## Running head: "I HAVE: CANCER"

"I Have: Cancer" An Educational Tool for Pediatric Patients with Intellectual and Developmental Disabilities and an Oncological Diagnosis

### Elizabeth Bradley Cotton

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1

#### Abstract

I have hypothesized a series of educational booklets that can be used to help pediatric patients with intellectual and developmental disabilities (I/DD) navigate an inpatient stay. For this project I have focused on pediatric cancer and created the first booklet, "*I Have: Cancer*." I envision the "*I Have*" series to expand and encompass more diseases and conditions as I continue my career and education. From my own experience and after consulting with people with multidisciplinary experience with pediatric I/DD, what seemed most helpful to the pediatric patient would be an individualized and interactive approach to patient education. This care booklet could be an inclusive and appropriate method of explanation of cancer for interdisciplinary use.

My intention is to promote appropriate language and terminology, advocate for pediatric patients with I/DD and their families, and above all, to educate these patients about the process of having cancer and being hospitalized. The hospital can be an alarming place for any child, and for those with I/DD it can be, confusing, and frightening, and disruptive to the routines that can be a source of comfort to them. I hope to alleviate some of the stress that these pediatric patients may experience, and provide a tool for communication between pediatric patients with I/DD and their caregivers.

After working with this population, I found it imperative to not only research, but to also provide an appropriate resource or tool for pediatric patients with I/DD, as the needs of these individuals differ from the standard needs of traditional pediatric patients. Children with I/DD are a diverse group whom healthcare professionals will inevitably see in practice. Nurses should be prepared to provide individualized, meaningful, quality care including patient education.

### Introduction

Life expectancy has increased significantly worldwide in people with intellectual and developmental disabilities (I/DD), resulting in an increased incidence of age related illnesses including cancer (O'Regan, & Drummound, 2008). The incidence of cancer is poorly documented for this population. Reports vary broadly, citing the incidence of childhood cancer in children with I/DD anywhere from five to eighteen percent (O'Regan, & Drummound, 2008). While little research exists for pediatric patients with I/DD and specific oncological diagnoses, it is generally accepted that individuals with I/DD have a significant risk of suffering from a serious illness at some point during their childhood. For instance, children with Down Syndrome have a 20 times higher risk for childhood Acute Lymphoblastic Leukemia than that of the general population ("Dana-Farber researchers," 2014) and there is evidence that relates autism to an increased cancer risk (Crepsi, 2011). Despite this increased risk; however, healthcare professionals may not be forthcoming with cancer information for people with I/DD. The reasons for this lack of and inconsistent patient education may be multifactorial, but are at least in part because of challenges associated with communication or a lack of understanding of the needs of this population (Jones, Tuffrey-Wijne, Bernal, Butler, Hollins, 2007).

Pediatric patients with I/DD deserve quality education about their disease and treatment options. A lack of information negatively affects the patient's care, as well as the patient's physical, psychological and social well-being (Tuffrey-Wijne, et al, 2006). Families of pediatric patients with I/DD are similarly impacted. There is no reason to believe that children with I/DD have less need for information than the rest of the population. In fact, having a better understanding of their disease and treatment may enhance not only compliance with treatment, but also their quality of life (Tuffrey-Wijne, et al, 2006).

3

In an effort to provide meaningful patient education to this population in need, I have created a tool to promote health literacy and understanding of cancer for pediatric patients with I/DD. I have hypothesized a series of educational booklets, to help these patients navigate an inpatient stay. For this project, I have focused on pediatric cancer and created the first booklet, "*I Have: Cancer.*" I envision the "*I Have*" series to expand and encompass more diseases and conditions as I continue my career and education.

The intention for this project was to create informational care packets for children with I/DD who have a neoplastic/hematological/oncological diagnosis. I hoped it would be an educational and interactive tool for preparation of an inpatient hospital stay, medical procedures, and overall experience of receiving cancer treatment.

From my own experience and after consulting with people with experience with pediatric I/DD, what seemed most helpful to the pediatric patient would be an individualized explanation. This care booklet could be an individualized and appropriate tool for patient teaching. No formal participant research was conducted for this project, but instead I created this resource based on my review of the literature, patient observations, and prior experience working with these children and their families.

#### Purpose

It is my hope that creating a tool specifically for those with I/DD will benefit these individuals and families by promoting person first language, and minimizing stereotypes (Disability awareness information, n.d.). Additionally, I would like to advocate a way in which nurses and other providers can speak directly to the patient, rather than speaking only to the caregiver and family. The booklet I have created provides such a tool for advocacy and communication (Disability awareness information, n.d.) Children with I/DD do not have less need for information about cancer than the rest of the population (Skorpen, Larsen, & Holthe, 2012). The lack of information and teaching materials related to cancer may prevent children with intellectual and developmental disabilities from understanding their inpatient stay and treatments, and may increase the stress that they experience while in the hospital.

In regards to developing this tool with a nursing lens, I felt that it was crucial for nurses and student nurses to have access to resources specifically for this population. Interaction with patients with I/DD is very likely, as over a billion people, about 15% of the world's population, have some form of disability ("Disability and health", 2014). Yet little education is provided in nursing school for interacting with patients with I/DD, and inappropriate language is still taught and used in the hospital. Specifically, pediatric oncology nurses should be aware of the learning needs of children with I/DD related to cancer diagnosis and treatment. Withholding information, either consciously or not, can cause unnecessary distress for the patient (Tuffrey-Wijne, et al, 2006).

#### Implementation

For an individualized approach, I intend for each page of the booklet to be on a loose, three holed page that can easily be removed, photocopied, and returned. Nurses, occupational therapists, child life specialists, social workers or physicians could take the pages that apply to the child and staple together the photocopied pages for a patient specific packet. While the booklet is written by a nursing student, and therefore is inherently from a nursing perspective, my intention is that it can be utilized by any health care worker or caregiver.

#### Research

Creating the booklet involved a review of the literature, observation, and a review of existing tools to incorporate a holistic nursing approach while developing a user-friendly and interactive tool. After reviewing the available literature, I found that research specifically about pediatric patients with I/DD and an oncological diagnosis is severely lacking. Much of the following research I tailored from several sources discussing oncology, I/DD education, pediatric cancer education, general health literacy, and availability of health education tools.

In my search for information about educating individuals with I/DD, I found the following literature in support of developing new educational tools. Development of ways to provide adequate information in a flexible and sensitive manner is necessary in healthcare. Effective communication of information is essential for empowering patients to make informed decisions about their care. However, patient autonomy is dependent on the clarity, consistency and completeness of the information they are provided and therefore use to base their decisions (O'Regan & Drummound, 2008). Many people with I/DD experience difficulties comprehending new or complex information, as well as learning new skills. Following a new cancer diagnosis, they have many learning challenges including understanding treatments and the associated side effects (O'Regan & Drummound, 2008).

After researching the needs of children and childhood cancer information needs I found that an effective system should allow the young user to navigate it with the help of intuitively meaningful metaphors and pictures, as they cannot read and write fluently (Ruland, Starren, & Vatne, 2008). Additionally, as children with cancer can be very ill, the application should be easy to use, and not too cognitively or emotionally demanding or draining (Ruland, Starren, & Vatne, 2008). While no tool existed specifically for children with I/DD and cancer, I did find some resources for related populations. For example, social stories are used with individuals with I/DD as an intervention for promoting behaviors or explaining situations ("Social Stories," n.d.). Social stories are short descriptions of a particular situation or activity, which include information about what to expect in that situation ("Social Stories," n.d.). They typically consist of an explanation of a behavior or topic and positive language (e.g, the individual *should* rather than *should not*). Social stories present information in a literal context, which may improve an individual's comprehension of a previously complex or ambiguous situation or activity ("Social Stories," n.d.).

A series of books exists, "Books Beyond Words" that features stories of adults with I/DD, written for adults with I/DD and their caregivers (Getting on with cancer, n.d.). The books discuss a variety of topics including depression, going to court, falling in love, going to the hospital, and cancer. "Getting on with Cancer" features an adult woman, Veronica, who has Down Syndrome and cancer. She has surgery and also chemotherapy and radiation (Donaghey, Bernal, Tuffrey-Wijne, & Hollins, 2002). "Getting on with Cancer" employs more of the concept of social stories, which I wanted to implore, but I wanted more interaction between the book and reader. However, the book does include a color-coded divider system that I think is effective and achieves a similar goal to my booklet's loose three-hole-page system. Based on where the patient is in the disease or recovery process, the caregiver can flip to the divider in "Getting on with Cancer" that best matches the patient's situation; "falling ill", "seeing a specialist and having a chest X-ray", "chemotherapy", and more, including additional resources for the caregiver (Donaghey, et al., 2002).

An intervention for traditionally developing pediatric patients that has been developed is the SISOM system (Ruland, Starren, Vatne, 2008). This system is designed for children aged 7-12 with cancer to help report symptoms and problems. The creators enlisted children to assist in designing the application so the interactive characters would be child-friendly and age-adjusted. An excellent point made by the authors was that a tool needs to have a "serious" nature, and should not tempt children to choose symptoms to report because the pictures or interactions are fun to watch. At the same time, the tool should be engaging so the child wants and continues to use it (Ruland, Starren, Vatne, 2008). I kept this idea of balance in mind as I developed the pictorial representations in the booklet.

Additionally (through clinical experiences and previous work as a camp counselor) I was able to observe adult and pediatric patients with oncological diagnoses, some with I/DD, and their caregivers. From my clinical interactions with them, and their interactions with their primary nurse, I further gathered understanding and information about this population and their families that aided me in creating my product.

#### **Detailed in the Booklet**

After spending time on the pediatric oncology unit for clinical rotations, I compiled a list of common concerns and procedures that a nurse could provide education about during the inpatient stay. From that list, the first draft of the I Have: Cancer booklet was developed. Topics included in this draft are listed in Table 1. This is not meant to be an exclusive list, but rather a starting point from which to continue work in this area.

Table 1: Content of "I Have: Cancer"		
Cover Page/Logo	Peripheral IV Start	Alopecia
• Letter to the Caregiver/Nurse	• IV Chemotherapy	Mucositis
• Explanation of Cancer	• Oral Chemotherapy	• Neutropenia
• Central Line Use and Care	• Nausea	• Hand hygiene

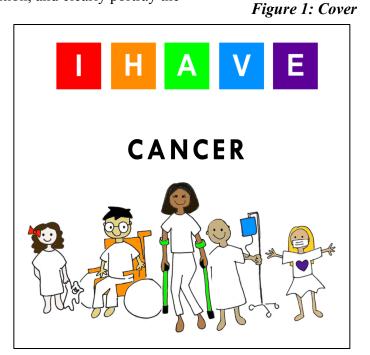
## **Graphics and Layout**

Along with researching and developing content, I additionally reviewed information about visual presentation that was used in creating the final product.

The cover graphic can influence the patient's attitude toward the information (Carolyn, 2006).

Cover graphics should be friendly, attract attention, and clearly portray the

purpose of the material to the intended audience (Carolyn, 2006). To grab the attention of the viewer and show the purpose, I chose to include a simple and colorful logo and a variety of children on the cover to portray the diversity of children with I/DD who can use the "*I Have:*" series (See Figure 1). I designed the cover page with hopes of using it on each booklet of the series,

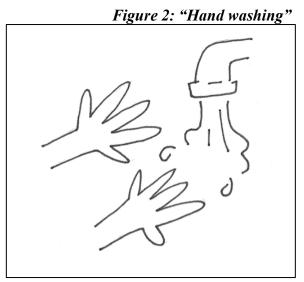


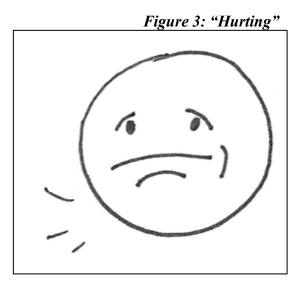
changing only the topic, to provide a unified and consistent look throughout the potential series.

In regard to relevance of illustrations, the literature suggests key points should be highlighted in the graphics included in the educational material (Carolyn, 2006). Illustrations

should present key messages visually so the viewer can understand the main ideas from the illustrations alone (Carolyn, 2006). Illustrations should be on the same page and adjacent to the corresponding text (Carolyn, 2006). Pictures related to written or spoken text, when compared to text alone, significantly increases attention to and recall of health education information (Houts, et al., 2006). Using simple drawing helps viewers with low literacy skills to understand the intended message without being distracted by irrelevant details (Houts, Doak, Doak, & Loscalzo, 2006). Furthermore, extra details can be distracting to the viewer, thus the simple line drawings featured in the booklet (See Figures 2 and 3). Additionally, I chose to primarily use black and white line drawings throughout the booklet so patients are able to color in the figures, thus increasing their interaction with the tool.

The text must be visually accessible for most readers. Many children with I/DD have visual impairment and therefore it is necessary to type the text in a large font and use double





spacing (Skorpen, Larsen, & Holthe, 2012). Consulting a list of strategies for improving patient education using written materials, I employed the following techniques: use simple words with one or two syllables, use simple sentences with 8-10 words per sentence, use simple large print front with a mixture of upper-and lowercase letters, avoid technical jargon, reinforce with verbal

## "I HAVE: CANCER"

instructions (letter to the caregiver/nurse), and use simple illustrations appropriate for the intended audience (Andrus & Roth, 2002). An example of the text is shown in Figure 4. Layout and sequence of information should be consistent, making it easier for the viewer to predict the flow of information (Carolyn, 2006). Each page uses the same fonts, style of illustration, and layout to provide consistency and flow for the reader.

According to Carolyn (2006) the viewer should interact with the text, as research has shown that memory improves when the viewer interacts with the information rather than passively reading it. I have included the following statement in the letter to the caregiver/nurse on the first page of the booklet: "Feel free to have the patient draw on the booklet; color the figures their skin and hair colors, draw a line from the bag of chemo through the tubing and into their blood stream, etc." I would like to encourage caregivers to encourage the patient to interact with the pages as much as possible to increase understanding and attention to the material.

## Figure 4: Sample Text

# SIDE EFFECTS OF CHEMOTHERAPY: HAIR LOSS

Sometimes cancer medicine can make your hair fall out.

This means the medicine is working really hard to fight the cancer.

Your hair might fall out in the shower.

Your hair might fall out while you are sleeping. You might see hair on your pillow.

This is normal.

Your hair will grow back, but it can take a long time. It can take months or years.

## **Future work**

With expansion and more research, I would like to continue this project by adding new pages to the booklet, with cancer related and general inpatient information. Eventually, my intent is to expand this tool beyond pediatric oncology, and do a set of booklets. Detailed in Table 2 is a proposed continuation of "*I Have: Cancer*" and ideas for more "*I Have*": tools.

Table 2: Proposed Continuation of the "I Have:" Series		
Pages that could be added to "I Have: Cancer"	"I Have: To go to the Hospital"	Other potential booklets in the series:
Blood products/anemia	Peripheral IV Start	• I Have: Diabetes
Radiation	• Vital signs	• I Have: Asthma
• Central line placement	• Bathing	• I Have: An Allergy
• Neutropenic fever	Dressing changes	• I Have: Kidney Disease
• Outpatient chemotherapy	EKG monitoring	• I Have: Cardiovascular
Isolation precautions	Oral/IV medications	Disease
• Side Effect: Fatigue	• Transport	
	• Hand hygiene	
	• Foley insertion	
	Nurse and Nursing	
	Assistant shift change	
	• Team rounds	
	Isolation precautions	

Furthermore, I would like to eventually move from a paper version to application

software for a smartphone or tablet. Some headway has been made in this area, as applications

for reporting side effects such as SISOM have been created, but this software is targeted at the traditionally developing child (Ruland, Starren, Vatne, 2008). I would like to continue to focus on providing appropriate health literacy and educational tools for children with I/DD. With the transition in healthcare from paper information to electronic records and information sharing, I believe that creating an application or system that could be used on a phone or tablet would allow the "*I Have*" series to potentially be more accessible and easy to interact with. I would like my application to include interactive touch-screen features and audio, showing videos of procedures and step-by-step explanations. Additionally, I would like for the patient to be able to "choose a character" so they can see an illustration of a patient of a similar age with the gender, hair color, clothing of their choice. My hope to include a patient-like character is based on a study participant quote from the Skorpen, et al., 2012 article, "It is easier to identify with someone looking like yourself."

#### Conclusion

With wide ranges of estimated individuals with I/DD affected by cancer, and very little research for pediatric patients with I/DD and cancer, I plea that more research be completed to provide education and interventions for these patients and their families. While this project is far from complete, I hope to have sparked an interest in an area of nursing that deserves more attention. Hoping to pursue pediatric nursing upon graduation, I wish to continue this research and implementation of appropriate education for all ages and stages of development.

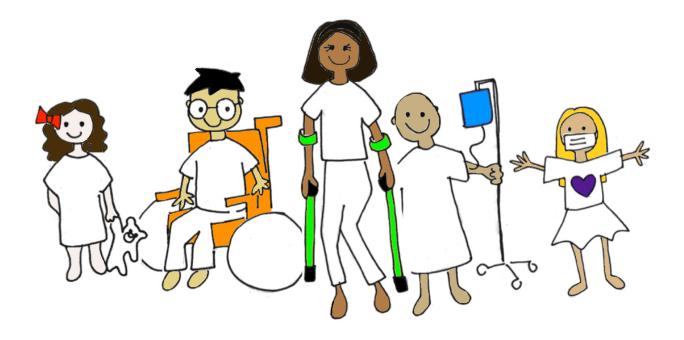
## Acknowledgments

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## Appendix



# CANCER



## Letter to the Nurse/Caregiver:

Thank you for using *I Have: Cancer*, a tool that with your help can better explain cancer and the treatment process to pediatric patients with intellectual and developmental disabilities.

Please use the included pages that most relate to your patient's situation, and work through them with your patient prior to a procedure and/or treatment or when the patient receives a new diagnosis of cancer.

This particular booklet has been written for pediatric patients with intellectual and developmental disabilities who understand literal audio, written, and visual direction.

Please feel free to use supplemental materials and resources as well as write in information as you see fit, if that child learns best that way.

Additionally, please take into consideration the timing of when to do this teaching. I recommend same-day teaching, as close to the procedure as possible, while still allowing time for working through and understanding. It is best for patient continuity if the nurse/caregiver who goes through this booklet with the patient can also be present during the procedure.

I also recommend making positive statements, praising the child for being an excellent helper and for holding still during certain procedures, like the IV start, at the end of the procedure.

Feel free to have the patient draw on the booklet; color the figures their skin and hair colors, draw a line from the bag of chemo through the tubing and into their blood stream, etc.

I hope you find this educational tool interactive and helpful with patients.

Thank you.

## I HAVE: CANCER

Your body is made up of lots of little things called cells.

Most cells are good and help you stay healthy.

Some cells are bad and make you sick. Cancer cells are bad cells.

Nothing you did gave you cancer.

You cannot give cancer to other people.

No one knows why you got cancer.

We are here to help you.

The nurses and doctors are going to help you fight the bad cancer cells. We will give you medicine.

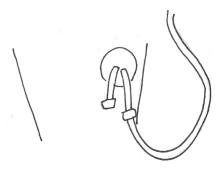
Cancer medicine tries to fight the bad cells.

Cancer medicine can make you feel sick or hurt.

The nurses will give you other medicine if you feel sick or hurt.

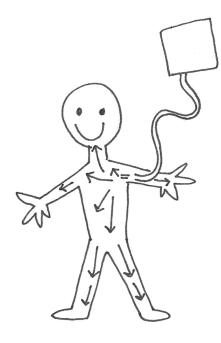


# CENTRAL LINE USE AND CARE



Some medicine can't be swallowed. Doctors

can use a tiny tube in your chest to put medicine in your blood.



This medicine will go to the rest of your body and help you when you are sick.

The tube in your chest is called a "central line."

There are caps on the tube so nothing can get in or out. The nurse can put medicine in the tube. The nurse can take a little bit of blood out of the tube.

The caps will be changed every week, so germs don't get in the tube.



If the skin where the tube is hurts, tell your nurse. Use your finger to show where the hurt is. Do not pull on the tube.

## **PERIPHERAL IV START**

Some medicine cannot be swallowed. Nurses can use a tiny tube in your arm to put medicine in your blood. This medicine will go to the rest of your body and help you when you are sick.

Look at your arm. Do you see blue lines? The nurse will put the tube inside one of the blue lines to give the medicine.

The nurse's job is to put in the tube. Your job is to hold still.

Your nurse may put Freezy Spray or Cream on your hands first. This is so it won't hurt.

First the nurse will look at your arms and hands and find the blue lines. The nurse will touch the blue lines.



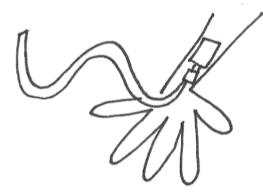
Then the nurse will tie a rubber band around your arm. If you look, the blue lines will get bigger. The rubber band will be tight, but remember it is your job to hold still. Next the nurse will use soap on the blue lines. The soap will be cold. Next the nurse will slip a tube into the blue line. It will pinch. Your job is to hold still.

The nurse will put some special liquid in the tube.

The nurse will then put tape on the tube to make sure it does not come out.

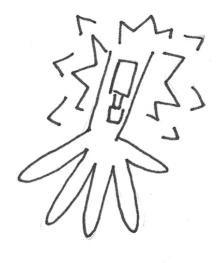
The nurse will close the cap on the tube so nothing comes in or out of the tube

Then it is all done. Your nurse will call this your "I-V"



The nurse will put medicine in the tube sometimes.

If it hurts or is scratchy, tell the nurse. Point to the hurt. Do not touch the tube if it hurts.



## **IV CHEMOTHERAPY**

Chemotherapy is a cancer medicine.

Some cancer medicine cannot be swallowed. This medicine cannot be taken at home. This medicine is put into your "I-V" or "central line."

Two nurses will come in your room. The nurses will check your name. The nurses will wear gloves and gowns.

One nurse will clean your tube with special soap and open the cap.

The nurse will put a bag of cancer medicine on a pole and connect it to the tube in your arm or chest.

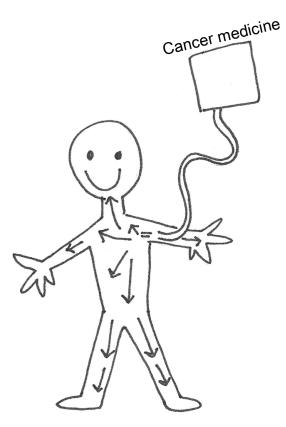
Chemotherapy can take a few hours. Your tube will be connected to the pole the whole time.

The nurse will program a box on the pole to tell the cancer medicine when to start dripping into your tube.

The box might make a "BEEP" sound. Call the nurse if the box makes a "BEEP" sound.

The medicine will drip from the bag on the pole, to the tubes, to the tube in your body, and will get to your blood.

The medicine can go everywhere in your body now to fight the bad cells.



# **ORAL CHEMOTHERAPY**

Chemotherapy is a cancer medicine.

Some cancer medicine can be swallowed.

Your nurse will give you pills or liquid to put in your mouth and swallow.

When you swallow this medicine, it goes to your tummy.

Your tummy tells your blood to come get the medicine, and the medicine then goes into your blood.

The medicine can go everywhere in your body now to fight the bad cells.

Cancer Medicine goes in your mouth

Goes to the stomach

Then to the blood

The medicine can go everywhere in your body now to fight the bad cells.



# SIDE EFFECTS OF CHEMOTHERAPY: NAUSEA

Sometimes cancer medicine makes you feel sick.

It can hurt your belly and make you throw up.



This means the medicine is working really hard to fight the cancer.

If you hurt, tell your nurse.

Use your finger to show where the hurt is.





If it hurts, tell the nurse.

The nurse will give you medicine to help your belly.

## SIDE EFFECTS OF CHEMOTHERAPY: HAIR LOSS

Sometimes cancer medicine can make your hair fall out.

This means the medicine is working really hard to fight the cancer.

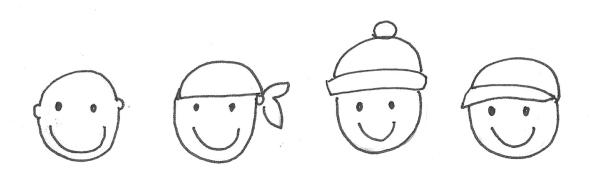
Your hair might fall out in the shower.

Your hair might fall out while you are sleeping. You might see hair on your pillow.

This is normal.

Your hair will grow back, but it can take a long time. It can take months or years.

Some people like to wear hats or bandanas when their hair falls out, because their heads get cold, or because they like to see how they look in different hats.

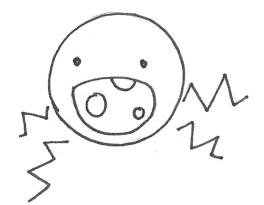


# SIDE EFFECTS OF CHEMOTHERAPY: MOUTH SORES

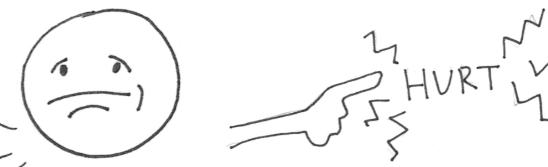
Sometimes cancer medicine makes you hurt.

It can hurt your mouth and give you spots in your mouth. It can hurt to eat. It can hurt to brush your teeth.

This means the medicine is working really hard to fight the cancer.



If you hurt, tell your nurse. Use your finger to show where the hurt is.



If it hurts, tell the nurse.

The nurse will give you medicine to help the hurt.

# SIDE EFFECTS OF CHEMOTHERAPY: NEUTROPENIA

Cancer medicine helps fight the bad cells.

To make sure all the bad cells are gone, sometimes cancer medicine will fight good cells too. But that's okay.

When this happens your nurse or doctor may say "your counts are low" or you are "neutropenic."Being "neutropenic" means you have to be careful not to get bad germs in your body. Being "neutropenic" means you can get sick easier.

To help keep the bad germs away... You should wash your hands before you eat. You should wash your hands after you use the bathroom. You should wash your hands if they are dirty.

You will have to wear a special mask on your mouth and a special shirt if you leave your room.

Your nurse will wear a special mask and a special shirt too. Nurses will wear gloves when they help you.



This is to help keep the bad germs away.

## HAND HYGIENE

Washing your hands can help keep bad germs away.

You should wash your hands before you eat. You should wash your hands after you use the bathroom. You should wash your hands if they are dirty.

To wash your hands...

First turn on the water at the sink.

Feel the water with your hands. Is it

too hot? Turn the COLD knob on the sink.

Feel the water with your hands. Is it

too cold? Turn the HOT knob on the sink.

Feel the water with your hands. Does

it feel good? Cover your two hands with the water.

Take your hands out of the water. Leave the water running.



Next, find the soap next to the sink. Pump the soap in your hand. Pump the soap in your hand again.

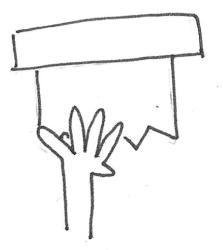
Rub the soap all over your hands. Rub your fingers. Rub your wrists. Rub your hands together.



Next, put your two hands back in the water. Rinse off your two hands.



Next, find the towels. Take one towel and dry your hands. Dry your fingers. Dry your wrists. Dry the front of your hands. Dry the back of your hands.



Throw away the towel.

Take another towel. Turn off the water at the sink.

Throw away the towel.

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