is often predictable and follows patterns. Barsevick (2002) noted that shortly following cyclic chemotherapy infusions, a patient’s fatigue level elevated, and fatigue levels of patients receiving radiation therapy increased over the course of the treatment. Insomnia, pain, nausea, and depression can also have an impact on a cancer patient’s level of fatigue. Fatigue management can be the key to increasing quality of life.

Fatigue management can be accomplished through education and pharmacological as well as non-pharmacological approaches. Educating patients about cancer related fatigue is important in order for patients to become aware of management and self care strategies to improve quality of life. Cancer patients are encouraged to exercise, but consulting with a physician first is important in order to become aware of contraindications and comorbidity. Exercise programs should be tailored to meet the demographic needs (age, gender, diagnosis) of each patient. (Barsevick, 2002)

According to Barsevick (2002), cancer patients are encouraged to incorporate energy conservation techniques into their daily life in order to decrease the depletion of energy. In order to conserve energy, cancer patients are encouraged to ask for help with tasks that they would normally complete independently. Some energy conservation techniques identified by health care professionals are pacing, prioritizing, adaptive equipment, and scheduling. The American Occupational Therapy Association (2002) defines pacing as maintaining a consistent effective rate or tempo of performance
throughout the steps of the entire task. Prioritizing is organizing tasks in a manner of importance. Adaptive equipment can be used to conserve energy by assisting the individual with the task at hand. Lastly, scheduling techniques help to organize an individual’s day to complete more exhausting activities at times of higher energy. Also, a fatigue diary can be used to monitor fatigue levels (Barsevick, 2002). These techniques allow cancer patients to preserve energy so it is available for tasks.

**Coping**

Coping is the way in which individuals handle their attitudes and behaviors in order to effectively manage emotions and deal with stress (Kneier, Behar, Rosenbaum, & Rosenbaum, 2004). Individuals cope in different ways and some methods are more effective than others. Effective ways for coping depend on the patient’s personality, past coping strategies, and current life situations. In the study conducted by Moody et al. (2006) noted that children and adolescents could identify stressors related to cancer. Children reported having feelings of anger in relation to the cancer whereas adolescents had more feelings of fear about death and how it would affect their parents. Coping with cancer may be a long process for patients and implementing different strategies may be dependent upon the stage of the illness and how the individual responds to the diagnosis of cancer.

In their study Bull and Drotar (1991) found that children with cancer reported stressors related to handicaps (physical disabilities), followed by treatment (going to the hospital), and general cancer related stresses (being diagnosed with cancer). The authors also found that the children were affected more by stressors related to life in general than by stressors related to cancer problems. Because of the different types of situations that
can cause stress for a child with cancer it is important to incorporate healthy coping strategies as part of the treatment process. Coping strategies are the processes individuals use to handle their attitudes and behaviors towards the stressors they are facing (Kneier, Behar, Rosenbaum, & Rosenbaum, 2004).

Treatment Team and Interventions

An interdisciplinary approach is often utilized because each discipline brings specialized information into the process. The interdisciplinary team is available to assist patients and families throughout the treatment process. Team members collaborate with one another to determine and plan the most effective and individualized treatment for each patient. During hospitalization or clinic visits, patients and families will become familiar with the treatment team. At times, other disciplines maybe consulted when specific situations arise. The American Cancer Society (2006) identified members of the oncology team to include: doctors, nurses, and social workers; often the medical team considers parents, patients, and siblings as part of the team. Other team members may include psychiatrists, teachers, chaplains, neurologists, dieticians, radiologists, pathologists, and occupational therapists. According to the American Cancer Society (2001), the roles of these team members are described below:

Pediatric Oncologist: Medical doctors specializing in oncology of children. They plan and determine the course of treatment for the patient.

Psychiatrists: Medical doctors specializing in mental health and behavioral disorders. They also provide counseling and prescribe medications.
Teachers: Individuals that help to bridge the gap between the hospital and school. They help instruct students based on plans outlined by the patient’s teacher from their home community.

Chaplains: Individuals who provide the spiritual needs of the patient and family.

Neurologists: Doctors who treat problems of the nervous system.

Dieticians: Health professionals that are experts in the area of food and diet.

Radiologist: Doctors with special training in diagnosing diseases by reading x-rays and other types of imaging studies.

Radiation Therapists: Individuals who are trained in delivering radiation treatments.

Pathologists: Doctors who specializes in diagnosis and classification of diseases by laboratory tests.

Occupational Therapists: Therapists that provide resources, build endurance, address psychosocial skills, increase strength, and aid in overall improvement of the quality of life.

The Role of Occupational Therapy

The role of occupational therapists in cancer treatment facilities is increasing. An occupational therapists goal is not to find a cure for cancer but to get the patients back doing activities they enjoy. With increased survival rates of cancer patients, occupational therapists can help manage the effects caused by chemotherapy, surgery, and radiation. Occupational therapists can play a role in a patient’s life by building strength and endurance and addressing psychosocial skills in order to reach a desired level of functioning (Strzelecki, 2006).
“Occupational therapy is so powerful and important because we are a discipline that addresses sensory motor skills, and cognitive and psychosocial aspects. We look at the environment, and we also try to find out functional goals, as well as coping and leisure activities”, stated Ivy, who was interviewed for this article (Strzelecki, 2006, p.7).

Occupational therapists also address equipment options, self care issues, individualized care, home evaluations, and meaningful occupations with the patients. Ivy an occupational therapist who was interviewed in Strzelecki (2006, p.8) stated that physicians thought they had good palliative care for their patients, “but he no longer thinks that people receive the full treatment unless they get occupational therapy.” Moore and Beckwitt (2006) identified the following areas that need to be addressed more frequently with patients and families: ways to deal with the illness, side affects of treatment, symptom management methods, educational handouts about tests, holding educational workshops, field visits, and in home procedure training. These areas can easily be fulfilled by the role of an occupational therapist in a cancer treatment setting.

Taylor and Currow (2002) found that leisure, work and driving were identified by patients as needs that were not being met. With physician screenings, these areas could be met by occupational therapists.

Effects of Pediatric Cancer on Family

Frequently, when a child is diagnosed with cancer, the balance and structure within a family is disrupted. “Diagnosis, treatment, possible remission and relapse, plus the extensive side affects of treatment, repeated hospitalizations and hospital visits represent disruption for all family members.” (Houtzager, Grootenhuis, & Last, 1999,
Often siblings of children diagnosed with cancer mention feeling lonely, isolated, anxious, rejected, fearful, jealous, frustrated, angered, and guilty. It has been noted that siblings internalize problems and use denial-like coping strategies when adjusting to the recent changes within the family. Behavioral problems and attention seeking behaviors were noted in school and at home. Communicating openly about the illness is an important way in which siblings adapt to the illness. When the illness is not discussed thoroughly feelings of guilt, confusion, and anxiety may result in siblings of patients with cancer. Including siblings in a patient’s treatment process was identified by parents as being important (Houtzager, Grootenhuis, & Last, 1999). In their study Moore and Beckwitt (2006) noted that sibling involvement was an intervention that was often ignored by treatment facilities; the patient’s ability to adjust to the illness was also compromised when siblings were not involved in the treatment process. When parents communicate limited information about the patient’s disease ignorance can cause siblings to isolate themselves within the family system. Siblings have the tendency to withhold discussing their worries and feelings with parents in order to protect themselves from threatening emotions (Houtzager, Grootenhuis, & Last, 1999).

According to Coffey (2006) parent’s feelings regarding their child’s diagnosis changed during the course of the illness. Parenting a child with a chronic illness often results in strong emotions to protect their child from harm; anger emerges as a strong emotion when parenting a child with health concerns. In the study conducted by Coffey (2006) the authors identified that parents focused their anger and frustration on healthcare providers. Parents are often faced with changes in the daily care of their child. Chao, Chen, Wang, Wu, and Yeh (2003) noted that parents adjusted their attitudes and
behaviors in ways such as being more protective, less demanding, and more lenient towards the child. Parents reported being more cautious about siblings’ activities of daily living (ADL’s). When caring for children with chronic illness parents felt overwhelmed, guilty, and helpless about the care their child needed (Coffey, 2006). The authors wrote that on a positive note, patients and parents noted enhanced relationships between siblings and the child with cancer. Interpretation of the disease by the family and their manner of coping will depend on the values, strengths, and the way in which the family adapts to stressful events.

**Communication**

Open lines of communication are critical when a child is initially diagnosed with cancer. The shock of the diagnosis often leaves the parents feeling overwhelmed with a multiple number of stressors. Scrimin, et al. (2005) observed that important information communicated after the diagnosis is often not absorbed by the parents. Parents are faced with making life threatening decisions at a time when stress and anxiety levels are high.

During a time when stress and anxiety are high, parents and children can turn to the internet to find information about their child’s specific diagnosis. The internet can provide information about treatment options which can assist in making difficult decisions. Emotional and psychosocial support can be gained through joining online community care chat rooms. According to Dickerson, Boehmke, Ogle, and Brown (2006) cancer patients that incorporated the use of the internet into the use of their care became more active in decision making in relation to their treatment options. The researchers encouraged the use of the internet but requested that patients bring questions and information back the medical team for further discussion.
According to Kelly and Porock (2005), the early stages of cancer treatment should focus on the disease, prognosis, and treatment options. Once these areas are addressed symptom management and psychosocial concerns should be addressed. The information needs shift throughout the child’s cancer treatment in order to meet the information needs of the parents. In the study conducted by Kelly and Porock (2005) nurses identified treatment, symptom management, and psychomotor skills as topics parents needed the most education on. Other topics identified by nurses as priority teaching areas included coping skills, chemotherapy, medication, bone marrow suppression, and psychosocial issues. (Kelly and Porock)

Parents have the right to be heard and understand care surrounding their child. Scimin, et al. (2005) stated parents should be spoken to in a clear, short, and truthful manner in order to ensure understanding. Healthcare professionals should not set false hopes for the patient and their parents but rely on realistic expectations; an easy everyday conversation with parents and patient is an effective way to keep lines of communication open. The researchers noted the importance of summarizing the parents’ thoughts and concerns by using key words. This technique effectively obtains the attention and clarifies understanding by the physician.

End of Life Issues

Improving the quality of life of a patient with a terminal illness should be of interest to healthcare professionals. Knowing when and how to discuss end of life issues can be difficult for these professionals. When healthcare personnel discuss end of life issues, they should use their intuition and common sense regarding the time of delivery (Clayton, Butow, & Tattersal, 2005). When the physicians discuss end of life information
they should provide emotional support while maintaining a calm and gentle manner. According to Clayton, Butow, and Tattersal (2005) patients, caregivers, and staff members identified the importance of censoring information about end of life issues to each patients liking. The patient’s preference may change over the course of the illness, and raising the topic of prognosis and end of life issues can be difficult for patients to discuss with their physician. Therefore, it is important for physicians to make the topic of end of life issues accessible and to approach the topic in a sensitive matter.

Making sure that a patient’s preferences for end of life choices are fulfilled requires frequent and open communication between family members and physicians. Engelberg, Patrick, and Curtis (2005) found that adult patients identified controlled levels of pain, breathing comfortably, avoiding medical measures to prolong life, and arranging for healthcare costs and funeral arrangement as important end of life decisions. Other important decisions that patients and family members identified included maintaining dignity and self respect, as well as avoiding fear and being at peace with dying. It is important to keep in mind that each patient is unique and has specific individual needs. Some patients include reminiscing about life experiences and telling family stories as part of their preparation for death (Jacques & Hasselkus, 2004).

Conclusion

When children are initially diagnosed with cancer, parents often feel overwhelmed with the diagnosis, information, and treatment options. The child’s outcome is interrelated to the parent’s understanding of their diagnosis. The literature demonstrates that there is a need for educational materials about childhood cancer, treatment options, and interventions. Active engagement in a child’s treatment process
may improve their functional well being and increase their perceived quality of life. The authors of this project found a Parent Education Handbook from The National Cancer Institute; this handbook was identified by these authors as not being user friendly because of the length, complexity, and use of medical terminology. The project proposed is an educational manual for parent’s to assist in understanding their child’s diagnosis and provide interventions to address side affect from treatment. This handbook is designed by occupational therapy students due their ability to address all aspects of an individual’s life. They are also trained in evaluating cognitive, physical, and psychosocial constraints that can decrease an individual’s perceived quality of life. This handbook will be designed to use as a quick reference and will be user friendly for parents and families.
CHAPTER III
ACTIVITIES/METHODOLOGY

Due to an interest in oncology, the authors of this scholarly project researched the roles that occupational therapists have in this area. An interest in pediatric oncology was developed through personal experiences the authors had with their friends at a younger age. After looking back on these experiences, we, the authors, could see the profound impact that childhood cancers have on parents as well as other close relationships. It was felt that occupational therapists could assist parents along with their child, in effectively dealing with the diagnosis.

A broad base of literature was reviewed on pediatric oncology and the effects the diagnosis has on the parents. The role an occupational therapist can play on the treatment team was also explored. The authors of this project did not find any information that would benefit the parents when their child is initially diagnosed with cancer. They did find two handbooks targeted to parents that have a child diagnosed with cancer, though these handbooks were extensive, lengthy, and contained medical jargon. Therefore, a topic proposal was written, submitted, and approved for the development of an education handbook for parents addressing immediate concerns regarding their child’s diagnosis. The final product of this scholarly project was the development of *Pediatric Oncology: Parent Education Handbook*.

The methodology used to gather the information for the development of the parent handbook included a review of the current literature and research on pediatric
cancer. The process of developing the literature review included search engines such as PubMed and Google, focusing on pediatric cancer. Other resources utilized included library information and data received from the American Cancer Society, the National Cancer Institute, and other related websites. After reviewing the literature the topics the authors felt occupational therapists could address and were most important included: energy conservation, nutrition, communication, family, end of life issues, team approach, and an overview of cancer, along with the specific skills of an occupational therapist practicing in a pediatric cancer treatment center.

The process of developing this manual began with a proposed outline of our product. The authors decided that the educational handbook should provide a brief overview of childhood cancers as well as definitions of important terminologies. The manual was divided into nine sections, starting with an introduction followed by explanation of the condition, oncology team members, ways to enhance communication, coping with cancer, tips to maintain schedules, nutrition, energy conservation, end of life issues, and ending with internet supports. Information that was found from the literature review was utilized to develop the educational handbook.

The authors of this scholarly project expect to have a parent friendly and easy-to-use guide that will assist parents when their child is initially diagnosed with cancer. The authors hope that occupational therapists as well as other health care professionals will be able to distribute this guidebook to their patients. It is important to take into consideration that this is not a complete manual but rather a starting point in which parents can begin to understand issues that could and will arise during their child’s treatment.
CHAPTER IV

The Pediatric Oncology: Parent Education Handbook is a manual that is designed to provide parents and caregivers with information about how to cope, handle, and survive when their child is diagnosed with cancer. When a child is initially diagnosed with cancer things may seem overwhelming; this handbook will outline what to expect and assist parents, to become an advocate and a supporter for their child’s treatment. Parents, know their child better than anyone else; an important part of their role is to provide the medical team with valuable information about their child’s behaviors, reactions, and what works for their child (American Cancer Society, 2001).

This handbook has its foundation from current literature and research. The Occupational Adaptation theory (Schkade & Schults, 2003) was used to guide the development of this product. Below is a list of what is included in the manual as well as a brief explanation of why it was included

- **Explanation of Condition and types of pediatric cancer:** This was chosen for the handbook to provide a written source that is easily accessible to gain a brief understanding of what cancer is and the type of cancer the child has.

- **Signs and Symptoms:** This was included in the handbook to educate parents on what they should be aware of. This list can vary from person to person depending on the specific type of cancer and treatment, in addition to the way the body handles the condition.
Oncology Team Members: This was included to inform the parents of all possible team members that could come in contact with their child throughout the treatment process. Often the different professions can become confusing and this will help them understand their role in the treatment.

Enhance Communication: This was included in the handbook to learn effective communication skills in order to avoid being overwhelmed by the amount of information. Communication with the treatment team was included as well as communication with family members.

Coping with Cancer: This was included to provide hints for management of emotions and to deal with stress in relation to cancer. Coping with cancer may be a long process for the child and his/her parents and implementing different strategies may be dependent on the stage of the illness.

Maintaining schedules: This section was included because parents and children have a difficult time maintaining schedules due to the treatment schedules, many physician appointments, and the overall health of the child. Maintaining a normal schedule helps to normalize life through all of the chaos.

Nutrition: This was incorporated into the handbook because of the special diets that the child going through treatment needs. Nutritional needs change throughout the course of the treatment. Some recipes are included to help parents provide nutritious meals for their child.

Energy Conservation: Since fatigue is identified as a frequent and distressing problem related to cancer and its treatment, it is beneficial to incorporate energy
conservation techniques into the child’s daily life in order to decrease the depletion of energy.

End of Life: Making sure that a patient’s preferences for end of life choices are fulfilled requires frequent and open communication between family members and physicians. It is important to keep in mind that each patient is unique and has specific individual needs.

Internet supports and valid websites: It is difficult for patents to retain all of the information provided from the healthcare team so a list of resources and organizations was compiled for parents to turn to for further information or help.

The areas listed above are intended to provide parents and/or caregivers an initial starting point as well as support when their child is diagnosed with cancer. This handbook is designed to be used as a communication source between parents and the physicians. Although, this is not an extensive guide about pediatric cancer it is a start to help you as a parent gain valuable knowledge and it will direct you to other sources of information as you are ready.
CHAPTER V
SUMMARY

The Pediatric Oncology: Parent Education Handbook is intended for use by parents when their child is first diagnosed with cancer. It is important to take into consideration that this is not a complete manual but rather a starting point in which parents can begin to understand issues that could and will arise during their child’s treatment. This guide should be used in conjunction with guidance by either an occupational therapist or other health care professionals that are involved in the treatment of the child.

The problem identified by the authors of this product is that there is a mismatch of available user-friendly resources for parents whose child has just been diagnosed with cancer. “Diagnosis, treatment, possible remission and relapse, plus the extensive side affects of treatment, repeated hospitalizations and hospital visits represent disruption for all family members” (Houtzager, Grootenhuis, & Last, 1999, p.302). When caring for children with a chronic illness parents felt overwhelmed, guilty, and helpless about the care their child needed (Coffey, 2006). At this time of chaos, it is important that parents have a resource guide they can resort to when questions arise, for support, or when looking for helpful hints. Occupational therapists have the knowledge base to develop and distribute a handbook for parents providing concise and important information regarding immediate areas of concern (diagnosis, treatment options, and intervention strategies).
Other roles that occupational therapists can fill on the treatment team include addressing strength and endurance concerns as well as psychosocial skills in order to reach a desired level of functioning (Strzelecki, 2006). Occupational therapists can also address equipment options, self care issues, individualized care, home evaluations, and meaningful occupations with the patients. Moore and Beckwitt (2006) identified the following areas that need to be addressed more frequently with patients and families: ways to deal with the illness, side affects of treatment, symptom management methods, educational handouts about tests, holding educational workshops, field visits, and in home procedure training. These areas can easily be fulfilled by the role of an occupational therapist in a cancer treatment setting. In addition, Taylor and Currow (2002) found that leisure, work, and driving were areas identified by patients as important needs that were not being met. After a referral from the physician, these areas could be met by occupational therapists.

The authors of this product hope to help other occupational therapists understand the needs of parents when their child is initially diagnosed with cancer. The authors of this product will introduce the manual through an oral presentation addressing the benefits of the handbook and covering information that is included within it. In addition, the authors hope to have the opportunity to share the manual with occupational therapists and other team members in the clinical setting. As the product is being used, a satisfaction survey will be provided to the parents, family members, and care providers to determine the effectiveness of the manual, and to gather possible suggestions for further improvement.
It is important to note that the authors of this product do not have special training in the area of pediatric oncology; this should be taken into consideration before the distribution of this product. In addition, parents should take into consideration the specific needs of their child when dealing with cancer; it is important to note that all the information provided in this handbook may not relate to your child’s specific needs. Every child diagnosed with cancer has a different way with handling the situation; the handbook provides a starting point in which parents can develop further strategies when caring for their child.


http://www.cancerbackup.org.uk/Resourcessupport/Eatingwell/Cancerbackuprecipes/Soupssalads/Avocadograpefruitsalad

http://www.cancerbackup.org.uk/Resourcessupport/Eatingwell/Cancerbackuprecipes/Drinks/Bubblybuildup

/Cancerbackuprecipes/Maincourses/Chickenbreaststuffedwithasparagusandcheese
http://www.cancerbackup.org.uk/Resourcessupport/Eatingwell

http://www.cancerbackup.org.uk/Resourcessupport/Eatingwell/Cancerbackuprecipes/Soupssalads/Tomatobasilsoup

http://www.cancercare.org/pdf/fact_sheets/fs_siblings.pdf


http://www.foreverfamilies.net/xml/articles/children_with_chronic_illness.aspx?&publication=full


Appendix A Product
Contents

I. Introduction........................................................................................................3
II. Explanation of the Condition...........................................................................5
   A. Types of Pediatric Cancer.................................................................7
   B. Signs and Symptoms.................................................................10
   C. Types of Treatment..............................................................13
III. Oncology Team Members.........................................................................15
IV. Ways to Enhance Communication.........................................................18
V. Coping with Cancer..............................................................................23
VI. Tips for Maintaining Schedules...........................................................27
VII. Nutrition..............................................................................................29
   A. Recipes.........................................................................................33
VIII. Energy Conservation.............................................................................38
IX. End of Life Issues....................................................................................41
X. Internet Supports and Valid Websites....................................................44
XI. References...............................................................................................47
Introduction
Introduction

The *Pediatric Oncology: Parent Education Handbook* is a manual that is designed to provide parents and caregivers with information about how to cope, handle, and survive when your child is diagnosed with cancer. When your child is initially diagnosed with cancer things may seem overwhelming; this handbook will outline what to expect and assist you, as the parent, to become an advocate and a supporter for your child’s treatment. As a parent, you know your child better than anyone else; an important part of your role is to provide the medical team with valuable information about your child’s behaviors, reactions, and what works for your child (American Cancer Society, 2001).

This handbook has its foundation from current literature and research. Although, this is not an extensive guide about pediatric cancer it is a start to help you as a parent gain valuable knowledge and it will direct you to other sources of information as you are ready. This handbook is designed to: provide an overview of cancer, describe roles of possible treatment team members, give ways to improve communication, help manage poor nutrition, give tips for energy conservation, provide coping strategies, help in maintaining daily schedules, and address end of life concerns.
Explanation of the Condition
Explanation of Condition

According to the American Cancer Society (2004), cancer is described as a cluster of related diseases that develops in cells, the body’s building blocks of life. Cancer results from the abnormal growth of cells in different parts of the body, and cancer cells have a longer lifespan than normal cells. The cancer cells continue to grow and divide at a rapid rate replacing normal tissue. The main formation of cancer is a tumor, but it can also develop in the blood and the blood forming organs. Often, cancer cells travel to different parts of the body, this process is called metastasis, which can spread the disease quickly.

Deoxyribonucleic acid (DNA) is located in every human cell and is responsible for the cells’ function. When the DNA in the cell is damaged cancer cells form; damaged DNA can be inherited or can be caused by exposure to environmental toxins (American Cancer Society, 2004). According to the American Cancer Society (2006), one way to acquire cancer is through inheriting damaged cells; this happens because damaged DNA is unable to repair itself. This damaged DNA can be passed on from generation to generation. Damage to cells also occurs because of exposure to environmental toxins such as radiation or chemicals. Environmental factors are not as prevalent for children as they are in adults diagnosed with cancer (American Cancer Society, 2006).
Types of Pediatric Cancer
Types of Pediatric Cancer

**Acute lymphoblastic leukemia (ALL)**
- The average age of onset of ALL in children is four years old.
- The cancerous cells are found in the bone marrow and formed by white blood cells.
- ALL is cancer of the white blood cells, this results in the inability of the body to fight infection.
- Leukemia quickly infects the blood stream and spreads throughout other parts of the body.
- A risk factor for ALL is exposure to radiation.
- The prognosis for this type of cancer is dependent upon gender, race, severity, lymphocytes, and a previous diagnosis of Down’s syndrome.

**Central nervous system (CNS)**
- CNS cancer develops in different areas within the brain and spinal cord and the cause is unknown.
- Risk factors for CNS include cigarette smoking, exposure to radiation, and exposure to environmental toxins.
- The prognosis of a child with CNS is dependent upon location, behavior, and appearance of the tumor.

**Non-Hodgkin lymphoma/Hodgkin lymphoma**
- Non-Hodgkin and Hodgkin lymphomas are cancer of lymphoid tissue and have the tendency to spread to other organs in the body.
- The causes and risk factors for these two types of cancer are unknown.
- Immune difficulties could increase the child’s risk of developing this type of cancer.
**Wilms' tumors**
- Wilms' tumors develop in the kidneys and are cancerous.
- The typical age of onset is three years old for this type of cancer.

**Retinoblastoma**
- Retinoblastoma is cancer that develops in the eye, specifically on the retina.
- Risk factors for this include genetics.

**Rhabdomyosarcoma**
- Rhabdomyosarcoma is described as cancer of the soft tissue (muscle).
- Risk factors include rare genetic disorders.

**Bone cancer**
- This type of cancer originates in the bone.
- Common forms of bone cancer include Osteosarcoma (bone tissue), Chondrosarcoma (bone cartilage), and Ewing sarcoma (bone marrow).
- Risk factors for bone cancers include exposure to radiation and genetics.

(The above information is adapted from the American Cancer Society, 2001, 2004, 2006; Clark & Fletcher, 2003; National Cancer Institute, 2006.)
Signs & Symptoms
Signs and Symptoms

The signs and symptoms of cancer vary from person to person depending on the specific type of cancer and treatment.

- **Fatigue:** A perceived sense of tiredness caused by bodily or mental exertion. Three different levels of fatigue have been identified in relation to cancer:
  - Typical tiredness - is indicated through drooping eye lids, sluggish behavior, quietness, or grumpy behavior
  - Treatment fatigue - is difficult to identify and predict though it often follows hospitalizations, chemotherapy, radiation, and surgeries
  - Shutdown fatigue - is identified by its intensity, duration, and immobilizing effects, for example an enormous loss of energy or a hibernating phase

- **Pain:** An unpleasant sensory or emotional sensation associated with perceived or actual illness or injury. Helping children identify their pain assists in possible diagnosis and treatment of this symptom.

- **Weight loss:** A decrease in the amount of heaviness or mass.

- **Difficulty swallowing:** The child has a hard time allowing food and beverages to pass from the mouth into the stomach due to sores in the mouth and/or dry mouth.

- **Weakness:** A lack of strength, firmness, and/or energy.
• **Nausea:** A feeling of sickness or queasiness, which can be experienced because of treatment.

• **Bruising:** The development of discolored spots on the skin.

• **Constipation:** A condition of the bowels in which the feces are dry and hardened and evacuation is difficult and infrequent.

• **Fever:** An abnormally high body temperature.

• **Psychological Symptoms:** Cognitive or emotional complaints perceived by the child in relation to their diagnosis or treatment. Children diagnosed with cancer often feel lonely, isolated, and lack a normal childhood experience.

• **Paleness:** A decrease in the color of the child’s skin tone.

(The above information is adapted from Davies, Whitsett, Bruce, & McCarthy, 2002; Harris, 2004; Moody, Meyer, Mancuso, Charlson, & Robins, 2006; Venes, 2005.)
Types of Treatment
Types of Treatment

The treatment of cancer is dependent upon each individual’s unique situation. Having knowledge about the child’s type of cancer is essential when determining a course of treatment because the various types of cancers respond differently to treatment options. The most common types of treatment for cancer include:

**Surgery**
- Surgery is usually the first treatment choice because there are fewer side effects and an increase chance of cure for some cancers.
- It is proven to be the most effective treatment for cancers that appear to be localized (contained in a specific area).

**Radiation**
- Radiation is designed to damage or destroy the cells that are cancerous.
- This choice of treatment can be used alone or in conjunction with other treatments.

**Chemotherapy**
- Chemotherapy is used to cure, slow the growth, decrease spreading, and relieve symptoms caused by cancer.
- It can be administered through injections, intravenously (IV), or orally through cycles that last approximately six months.

**Biologic Therapies**
- This type of therapy utilizes the body’s natural defense system (immune system).
- Biological therapy helps to fight cancer by stopping or slowing cancer cell growth and it assists in preventing the spreading of cancer throughout the body.
- It can also be used in combination with other treatments such as radiation/chemotherapy.

(The above information is adapted from American Cancer Society, 2004.)
Oncology Team Members
An interdisciplinary approach is often utilized because each discipline brings specialized information into the process. The interdisciplinary team is available to assist patients and families throughout the treatment process. Team members collaborate with one another to determine and plan the most effective and individualized treatment for each patient. The roles of the different team members are described below:

- **Pediatric Oncologist**: Medical doctors specializing in oncology of children. They plan and determine the course of treatment for the patient.

- **Psychiatrists**: Medical doctors specializing in mental health and behavioral disorders. They also provide counseling and prescribe medications.

- **Teachers**: Individuals that help to bridge the gap between the hospital and school. They help instruct students based on plans outlined by the patient’s teacher from their home community.

- **Chaplains**: Individuals who provide the spiritual needs for the patient and family.

- **Neurologists**: Doctors who treat problems of the nervous system.

- **Dieticians**: Health professionals that are experts in the area of food and diet.
- **Radiologist**: Doctors with special training in diagnosing diseases by reading x-rays and other types of imaging studies.

- **Radiation Therapists**: Individuals who are trained in delivering radiation treatments.

- **Pathologists**: Doctors who specializes in diagnosis and classification of diseases by laboratory tests.

- **Occupational Therapists**: Therapists that provide resources, build endurance, address psychosocial skills, increase strength, and aid in overall improvement of the quality of life.

(The above information is adapted from the American Cancer Society, 2001; Strzelecki, 2006; Canadian Cancer Society, 2006.)
Ways to Enhance Communication
Ways to Enhance Communication

When learning about your child’s diagnosis the treatment team will be providing you, as the parent, with a lot of valuable information. It is important to learn effective communication skills in order to avoid being overwhelmed by the amount of information and your emotions. This is a stressful time and the treatment team realizes that parents usually do not remember everything. Here are possible suggestions to improve effective communication:

**Communication with the treatment team**

- Keep a separate notebook for writing down questions that arise regarding your child’s diagnosis/treatment.

- Ask for an explanation about procedures or about follow-up treatment.

- Bring a friend or family member with you to help gather information and listen with you.

- Use a tape recorder to record conversations with the healthcare provider (with their permission), this allows you to go back and listen for any information you may have missed during the appointment.

- Request an interpreter, if needed, in order to enhance communication and fully understand information about your child.

- Prior to the appointment, write out specific questions you would like answered or other information you are seeking.

- Share information with the physician about your worries, concerns, and problems.
• Don’t be afraid to talk about information, ask questions or get clarification, the treatment team is available to help you and your family get through this difficult time.

• Bring in additional information you have found, to have others help you determine the relevancy of the information.

• Don’t be afraid to re-schedule appointments for sooner than expected if things arise that concern you.

• Don’t be afraid to call, email, or fax your healthcare team with questions or concerns you may have.
**Communication with family members**

- Communicate openly with family members (including the patient’s siblings) about feelings and emotions.

- Tell children that being diagnosed with cancer is not their fault.

- Give honest and age appropriate information about the cancer to all family members.

- Spend time with your other children and include them in caring for the child with cancer when appropriate.

- Explain the diagnosis to the child with cancer and other siblings in age appropriate terms.

- Decide who should tell your child that they have been diagnosed with cancer. It is important to take into consideration the timing of this event.

- Decide who should tell the siblings of the child diagnosed with cancer. It is important to take into consideration the timing of this event.

- Let your child make choices, ask them what they think, feel, or want to know about the cancer.

- Inform the child with cancer about treatment and treatment effects (hair loss, weight loss, fatigue, etc.).
• Prepare family members for changes in the ill child’s appearance (weight loss, hair loss, etc.).

• It is important to take time everyday to love and support each other this will help to keep a positive outlook on treatment and the diagnosis.

• Being able to express your feelings as a parent, in turn shows children that it is okay to express their feelings.

(The above information is adapted from Livestrong The Lance Armstrong Foundation, n.d.; CancerCare, 2005; Canadian Cancer Society, 2006.)
Coping with Cancer
Coping with Cancer

Coping is the way in which individuals handle their attitudes and behaviors in order to effectively manage emotions and deal with stress. Individuals cope in different ways and some methods are more effective than others. Effective ways for coping depend on the patient’s personality, past coping strategies, and current life situations. Coping with cancer may be a long process for patients and implementing different strategies may be dependent upon the stage of the illness. The following suggested coping strategies can be utilized by cancer patients, parents, siblings, and other family members to promote mental well-being.

- **Humor:** The use of laughter for relief of pain (physical and emotional), reducing stress, and improving quality of life. Helps to promote health by stimulating the circulatory system, immune system, and other systems in the body.

- **Keep Optimistic:** The belief is to look on the bright side of events or conditions and to remain confident and cheerful. Optimistic patients have been shown to adjust to the illness/diagnosis better than individuals who are pessimistic.

- **Develop a Support System:** Developing a support network will assist patients, family members, and siblings to cope and adjust with the illness. Support groups provide a safe and supportive environment for expressing feelings, thoughts, and concerns. Support could also entail accomplishing small tasks (i.e. play a game, provide a nutritious snack, or just to listen).

- **Express Emotions:** Emotional expression is an outlet which individuals express their feelings. It requires open communication and provides a means for working through ones emotions. It is important to express emotions with individuals who provide a supportive environment.
• **Ask Questions:** It is important to ask questions to ensure understanding of the various treatments, medications, and overall diagnosis. You are provided with a vast amount of information and the healthcare team realizes that not all the information presented will be remembered; therefore asking questions is a common occurrence and is encouraged and expected.

• **Relax:** Find ways to release your emotions whether it is through exercise, meditation, crafts, breathing, reading, or finding an activity that is calming and enhances your mental health.

• **Religion and spirituality:** This can provide a variety of benefits for a cancer patient such as inner strength, peace of mind, and overall improvement of psychological adjustment.

• **Create a more friendly hospital environment:** Provide the opportunity for friends to visit the hospital when the child is medically stable and has sufficient energy (i.e. play dates). Include more stuffed animals, posters, plants, and flowers to provide a friendlier environment; make sure this is acceptable if the child is hospitalized. To enhance socialization with peers try to create an environment for specific interests (music room, play room, teen room, and game room).

• **Provide a safe atmosphere:** Providing a safe atmosphere allows for children to express their feelings of anger and fear in a healthy manner. If the child is reluctant to express feelings, this can be achieved through art or play therapy.

• **Support your child’s friendships and activities:** This will help your child stay connected to their peers and assist in decreasing feelings of loneliness and isolation.
• **Stick to a routine:** Your child is used to routine, so try to maintain daily structure as much as possible. This may be difficult because of medical appointments but it will help your child feel connected to everyday life.

• **Maintain limits on usual rules:** It is important to discipline your child as you did before the diagnosis of cancer; allowing your child to get by with inappropriate behavior does not make your child stronger. It may also help eliminate the perception by siblings that the child with cancer is getting special treatment.

(The above is adapted from Kneier, Behar, Rosenbaum, & Rosenbaum, 2004; Moody, Meyer, Mancuso, Charlson, & Robbins, 2006; Churchill, n.d.)
Tips for Maintaining Schedules
Tips for Maintaining Schedules

- As a parent, continue your “normal” daily routines such as shopping, laundry, meal preparation, etc.

- Allow your child to live life as they previously did before cancer, but be aware that after treatment your child may need more rest than usual.

- Encourage your child to stay in school when he/she is medically stable.

- Encourage your child to complete homework assignments when he/she is not capable of attending school.

- Keep household chores enforced; your child with cancer may need modifications depending on energy levels and physical capabilities.

- Follow through with regular disciplinary procedures for the child diagnosed with cancer and their siblings.

- Have reasonable expectations of your child with cancer keeping in mind the physical and mental capabilities of your child may change.

(The above information is adopted from NewYork-Presbyterian Hospital, n.d.; Dana-Farber Cancer Institute, 2006.)
Nutrition
Nutrition

Children diagnosed with cancer need a special diet when going through treatment to ensure that the patient feels better and stays strong. Nutritional needs change throughout the course of the treatment. Some of the changes include a need to increase the amounts of protein, carbohydrates, fat, water, vitamins, and minerals in the child’s diet. After a child receives treatment, an increased need for protein is essential to help heal tissues and fight off infections. Listed below are helpful nutritional hints to address the dietary needs of your child, in addition some healthy recipes will be provided.

Helpful Tips to Consider When Addressing your Child’s Nutritional Needs

- It is recommended that the child consumes at least:
  - six servings of breads, cereals, and grains daily
  - three or more servings of vegetables daily including leafy greens
  - two or more servings of fruit daily
  - two servings of meat or poultry
  - two servings of milk products daily

- The child should eat small amounts of food frequently, throughout the day.

- To ensure your child’s nutrition, schedule meal and snack times as you would with medications.

- Develop a list of foods your child tolerates and put it in a safe place for referencing.
- Have your child brush their teeth regularly to avoid bacteria growth and tooth decay that may alter the taste of food.

- If your child experiences a bitter or metallic taste in their mouth, try plastic utensils or try using mints or sour foods before a meal.

- Rinse away bad tastes by using water, salt or baking soda solutions, ginger ale, teas, or fruit flavored drinks.

- Because chemotherapy can cause nausea, be aware of foods that are given close to treatment times; this may cause your child to develop an association between that food and the nausea.

- Cancer and treatment symptoms can have an affect on your child’s nutritional consumption; there may be a significant decrease in appetite.

- When preparing meals for your child, explore stronger flavored or spicy food (i.e. Mexican, Italian, barbeque, sauces, and gravies).

- Preparing cold foods for your child can help to decrease odors that can affect the taste of food.

- Consult with your child’s oncologist about supplements such as vitamins and minerals to complement your child’s diet.

- Ensure that your child drinks plenty of fluids to prevent dehydration.

- If your child is experiencing diarrhea increase or try to include sodium and potassium in their diet (i.e. bananas, potatoes, avocados, and sports drinks).
• Avoid high fiber diets when your child is experiencing an episode of diarrhea.

• When your child is experiencing constipation talk to their physician about exercises that will increase bowel movement (i.e. walking).

• If experiencing constipation, increase fiber consumption in your child’s diet (i.e. fruits, vegetables, whole grains, and beans).

(The above information is adapted from Skolin, Wahlin, Broman, Hursti, Larsson, Hernell, 2006; People Living with Cancer, n.d.)
Recipes
Recipes

These recipes are intended to provide the nutrition needed for your child as well as to provide an enjoyable taste. The recipes from Cancerbackup.org (2006) are intended to be quick and easy to prepare. Here are a few examples of the recipes provided by this resource:

**Tomato basil soup** Serves 2

**Ingredients**
- 295g/10.5oz can of condensed cream of tomato soup
- 1 carton Neutral Fortisip
- 1 tablespoon pesto basil sauce

**To serve (per serving)**
- 28g/1oz croutons
- Sprinkling of grated parmesan cheese
- 2-3 fresh basil leaves

**Instructions**
1. Pour the soup into a saucepan.
2. Add the Neutral Fortisip and pesto basil sauce and heat gently, stirring constantly. Do not boil.
3. Pour into soup bowls and sprinkle each with croutons and grated parmesan cheese.
4. Garnish with basil leaves and serve.

**Specific conditions:**
Problems chewing or swallowing
Loss of weight/appetite

**Nutritional information** (approximate values per portion)
Energy: 565 kcal; Protein: 15g; Fat: 33g; Carbohydrate: 54g; Fiber: 2g.
Avocado and grapefruit salad  Serves 4

Ingredients
- 2 large ripe avocado pears
- 1 medium grapefruit
- 2 heads chicory
- 1 bunch watercress
- French dressing

Instructions
1. Peel and stone the avocados. Cut in slices lengthwise.
2. Peel and slice the grapefruit. Halve the slices.
3. Separate the chicory leaves and arrange around the sides of a serving bowl.
4. Wash and trim the watercress and pile into the centre of the dish.
5. Arrange the avocado and grapefruit slices over the top.
6. Drizzle with French dressing before serving.

Nutritional information
Energy: 205 kcal; Protein: 2.5g; Fat: 19g (of which saturates: 4g); Carbohydrate: 6g; Fiber: 4g.
Chicken breast stuffed with asparagus and cheese Serves 4

Ingredients
- 4 cornfed chicken breasts
- 12 pieces asparagus, cooked
- 115g/4oz emmenta cheese
- 1 tablespoon olive oil
- 28g/1oz butter
- Salt and pepper

Instructions
1. Preheat the oven to 200C/400F/Gas mark 6.
2. Heat the oil in a frying pan. Add the chicken breasts, skin side down, and fry gently to seal and color.
3. Turn the breasts over to seal on the other side. Leave to cool.
4. Trim the tips of the asparagus to about 4cm/1.5 inches and put to one side. Dice the remaining stems.
5. Dice the cheese and mix with the diced asparagus.
6. When the chicken breasts are cold, make an incision in the skin side of each about 5cm/2 inches long.
7. Use half of the asparagus and cheese mixture to fill each incision. Lay in the asparagus tips, 3 per breast, and then sprinkle the remaining asparagus mix over.
8. Put the breasts into an ovenware dish with the butter. Season and bake for 15–20 minutes until the chicken is cooked through.

Specific conditions:
Loss of weight/appetite

Nutritional information
Energy: 420 kcal; Protein: 47g; Fat: 25g (of which saturates: 11g); Carbohydrate: 0.5g; Fiber: 0.5g.
Bubbly build up

Ingredients
- 1 sachet Build Up
- 200ml/7floz whole milk
- 1 scoop ice cream

Instructions
1. Combine all the ingredients in a blender and process until well mixed and frothy.
2. Serve immediately.

Specific conditions:
Dry or sore mouth
Problems chewing or swallowing
Loss of weight/appetite

Nutritional information (approximate values per portion)
Energy: 390 kcal; Protein: 17.5g; Fat: 15.5g; Carbohydrate: 48g; Fiber: 0g.

(The above information is adopted from Cancerbackup.org, 2006)
Energy Conservation

Fatigue has been identified as a frequent and distressing problem related to cancer and its treatment. Cancer related fatigue interferes with a patient’s ability to function and fulfill daily roles and activities, therefore decreasing their quality of life. Cancer related fatigue is often predictable and follows patterns. Fatigue management can be the key to increasing quality of life. According to Barsevick (2002), cancer patients are encouraged to incorporate energy conservation techniques into their daily life in order to decrease the depletion of energy.

- It is important to document fatigue levels to understand their pattern which, in turn, allows the patient or family members to plan activities accordingly.

- It is important to schedule high energy activities when your child has the most energy throughout the day.

- As parent, assist your child in prioritizing what needs to be accomplished in a day and focus on the activities that are more important first.

- Make sure your child paces themselves throughout an activity in order to avoid exhaustion.

- Advise your child to sit down during bathing and dressing activities.

- Your child should try to decrease reaching by wearing button front shirts rather than pull-over shirts and teach him/her to bring their foot to their knee while putting on shoes.

- Have your child lay-out clothes and other necessary items before dressing to prevent excessive standing and to allow breaks.
• Have your child dress in comfortable clothing and shoes.

• Schedule rest periods throughout the day.

• Plan activities that can be accomplished by sitting.

• Arrange the environment (home or school) for easy access to needed supplies or equipment.

• Ensure that a nutritional and healthy diet is provided.

(The above is from Cancer Symptoms.org, 2006; Barsevick, 2002; UPMC Health System, 2002.)
End of Life Issues
End of Life Issues

Making sure that a patient’s preferences for end of life choices are fulfilled requires frequent and open communication between family members and physicians. Important decisions that patients and family members identified included maintaining dignity and self respect, as well as avoiding fear and being at peace with dying. It is important to keep in mind that each patient is unique and has specific individual needs. Some patients include reminiscing about life experiences and telling family stories as part of their preparation for death (Jacques & Hasselkus, 2004). Below are further suggestions that you, as a parent, can utilize when faced with end of life issues with your child:

- Use age appropriate language when talking to your child about end of life issues.

- Adapt the information to your child’s preference and be aware they may need/want to know more later, depending on the current situation and state of mind.

- Use common sense and intuition about the timing of discussing end of life issues with your child.

- Use simple terms and be upfront and honest with your child about death.

- Provide a comforting environment that allows your child to ask questions about death and dying.

- Ensure that your child understands that they will not die alone, that you will be by their side to provide them with comfort and love.
• Discuss with your child your family’s religious and spiritual beliefs about death and what happens after death.

• Allow your child a chance to say good-bye to loved ones and other special people in their lives. This can be accomplished in person, with letters, video tapes, or other creative ways.

• Give your child “permission” to die, so they don’t feel guilty about leaving family and friends.

• Reassure your child that they are special and have made a difference in the lives of many people (friends, families, school teachers, church members, etc.).

(The above information was adopted from Clayton, Butow, & Tattersall, 2005; Jacques & Hasselkus, 2004; People Living with Cancer, 2006.)
Internet Supports & Valid Websites

We're in this Together!!
When your child is first diagnosed with cancer, it is difficult to retain all of the information provided. Listed below are resources and organizations that you, as a parent, can turn to for further information or help.

- People living with cancer - provides a more extensive handbook for parents with a child that is terminally ill
  - http://www.plwc.org/portal/site/PLWC/menuitem.9020a4e60af864cfdf4b8f68ee37a01d/?vgnextoid=9c0c20c421779010VgnVCM100000f2730ad1RCRD

- Cancer Care
  - www.cancercare.org

- American Cancer Society
  - www.cancer.org

- The Wellness Community
  - http://www.thewellnesscommunity.org/default.asp

- National Cancer Institute - provides a more extensive handbook for parents with children diagnosed with cancer
  - www.cancer.gov

- Cancer Symptoms
  - http://www.cancersymptoms.org
• Ronald McDonald House
  • http://www.rmhc.com/rmhc/index.html

• Make-A-Wish Foundation
  • http://www.wish.org

• Dana-Farber Foundation
  • http://www.dana-farber.org/

• Canadian Cancer Society
  • http://www.cancer.ca

• Pediatric Brain Tumor Foundation of the United States
  • http://www.pbtfus.org/index.htm

• Dream Factory
  • http://www.dreamfactoryinc.com/Have_Dream/have_dream.html

• Children’s Cancer Research Fund
  • http://www.childrenscancer.org/
References


