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Medical information design: Empowering the patient

Jon Benjamin-Rupp

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MEDICAL INFORMATION DESIGN
EMPOWERING THE PATIENT

By Jon Benjamin-Rupp

A thesis submitted to the Faculty of the College of Imaging Arts and Sciences in candidacy for the degree of Master of Fine Arts

May 2002

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15 May 2002

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5/15/02

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MEDICAL INFORMATION DESIGN
EMPOWERING THE PATIENT

By Jon W Benjamin

Submitted to the Graduate Graphic Design Program, School of Design, College of Imaging Arts and Sciences, in partial fulfillment of the requirements for the Master of Fine Arts Degree in Graphic Design at the Rochester Institute of Technology.

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ACKNOWLEDGEMENTS

Dedication
This thesis is dedicated to my loving and devoted wife Abby. Without her love and support this project would not have been possible.

Special Thanks
Special thanks to my thesis advisors Deborah Beardslee, James Perkins and William Walence PhD. Special thanks to my fellow graduate students for all of their support and recognition. As always, special thanks to my parents Robert and Lois Benjamin, their love and respect has given me the confidence and ambition to continually succeed in all of my endeavors.
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The complexity of modern medicine demands the innovative use of design to help provide patients with greater access to healthcare information. This thesis project explores the application of information design theories in patient education materials. In an effort to reduce anxiety and to ensure the best possible care is being provided, it is imperative for patients to take an active role in their healthcare. Taking an active role requires both being able to communicate with the healthcare provider and having access to the latest healthcare information.

While information is now widely available, trying to find it in an appropriate and understandable format can be a daunting task. This thesis project involves the development of an information source book that provides an accessible starting point for seeking information.

**Situation**

The majority of education materials that are currently available to patients are focused on prevention and chronic illness. As our population continues to age, chronic illnesses have become more abundant. Cancer is one of the more enigmatic and bewildering chronic illnesses. Cases of cancer have dramatically increased in the United States over the last 50 years, and are continuing to increase. Cancer is the third leading cause of death in the United States today, trailing behind heart disease and accidents. For this reason and others, cancer has become one of the most widely written about diseases. The amount of information that can be accessed concerning the topic is overwhelming.

In response to this abundance of information, a source book that provides an accessible resource of information was created. The source book includes: imperative fundamental information for patients, information and vocabulary that can increase the effectiveness of communication between patients and providers, and information about resources such as books, web sites and cancer centers that can provide reliable and accessible information.
Goals of the Designer

The goals of this project revolve around the development of a cancer information source book that will provide an accessible resource for cancer patients upon or soon after diagnosis. The following goals reflect the project’s focus on information design solutions as applied to the subjects of cancer and cancer treatment.

• Gain an in-depth understanding of cancer through research
• Create a system for cross referencing information
• Create a structure that will augment the content of the book
• Provide a calming tone for the book
• Direct the reader to a variety of resources
• Include an accessible glossary of common medical terms
• Encourage the reader to further explore the subject
Background

Historic Examples of Information Design in Medicine

In 1854, John Snow elucidated the cause of the cholera epidemic in London by charting out a map that showed a close link between incidence of cholera and the water supply pump on Broad Street.

Florence Nightingale developed a series of charts in 1857, now referred to as Nightingale's Roses, that helped to improve the sanitary conditions of the British army after the Crimean War. The charts clarified that unsanitary conditions had caused more deaths in the Crimean War than the enemy.

Will Burtin's exhibitions for the Upjohn Pharmaceutical Company in 1960 used large-scale, three-dimensional models to explain the complex processes of the human cell and the brain. For the first time these complex subjects were explained to the public in large scale interactive models.

In 1978, the Salford Form Market began the process of redesigning medical forms used to communicate between patients and doctors. The four year project successfully increased the exchange of information through the redesign of the forms. The Department of Health and Social Security (DHSS) in Britain determined that the forms saved the government 13 million pounds per year in medical costs.

Richard Saul Wurman published Medical Access in 1981 in response to his own awkward experience during a medical examination. He failed to find adequate information upon which to base questions to ask a physician. Medical Access is an attempt to make medical diagnostic tests and surgical procedures clear and understandable for the average patient.
The following precedents support the need for applying information design techniques toward patient education materials.

**Precedents for Information Design Formats and Objectives**

Many of the design concepts that have been incorporated into this project were influenced by two pioneers of medical information design, Will Burtin and Richard Saul Wurman.

**Will Burtin**

Burtin's work for the Upjohn Pharmaceutical Company displayed an innovative use of information design. His guidebooks and brochures presented doctors, pharmacists, dentists and veterinarians with clear and concise visual explanations of the complicated processes that occur when pharmaceutical drugs interact with cells in the human body. His approach included the ample use of white space which can give the reader visual rest and avoids a feeling of being overwhelmed with information. Burtin also used simplified imagery and deleted unnecessary information from his design solutions. Many of his guides incorporated transparency, and the innovative use of tabs and folded pages to add visual interest and enhance the effectiveness of communication. Burtin's information design solutions serve as important models for other designers.

**Richard Saul Wurman**

*Medical Access* and *Information Anxiety* are two very important information design texts that had a profound influence on this project. *Information Anxiety* provided the foundation and a structure for this undertaking. Chapter Six of *Information Anxiety* deals specifically with access guides and what elements should be considered to ensure their success. *Medical Access* not only helped to provide a solution for the presentation of the anatomical information in the *Cancer Information Source Book*, it also provided an excellent precedent that displayed the need for accessible biomedical information.
Precedents for Book Structures

Several examples of book structures influenced the decisions that were involved in the organization and structure of *Cancer: An Information Source Book*. The Wallace Memorial Library Archives provided an important resource for book structure precedents.

200 Books Annotated Bibliography by Keith Smith
This book displays 200 different ways to structure a book. It provides many different techniques for binding and arranging pages as well as examples of tabs and page dimensions. This book inspired many of the prototypes that were created in the development of this project (please refer to pages 25-27).

The artist book collection in the Wallace Memorial Library Archives
A wide variety of books were explored from this collection. The most important example was Susan E. King’s book titled *Treading The Maze*. This unique book has a butterfly binding and takes a non-linear approach to the organization of the content. The impetus for the placement of the source book’s glossary began after seeing King’s book.
Precedents for Specific Content and Information Goals

Currently there is an abundance of appropriate and reliable information concerning cancer. Unfortunately for many readers this information can sometimes seem dense, disorganized and unappealing. It was the intent of the author to syphon and consolidate the information provided in successful source books and present it in a more accessible format. The following sources provided an important portion of the information contained in the book created during this thesis study.

**The Complete Cancer Survival Guide** by Peter Teeley

This lengthy and dense resource provides the most complete information that can possibly fit into one guide. It is one of the top selling cancer guides in the nation and provides a broad spectrum of information on diagnosis, staging, treatment options, procedures, medications and clinical trials. This text is a virtual encyclopedia for cancer care options without the organization of an encyclopedia. The book is a mixture of information from the author's firsthand experience with cancer intermixed with direct factual and resource information. *The Complete Cancer Survival Guide* also includes tables and illustrations that explain a variety of issues. This book influenced the project by providing examples of important current information such as a list of cancer centers and where to find information about clinical trials. Teeley's guide also exemplifies an approach of consolidating a wide variety of information into one source book.
The Cancer Patient's Work Book by Joanie Willis

This text provides an excellent example of the innovative use of design to help cancer patients take control of their situation. The Cancer Patient's Work Book serves as a personal organizer for procedures, finances, physicians, medications and more. Each section of the book is color-coded for easy visual reference. The color palette consists of pink and blue pastels that instill a light and airy feeling for the reader. Comic illustrations provide a child-like atmosphere to counteract the dark and oppressive nature of the disease. This booklet's innovative use of color and typographic hierarchy influenced the typographic treatment and color choices that were used in the development of this project.

After Diagnosis: A Guide for Patients and Families

by the American Cancer Society

This small and concise guide is provided free from the American Cancer Society. It includes a wide variety of clear and understandable information in a question and answer format. This small handbook clarifies some basic information for patients using a very general approach. The type size is larger to increase readability and the content is very simple. This booklet influenced the project by providing cancer information in a format that is accessible to the lay reader. One challenge of this thesis project was in the attempt to provide as much introductory information as possible without overwhelming the reader, while still including enough essential information. After Diagnosis: A Guide for Patients and Families served as an excellent example of simplified technical information.
Research for this project involved the exploration of historic precedents of information design, book structures, and cancer information. In addition, extensive interviews were conducted with oncology social workers from several cancer centers in the Rochester area. Another important segment of the research was devoted to an analysis of existing cancer guidebooks.

Interviews

Interview 1

Jennifer Schackart Medical Librarian
Southern Ohio Medical Center
10 am Thursday November 16, 2002

Jennifer’s largest concern with providing a patient with access to medical information involved the patient’s lack of a solid foundation of information concerning their disease. She has encountered a large number of patients that haven’t been provided with enough information about their disease to ask the correct questions. When patients understand very little about the fundamentals of their diagnosis, they have a greater potential of looking up inappropriate information that can actually increase their anxiety. The role of the medical librarian has evolved into individual searches that include a copy of the patient’s diagnosis and treatment.

The interview with Jennifer clarified the importance of providing patients with supplemental information. It also identified and explained the important role of the Medical Librarian. One page in Cancer: An Information Source Book is devoted to the importance of the Medical Librarian.
Interview 2

Susan Vetter  Oncology Social Worker  
Pluta Family Cancer Center
10am Thursday December 20, 2002

Susan provided a great source of inspiration for this project. The Pluta Family Cancer Center is a private practice that already provides a successful source book for local services. The source book provides some basic information concerning the disease. Susan discussed the importance of diffusing the self blame that some patients can feel upon diagnosis. She also discussed how knowledge and understanding can help reduce anxiety in patients and increase their confidence.

Susan helped to reinforce the need for providing patients with information in a clear and accessible format, therefore supporting the fundamental goals of this thesis project. Susan provided a copy of the Pluta Family Cancer Center's source book which supplied an excellent resource that aided in the selection of appropriate content information such as the Financial Assistance section in Cancer: An Information Source Book.
Interview 3

**J E Giarrizzo** Oncology Social Worker

*James P Wilmot Cancer Center*

*10:30am Thursday January 10, 2002*

J E had discussed several important points that are crucial to educating patients about cancer. She mentioned the need for patients to be aware of the importance of finding a specialist. She discussed the problem of older patients receiving old and outdated information and how it is important for these older patients to understand that treatments have improved as well as the survival rates. Dispelling myths about cancer treatment and cancer survival became a central theme of the interview. J E also introduced the organization AOSW (Association of Oncology Social Workers).

Conversations with JE inspired the incorporation of information such as the importance of the Oncology Social Worker, as well as the need to dispel myths about cancer treatment and mortality.
Interview 4

Therese O’connor  Oncology Social Worker
Rochester General Hospital Cancer Center
10am Wednesday January 16, 2002

Therese discussed the importance of finding a good cancer center. She stressed the importance of clinical trials and their role as barometers for excellent care. Therese also mentioned the importance of recognizing that some cancer patients respond very well to traditional treatment and may not require or benefit from being involved with a clinical trial.

Conversations with Therese inspired the incorporation of the list of cancer centers and the importance of clinical trials into Cancer: An Information Source Book.
Library Research

Library research was conducted in the areas of graphic design, book structure and patient education materials.

Graphic Design

In addition to the research devoted specifically to cancer, research was conducted in the field of graphic design and design related subjects. The archives in the Wallace Memorial Library became a great resource for this project. The archives provided access to a large number of artists’ books and the work of medical information design icons such as Will Burtin and George Giusti. Other information designers such as Richard Saul Wurman, Edward Tufte, and Ladislov Sutnar provided examples of enhancing the accessibility of technical information. Richard Saul Wurman’s Access Guides provided examples of how to simplify and arrange information in an accessible manner through the use of pictograms and simplified maps. The incorporation of visual codes such as the shapes of the diagrams and the tone of the color palette in this thesis project was influenced by a variety of sources including Ladislov Sutnar’s *Catalogue Design* and Edward Tufte’s *Visual Explanations*. Information Design Journal provided several examples of medical and technical information designed to be more accessible through the use of design decisions which emphasize particular visual hierarchies.

Book Structures

In an effort to discover the most effective way to present the information, an exploration of book structures was conducted. This search involved the analysis of a large number of artists’ books and resource guide books on a range of topics. The artists’ books were analyzed for their ability to form a relationship between their structure and content, and for their nonlinear arrangement of information.
Cancer and Patient Education

The first area of research involved an exploration of current guides and other materials related to patient education. This process included reading medical journals and discovering what forms of patient education materials are currently being used by the profession. Many guides were collected from cancer centers and other medical facilities. Many other guides were ordered and delivered for free from national organizations such as the American Cancer Society, the National Cancer Institute, and from cancer centers around the country.

A review of current guide books was conducted in an effort to establish a need for a new patient source book. Research for available guidebooks began from online lists from cancer information web sites and from Amazon.com. Some research was conducted by visiting bookstores, reading through their selections and taking notes on their content and design. The results of this research were then organized into a comparative matrix to easily view the relationships between the contents and approaches used in other source books (please refer to page 19).

To ensure the accuracy of the content of the source book and to develop a broader understanding of the disease, technical research was conducted concerning the biology and treatment of cancer. Initially, the fundamentals of cellular biology and cancer were studied. Next, clinical aspects of the disease such as treatment and management were researched.
### External Audit Matrix

<table>
<thead>
<tr>
<th>Contents</th>
<th>Approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biology &amp; Cancer</td>
<td>Nuclear Medicine</td>
</tr>
<tr>
<td>Nursing Administration</td>
<td>Medical Imaging</td>
</tr>
<tr>
<td>Mental Health Care</td>
<td>Financial Management</td>
</tr>
<tr>
<td>Family Health Care</td>
<td>Oncology Systems</td>
</tr>
<tr>
<td>Cancer Care</td>
<td>Nursing Education</td>
</tr>
<tr>
<td>Social Work</td>
<td>Community Health Programs</td>
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</tbody>
</table>

#### Contents

<table>
<thead>
<tr>
<th>Guide Books</th>
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<tbody>
<tr>
<td>The Complete Cancer Guide: First Series 2021</td>
</tr>
<tr>
<td>The Cancer Patients Work Book: Jobs With 2021</td>
</tr>
<tr>
<td>Supportive Cancer Care: A Guide for Patients 2021</td>
</tr>
<tr>
<td>Comprehensive Cancer Care: A Guide for Patients 2022</td>
</tr>
<tr>
<td>Diagnosis Cancer: A Guide for Patients 2023</td>
</tr>
<tr>
<td>The New Cancer Source Book: Jobs With 2024</td>
</tr>
<tr>
<td>The People's Cancer Guide Book: Jobs With 2025</td>
</tr>
<tr>
<td>Choosing a Hospital Michael Center 1994</td>
</tr>
<tr>
<td>20 Essential Things to Ask Your Doctor 1997</td>
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<table>
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<tr>
<th>Free Guides</th>
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<tbody>
<tr>
<td>National Cancer Institute 1972</td>
</tr>
<tr>
<td>American Cancer Society 2006</td>
</tr>
<tr>
<td>Cancer Centers' Guide</td>
</tr>
<tr>
<td>University of Michigan Cancer Center 2020</td>
</tr>
<tr>
<td>Mayo Clinic Cancer Center 1999</td>
</tr>
<tr>
<td>The Dana-Farber Cancer Institute 2022</td>
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<tr>
<td>Roswell Park Cancer Institute 2009</td>
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<tr>
<td>Cancer Information Service: Jobs With 2008</td>
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#### Approaches

<table>
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<th>8th</th>
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<td>12th</td>
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</table>
A fundamental design problem for this project was the selection and organization of content. After research was conducted it became necessary to organize pertinent information and to develop a system for arranging it.

**Index Cards**

This process involved writing down key words recorded from research on index cards. The cards were then laid out on a large flat surface and rearranged in a variety of ways to discover which information to include and what the best sequence of information would be. The cards were then arranged in groups of subject similarity, then by forced juxtaposition of dissimilar subjects. The results of this process aided in the selection of the content headings and subheadings in the source book. The use of the index cards also aided in the development of the navigation diagram (Please refer to page 24).

**Interviews**

Some decisions to include or delete information was influenced by suggestions and comments from the interviews with medical professionals and from thesis committee members. The decision to include the *Complementary Medicine* section was under the direction of the thesis committee. Simplification of the written content in an effort to make the book accessible to a larger population of people was under the direction of medical professionals that were interviewed throughout this project.

**Review of Existing Materials**

Some decisions to include or delete information also developed from the information that was provided in other successful resources such as cancer source books, medical journals and web sites. After collecting and reviewing a wide variety of existing materials it became necessary to summarize the collective ideas that were presented in them. This summary developed into the foundation from which the content of the final application could build upon.
Navigation Diagram

A navigation diagram was developed to display the best possible arrangement of information in the source book. The diagram also displayed the possible cross referencing between headings and subheadings. The creation of the diagram involved research and several revisions. Research began with a review of books about games to help inspire a variety of possibilities for arranging and sequencing information. Books related to the creation of diagrams and flow charts were also investigated.

The first diagram (please refer to page 22) was developed around the form of a board game. This diagram helped to group the information into four categories containing related subjects. The blue section contains introductory information, the purple section contains scientific information, the red section contains information related to the health care industry and the yellow section contains information concerned with the patient taking an active role in their health care. This diagram also illustrates a nonlinear sequencing of information.

The second diagram (please refer to page 23) was an attempt to simplify the first diagram. The form of this diagram developed from analyzing flow charts and other diagrams. The two important developments that occurred in this diagram were: the clearer establishment of hierarchy and the emphasis on the glossary and resource sections.

The third and final diagram (please refer to page 24) developed after researching texts devoted to the creation of flow charts. This final diagram is clearer and more simplified than the previous attempts. The hierarchy is clearly established and the book is divided into three major headings.
First Attempt: Navigation Diagram

Cross Referencing Diagram

Lists of resources
- Definitions
  - Listed Information
Second Attempt: Navigation Diagram

Introduction / Contents

Basics
- Cells
- Cell Division
- Carcinogens
- Metastasis
- Cancer the Disease
- Risk Factors
- Immune System

Anatomy
- Nervous
- Digestive
- Lymphatic
- Circulatory
- Skeletal
- Endocrine
- Urogenital

Resources

Clinical Trials
- Definition
- Importance
- Not for Everyone
- List of Resources

Alternative Medicine
- Definition
- OAM
- Category
- Check with Oncologist
- List of Resources

Health Care Team
- Team Approach
- Finding a Specialist
- Second Opinion
  - List of Cancer Centers

Financial Assistance
- List of Resources

Glossary

Reason for Optimism
- Medical Advances
- Misinformation
- List of Changes

Living Well
- Nutrition
- Light Exercise
- Sleep
- List of Resources

Cancer Source Book Navigation Diagram
Third and Final Attempt: Navigation Diagram
This thesis project is multifaceted. Each of the facets of the project developed separately yet concurrently with one another. Each facet developed from an initial brainstorming method, ideation, and the creation of prototypes.

**Book Structure**

Ideation for the structure of the book began with a review of a wide variety of artists' books. Initial concept sketches were inspired by the research, then new ideas arose from the sketches. The possible success of each structure was determined by the relationship to the content, the sequencing of information and relative simplicity of the structure. Upon reviewing the most successful approaches from the sketches, prototypes were created. 25 prototypes were developed ranging in size and shape. Several of the mock-ups were chosen based upon how applicable their structure was to the content and the objectives of the thesis project. They were then developed further by incorporating the source book content. The prototype structures involved various approaches to tabbing, multiple folds, pockets and different approaches to binding.

**Diagrams of possible book structures**

*Possible tabbing system*

*Separate folds or bindings*

*Extra flaps or pockets*
Cross Referencing

Ideation for cross referencing possibilities evolved from the research and ideation of book structures and navigation possibilities. The concept development and prototypes for the cross referencing system were intertwined with and occurred alongside the navigation and book structure ideation. The tab system began with planning and was then tested in the prototypes. Content considerations that were involved in the development tab system included the importance of seeing the tabs on every spread so that specific information could be cross referenced from any section of the book. The following are a few examples of prototypes that contained tabs that could be seen on every spread.

Other considerations for the development of the tabs included their shape and color. The shape needed to reflect the circular element contained in the book. The colors needed to aid in the establishment of a calm and serene feeling for the reader.

Navigation

Ideation for the navigation system of the book incorporated ideas that arose from the creation of prototypes, the process of arranging index cards, research of other diagrams and from looking at the organizational structures of board games. A navigation diagram was developed to consolidate and display the most effective and efficient arrangement of the content of the book. More ideas developed from the process of developing and revising the navigation diagram. As the diagram was refined and adjusted new ideas arose from the increased clarity that each new diagram provided (please refer to pages 22-24).
Aesthetic Considerations

Ideation of aesthetic considerations also occurred simultaneously with the other ideation processes. Aesthetic considerations include: color decisions, typeface choices, page size, grid construction, placement of the tabs, and the style and placement of the illustrations and diagrams. Initially the brainstorming method known as mind mapping provoked the original ideas for the tone of the book (please refer to pages 30-32). From the fundamental concepts that developed out of the mind maps other methods of ideation, such as thumbnail sketches, were used to discover effective ways of executing those ideas.

Color

The decision to conceptually represent the sky and water with two shades of blue originated from the mind maps. Some of the early layouts included a light blue page and a dark blue column. Other ideas included a split page with half light blue and half dark blue. A variety of different solutions were printed out and observed for their effectiveness and their relationship to the content. The following are a few of the ideas that were explored:

The final selection was a descending progression of a horizon line between a light blue color representing the sky, and a dark blue color representing the water. Once this decision was made it became necessary to explore possibilities for the most appropriate colors of light and dark blue. For this ideation a wide variety of blue colors were printed and compared for their effective representation of sky and water.
**Typeface**

The choice of typeface developed out of a brainstorm that included a list of goals for the project and comparing them with the attributes of several typefaces. The first decision involved the use of a san serif versus a serif type face for the body text. One of the initial goals of the book was to instill confidence into the reader. The layout of the book needed to seem scientific and sophisticated without appearing impersonal. A san serif type face would convey the idea of a sophisticated and scientific subject. Several san serif typefaces were chosen and observed for their ability to convey these goals. Futura became the final choice based on the relationship between the circular geometry of the type face and the circular representation of the cell. Limiting the amount of text on each page and opening the leading of the body text helped to maintain the readability of the text and diminished an impersonal tone by creating an open space. The open space between and around the type can appear more approachable to the reader avoiding feelings of being overwhelmed with information.

**Page Size and the Grid Construction**

Exploration for the page size originated with the development of the book structure (please refer to page 25). Once the idea for the book structure was narrowed down the next decision was to choose an appropriate page size and a grid to place the text, illustrations and diagrams within. Ideation for the grid was based on the length of text, the form of the book and the cross referencing system. Initially thumbnail sketches of the book layout were made consisting of a butterfly binding with the glossary positioned on the right. The sketches that were selected to be developed were chosen based their ability to reflect the content and simple geometric qualities of the typeface, illustrations and diagrams. The page size was developed based on the constraints provided by the grid system while attempting to maintain a reasonable size to the book. Several page sizes were chosen based on thumbnail sketches and tested out in full size prints. The final decision was based on the unified form of the book and a basic geometric grid.
Illustrations and Diagrams

One of the fundamental goals of the project is to create an accessible source book by maintaining a level of simplicity. The illustrations and diagrams needed to be as simple as possible while still maintaining a high ability to communicate the information. Sketches for the diagrams began with a common circular form to emphasize the concept of the cell and to enhance the visual continuity of the book through the repetition of the form.

The anatomical illustrations were developed to be simple while maintaining a recognizable form to the organs being represented. The main goals of the anatomical illustrations are to communicate their basic location in the body and to emphasize their interrelationship. The selection of the final illustrations was based on how effective they communicate the assigned goals and how well they will function inside the book as a series of transparent overlays. Once the final anatomical illustrations were chosen, appropriate colors were explored based on how opaque they appeared on the transparent overlays and how easily they could be distinguished from one another.
IDEATION CONTINUED

Mind Maps

Central node Comprehensive
Central node *Empowerment*
Central node Patient
IMPLEMENTATION

The application became an information source book for cancer patients. The final decisions that were implemented into the creation of Cancer: An Information Source Book are summarized and divided into the following two categories: content and design.

Content

The book consists of 3 major divisions titled: Cancer, Reference and Glossary. The Cancer section contained 9 subsections titled: Introduction, the Biology of Cancer, Anatomy, Living Healthy, Reasons for Optimism, Health Care Team, Financial Assistance, Clinical Trials and Complementary Medicine. The introduction explains how the book functions and why it was created. The next eight sections are grouped by similar content and ordered in a sequence of layering knowledge.

Cancer

The first three sections relate to how cancer works and what can be done to prevent it. The first section The Biology of Cancer describes cancer on a scientific level in an effort to help people understand what is happening in their bodies. The second section, titled Anatomy, introduces some basic anatomy and physiology to help patients visualize where their organs are and how they are all interrelated. Simplified graphic illustrations are displayed on transparencies along with brief descriptions of the major organ systems. The decision to include this section was based on the lack of anatomical information that was found to be provided for patients in other available materials. The third section is titled Healthy Living. This section describes things that patients can control in their lives to prevent cancer from occurring or reoccurring; and activities that may ease the side effects of treatment and aid in the healing process. The next two sections introduce the reader to the current health care system. The fourth section is titled Reasons for Optimism. This section is intended to relieve some anxiety and eliminate misconceptions concerning current cancer treatment and mortality.
The content of this section developed as a result of the abundance of outdated information circulating around such as the old view that a person with cancer was certain to die from it. Section five is titled Health Care Team. This section introduces the reader to the importance of finding an oncologist and an oncology social worker. This section also clarifies that the current health care system provides a team of professionals as apposed to one family doctor. The sixth section is titled Financial Assistance and it provides information and resources that can help people pay for expensive medical costs. The next two sections introduce clinical trials and complementary/alternative medicine. These sections were included because of their importance and also due to the lack of accessible information concerning the two topics.

Reference
This section is divided into four subsections titled: Books, Online Resources, Cancer Centers, National Organizations and Notes. The purpose of this section is to consolidate a variety of resources for patients to access and explore. The Notes section provides a place for the reader to add additional resources as well as a place to write down questions to ask their provider.

Glossary
The decision to include a glossary originated with the need to enhance the communication between patients and providers. As the project progressed, it became increasingly apparent that the glossary was an equally important source of information. After witnessing an example of butterfly binding and testing a variety of possible book structures, the decision was made to place the glossary to the right of the main body of content with its own binding. This structure allows the reader to access the glossary simultaneously while reading through the other sections of the book. This solution also gives emphasis to the glossary so the reader will have more exposure to it.
Design

The design of the cross referencing system increases the accessibility of the information contained in Cancer: An Information Source Book. This book is primarily intended for patients who wouldn't normally seek out information on their own. The graphic elements and color decisions provide a reassuring and restful tone for a patient facing the bewildering diagnosis of cancer.

Cross Referencing System

An important facet of this source book was the development of a cross referencing system. By enabling the reader to quickly access related sections of the book they may begin to recognize the importance of the interconnections between the information. This may also emphasize an all encompassing or holistic approach to medicine. The development of the navigation map served as a tool in the creation of the most appropriate and effective cross referencing system. The navigation map consolidated and arranged the content of the book so that new pathways for cross referencing were illuminated. Words and subjects that can be cross referenced are color coded to match a color tab that represents a particular section of the book. This system is exemplified on pages 38-39.

Color

The two shades of blue used throughout this source book are intended to represent sky and water. The colors are meant to establish a calm and serene feeling in the reader. The horizon line progressively lowers as the pages are turned to reflect the reader's increased awareness. The lowering line also serves as a signal to carry the reader through the pages of the Cancer section. Then the line disappears at the end of the Cancer section to signal the beginning of the Reference section. The Reference section remains sky blue because the additional information can bring greater clarity.
Typeface
The geometry of the typeface Futura reflected the geometry of the circular elements that occur throughout the book. The pure geometry of Futura also added a modern appearance to each page, instilling a feeling of confidence in the reader. The leading was opened and the line length decreased to ensure that the text was readable and approachable.

Page Size and Modular Grid
Decisions about the page size and the modular grid reflect the simple geometry of the diagrams, tabs and the typeface Futura. The page size is 8 inches by 10 inches. The page size was based on the constraint of an 8.5 x 11" page with a 0.25 inch printer margin. This page size was chosen to maintain lower production costs. The grid structure contains three text boxes for the body text, text in the margin and the glossary. The body text and the glossary are identical in size to place an equal emphasis on both. The outside margins are larger to compensate for the spiral binding. The width of the first page is based on a six inch circle. The circle reflects the concept of the cell. The decision to make the circle six inches was determined by a one inch margin on the top and bottom of an eight inch page. Page numbers were excluded from the pages to enhance a nonlinear use of the book.

Repetition of Form
The repetition of the circle in this source book is intended to conceptually represent the cells role in cancer. The decisions to develop diagrams composed mainly of circles and tabs composed of half circles were based on this concept.
Final Considerations

The creation of the final application involved the incorporation of all of the feedback from faculty, oncology social workers and committee members, then deleting unnecessary elements in an effort to create the most efficient and successful application. Final decisions for the source book developed through test prints and test assemblies. Once these changes were incorporated a version of the source book was printed and presented in the thesis show (please refer to page 43). After the show the source book was presented to the thesis committee and the oncology social workers for review. The suggestion for changes are summarized in the following list:

- Explore further possibilities for the structure and arrangement of the tabs.
- Explore different possibilities for distinguishing the reference section.
- Include a color system on the content page that correlates with the tabs.
- Include an explanation for the cross referencing system on the content page.
- Include headings for each illustration.
- Include the headings for the organ systems on each respective transparency.
- Change the order of the anatomical illustrations.
- Include illustrations that explain the role of the cell in cancer.
- Ensure that the horizon line on each page highlights a specific sentence.

These suggestions were tested and implemented into a final application that was reviewed by health care professionals and cancer survivors. A survey was provided for the reviewers and the results are recorded in the Intermediate Evaluation section (please refer to page 42).
**Cover**
The shaded blue transparent overlay eludes to the water and sky theme of the interior.

The circle reflects the circular elements occurring inside the book that conceptually represent the cell.

**Table of Contents**
The color dots correlate to the colored tabs of each section.

Instructions on how to use the book are located adjacent to the Table of Contents.
Cross Referencing
The color tabs correlate with specific sections in the Table of Contents.

By matching colored words or phrases with the correlating colored tab, the reader can find more information on the specified word or phrase.
Anatomy
Clear overlays present graphic illustrations of the major organ systems of the human body.

Glossary
The glossary is bound separately and to the right of the main body of the book.
Reference Section
A white tab separated from the rest on a different threshold signifies the importance of the reference section.

The reference section is colored entirely in sky blue to represent the illumination that can occur by discovering more information.
A questionnaire was developed which asked cancer survivors and health care workers to determine how effective *Cancer: An Information Source Book* was.

The book was reviewed by employees and patients at the Pluta Family Cancer Center in Rochester, New York on April 24-25, 2002. The book was also reviewed at the National Convention for Oncology Social Workers in Atlanta, Georgia on May 4-12, 2002. In addition, three medical illustration students at the Rochester Institute of Technology also supplied feedback on May 10, 2002. The results of the questionnaires are summarized below. The completed questionnaires are located in Appendix B (please refer to page 70).

The following are the average scores to each of the questions on the survey.

1 = No, Not at all    5 = Yes, a great deal.

1) Would this source book be useful to you?  
   3.8

2) Do the colors establish a calming mood?  
   4.5

3) Do the diagrams help to reinforce the information?  
   4.5

4) Do you find the anatomical illustrations useful?  
   4.4

5) Is the position of the glossary effective?  
   4.4

6) Did you learn anything new from the book?  
   3.4

7) Do you feel the book would assist you in finding more information?  
   4.1

8) Do you feel the book would help enhance the communication between you and your health care provider?  
   3.5

Overall there was a positive response by survivors, family members of survivors, health care professionals and medical illustration students. The lower score on question 6 is due to the fact that several of the people surveyed were healthcare professionals with a vast knowledge base. The constructive comments included a concern that the reading level may be too high for many cancer survivors.
DISSEMINATION

*Cancer: An Information Source Book* was first shared as part of an exhibit in the second thesis show in the Bevier Gallery at the Rochester Institute of Technology campus.

**Bevier Gallery Exhibit**

A series of explanatory panels were designed for this exhibition. The overarching goal of these panels was to communicate the design process that was undergone in the creation of the final application: *Cancer: An Information Source Book*. The specific goals of the panels were to reflect the concept of progression from water to sky that is incorporated in the book, and to display the progression of time from beginning to the current status of the project. The panels included information about the processes that occurred during the development of the project, important spreads of the source book and information explaining the aesthetic considerations and future prospects for the project. The book was placed on a pedestal in front of the last exhibit panel. A second pedestal was used to display other successful source books to allow for a comparison with the project application. A small versions of the panels are located on pages 45-48.
Future Dissemination Plans

*Cancer: An Information Source Book* and the exhibit will be displayed in the lobby of the James P. Wilmont Cancer Center at Strong Memorial Hospital in Rochester, New York. The exhibit may also be displayed in other cancer centers in the future as well. The director of publishing strategies, Diane Scott-Lichter, will be reviewing the book for possible future developments.

In the future, this source book could potentially be mass produced and distributed through a range of different channels. Some of the primary channels would be medical publishers such as Quality Medical Publishing, Inc in St. Louis, and Medtext Medical Publishing Company in California. The book may be distributed to several cancer centers for review with the possibility of adding it to their permanent collection.
**Problem Statement**

The diversity and complexity of America's current healthcare system can be overwhelming for patients. In an effort to reduce anxiety and to ensure the best possible care is being provided, it is imperative for patients to take an active role in their healthcare. Taking an active role requires both being able to communicate with your healthcare provider and having access to the latest medical information. While information is now widely available, trying to find it in an appropriate and understandable format can be a daunting task. After an exploration of various solutions to this problem I have developed a more accessible source book for cancer patients.

**Goals for the Designer**
- Gain an in-depth understanding of cancer through research.
- Create a system for cross-referencing information.
- Create a structure that will augment the content of the book.
- Provide a calming tone for the book.
- Direct the reader to a variety of resources.
- Include an accessible glossary of common medical terms.
- Inspire the reader to further explore the subject.

**Research**

Research for this project involves the exploration in historic precedents of information design, book structures, and cancer information. In addition, I conducted extensive interviews with oncology social workers from several cancer centers in the Rochester area. Another important segment of my research was devoted to an analysis of existing cancer guidebooks. The majority of guidebooks can be divided into two distinct categories. The guides I found were either too complex or too simplistic and lacked additional resources.

**Analysis of Existing Cancer Materials**

An external audit of existing printed materials was conducted and summarized within a comparative matrix. I selected a wide spectrum of materials for this summary. Content categories are based on the sections of my source book. Approach categories are based on common cancer guide formats.
Content Development
The content of the book developed from library research, the analysis of existing guides, discussions with several oncology social workers, members of my thesis committee and my own experiences. I chose information that the oncology social workers and my committee members had suggested were important but not readily available to patients. I also chose information that would increase a patient's general knowledge of the subject in an effort to help increase their confidence through increased understanding. The contents of this source book have been divided into three main sections: Cancer, Reference and Glossary.

Cancer
This section is divided into eight subsections. Biology of Cancer, Anatomy and Living Healthy are intended to help a person make more informed decisions concerning their health. Health Care Advances and Health Care Team introduce the reader to the modern health care system. Financial Assistance, Clinical Trials and Alternative Medicine provide additional options to patients that may not be presented to them by their diagnosing physician.

Glossary
The glossary of this source book is meant to help increase a patient's knowledge of common medical terms related to cancer so that they can communicate more effectively with their health care team.

Reference
The reference section is divided into four subsections which include the following: Books, Online Resources, Cancer Centers and National Organizations. This section is intended to direct patients toward more detailed and complete information.

Navigation
Once the content of the book was developed the next step was to explore the most appropriate arrangement of the information and possible solutions for effective navigation through the book. This process began with an intense analysis of the developed content. The results from this analysis were then implemented in the following navigation diagram.

Navigation Diagram
The large circles encase each section heading and the subheadings are designated in boxes. The arrows show possible pathways for cross referencing. The form of this map emerged from library research of flow charts and existing navigation maps. One important solution that arose from the development of this map was the decision to place equal emphasis on the Glossary, the Cancer and the Reference sections.
Cross Referencing

An important facet of this source book was the development of a cross referencing system. By enabling the reader to quickly access related sections of the book they may begin to recognize the importance of the interconnections between the information, and thereby emphasizing an all encompassing or holistic approach to medicine. The development of the navigation map served as a tool in the creation of the most appropriate and effective cross referencing system.

The above spreads of the book demonstrate this system at work. Words and subjects that can be cross referenced are color coded to match a color tab that represents a particular section of the book. This approach is meant to mimic the highlighted words that appear on web pages and provide links to further information.
Aesthetic Considerations

This book is primarily intended for patients who wouldn't normally seek out information on their own. The graphic elements and color decisions provide a reassuring and restful tone for a patient facing the bewildering diagnosis of cancer.

Color

The two shades of blue used throughout this sourcebook are intended to represent sky and water. The colors are meant to establish a calm and serene feeling in the reader. The horizon line progressively lowers as the pages are turned to reflect the readers increased awareness. The lowering line also serves as a signal to carry the reader through the pages of the Cancer section. Then the line disappears at the end of the Cancer section to signal the beginning of the Reference section. The Reference section remains sky blue because the additional information will bring greater clarity.

Repetition of Form

The repetition of circular elements in this sourcebook are intended to conceptually represent the cell. Cells are both the cause and the cure to cancer. I believe it is important to stress the role of the cell in an effort to provide a broader understanding of this disease.

Further Developments

This version of the Sourcebook is a work in progress that will continue to develop during the months ahead. One month after the thesis show the book will be disseminated to a selected group of health care experts for evaluation. After their feedback is incorporated, the book will also be disseminated to a group of patients for review. The book may continue to be revised and developed beyond graduation.
Cancer: An Information Source Book is a work in progress that will continue to develop during the months ahead. The book will continue to be reviewed by health care professionals, cancer survivors and publishers in the future. Once these reviews are completed the feedback will be incorporated into a more complete and finalized version of this source book.

The use of color throughout the book successfully establishes a calm and serene feeling in the reader. The position of the glossary proved to be a good solution for emphasizing the importance of the glossary and making it more accessible to the reader, although a few people surveyed did mention that they found it to be somewhat cumbersome. The cross referencing system successfully increases the nonlinear approach to the book. The cross referencing system could be improved by bringing the reader to more specific information related to the word that is cross referenced. The current solution for the tabs successfully fulfills the goals of the project, but they still lack durability. The book requires more information specific to individual cancers, for instance: the book currently lacks information pertaining to bone, skin and breast cancer. The medical content will be updated and refined for accuracy. The anatomical illustration seemed to be moderately effective at communicating some basic anatomy. The content of the anatomical information could possess more similarity between the different organ systems.
CONCLUSION

The field of medicine needs to shift towards more preventive solutions for health care. One of the most important aspects of preventive medicine is patient education. Information design applications directed towards patient education play an imperative role in disease prevention. Patient education materials need to be designed to communicate complex, technical information simply and efficiently to a lay audience.

Books containing complex and dense information can be made more accessible to the average reader through the application of graphic design theory and methods. Cancer is a disease that has been widely written about, but the information available is often difficult to find and decipher. This thesis project attempts to consolidate the abundance of available cancer information into a clear and accessible format.

The development of Cancer: An Information Source Book involved research, synthesis, ideation, selection, implementation and dissemination. The collective incorporation of these processes into this project has helped to successfully develop an important and accessible source of information for cancer patients and their families. The results of the evaluation of the book clearly display the need for information design applications in patient education materials. It has become apparent through research and interviews that informed patients are better equipped to make health care decisions. The use of better designed education materials also has an imperative role in enhancing communication between patients and their providers.
The designer of *Cancer: An Information Source Book* has gained an increased knowledge and understanding of the role of information design in the communication of health care material. It is a complex and challenging process to successfully develop graphic design solutions to address this problem. It is the responsibility of designers to accept this challenge and enhance the communication of healthcare information to patients thereby enabling them to make more informed healthcare decisions.
Alternative Medicine: Medicine or treatment that is not used by mainstream medicine. Generally the term also refers to the treatment of the whole person instead of focusing exclusively on the treatment of the tumor.

Complementary Medicine: The use of alternative treatments in conjunction with mainstream medicine. Generally complementary treatments are used to alleviate discomfort from the side effects of mainstream treatments such as chemotherapy.

Patient Education: The process of informing a patient about their particular disease and the treatments that will be administered. The process can include, a patient interview by the provider, printed information, patient education classes, and multimedia source materials.

Provider: Person directing the patient’s health care needs. Includes medical doctors, physician assistants, nurse practitioners and nurses.

Information Design: The defining, planning, and shaping of the contents of a message and the environments it is presented in with the intention of achieving particular objectives in relation to the needs of users.

Ideation: Describing the generation of conceptual solution and preparation of a range of preliminary design approaches.

Implementation: Describing how the project was refined, developed and produced to its final form or application.

Dissemination: Describing plans for future audience interaction, how could this project or information be distributed/used in the future?

Modular Grid: A system of parameters used consistently to unify a series or sequence of designs. Consistent use of type sizes and styles, placement of page numbers, and a color plan are factors that might be included.

Mind Map: A brainstorming method used to discover new ideas. Mind maps begin with a central word or node and other words or ideas are written around, branching out from the central node.
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APPENDIX A: Selected Spreads

Cover
The shaded blue transparent overlay eludes to the water and sky theme of the interior.

The circle reflects the circular elements occurring inside the book that conceptually represent the cell.

Page 1
The content page contains a list of the three main sections and corresponding subsections.

The colored dots correlate with the colored tabs of each section.

Instructions on how to use the book.
APPENDIX A: Selected Spreads

Page 3
Introduces the Cancer section and the Glossary with a brief description of each.

Page 5
Introduces the The Biology of Cancer section.

The diagram of a cell is composed of a simple graphic circle. The repetition of the circle element throughout the book is meant to conceptually represent the cell in an effort to emphasize the important role it has in cancer.
**Page 6**

Explains the role of cell division in cancer.

- **antigen** (AN-tih-jen) Any foreign substance in the body (such as a virus) that can cause infection or disease. Antibodies fight antigens.
- **anti-metabolite** (AN-tih-meh-TAB-ol-it) A drug that stops cancer cells from dividing. After cancer cells divide, they grow and spread.
- **anus** (AN-us) The opening in the body where feces (bowel movements, or BMs) leave the body. The anus is part of the rectum. (The word "anal" is another form of the word "anus").
- **aplastic anemia** (A-plas-tik uh-NEE-mee-uh) A kind of anemia. When a person has aplastic anemia, the bone marrow doesn’t produce enough blood cells.
- **areola** (uh-REE-oh-luh) The dark skin around the nipple on the breast.
- **artificial saliva** (ahr-rih-FIL-uh-luh) A medicine that is used to treat "dry mouth." Sometimes a person’s mouth can become very dry after radiation or chemotherapy treatments. Artificial saliva can help with this side effect.

**Cell Division**

Normal cells grow, divide, and die at different rates depending on the type of cell and a person’s age. When people are young, their cells divide more rapidly until they become adults. After that, most normal cells only divide to replace worn-out or dying cells and to repair injuries. Cells of the skin and the lining of the digestive tract divide regularly to replace cells that have been brushed off by abrasion. The cells of your blood also need to be replaced quite regularly. During the process of cell division occasional mistakes occur called mutations. Each cell is equipped with complex mechanisms that will either correct the error or destroy the cell itself if a mutation occurs.

- Cells that kill due to abrasion are replaced daily.

**Page 7**

Explains the role of carcinogens in cancer.

The illustrations are kept simple to effectively communicate the information to a wide audience.

Colored words appear throughout the text to signify that more information can be found on that topic.

- **Carcinogens**
  - Carcinogens, or cancer-causing agents, can disrupt the cellular mechanisms that correct mutations. Mutations occur naturally when cells divide. Mutations that disrupt the mechanisms of cell division, if left uncorrected by a carcinogen, can lead to a cell dividing uncontrollably. Carcinogens fall into three categories: viruses, chemicals, and radiation.
  - As the cancer cells continue to divide they will begin to form a mass of cells called a tumor. Cancer cells do not form tumors because the blood is fluid; they divide and disrupt the circulatory system. Tumors become dangerous if they compress, invade, and destroy normal surrounding tissues.

**Unregulated cell division occurs and a tumor begins to form.**

- **antiseptic** (AN-tih-SEP-tik) Loss of pain.
- **anaesthetic** (AN-uh-THET-ik) The medicine that a person takes to cut down on pain. Anaesthetics are also used to put people to sleep during surgery.
- **angiogram** (AN-jee-oh-grahm) An X-ray of the blood vessels. Before a person has an angiogram, a radiopaque dye is injected in a vein to make the vessels easier to see.
- **anorexia** (AN-or-uh-HEE-uh) Loss of appetite for food. Some cancer treatments make people lose their appetites.
- **antibiotic** (AN-tih-BY-tik) A medicine to fight infection. Penicillin is the most well-known antibiotic. People with cancer may need to take antibiotics to prevent infection.
- **antibody** (AN-tih-buh-dee) An antibody is a part of a person’s immune system. Antibodies are made by a person’s body to fight infection and disease.
- **anti-emetic** (AN-tih-EM-uh-lik) A medicine to control nausea and vomiting.
Page 8
Explains the process of metastasis.

The basic form of the illustration is repeated for continuity and association.

Page 9
Explains that cancer is a grouping of over 100 separate diseases.
Page 12
The illustrations repeat the circle form while comparing the strength of a person's immune system to the level of carcinogen exposure.

Page 13
Introduces the Anatomy section.

As the reader progresses through the book the horizon line progressively lowers.

Page numbers are absent from the pages to reinforce a nonlinear use of the book.
APPENDIX A: Selected Spreads

Page 15
Displays a transparent overlay of the circulatory system. Transparencies of the lymphatic, respiratory, digestive, urogenital, nervous and endocrine systems are also included in this section.

Page 23
Introduces the Healthy Living section. Related resource information is contained in the margin. Futura Light is used, Futura book is used for the body text. The leading is reduced to help differentiate from the body text.
APPENDIX A: Selected Spreads

Page 25
Introduces the Reasons for Optimism section. This section introduces the reader to new advancements in treatment and care.

The horizon line separates information.

Page 29
Introduces the Health Care Team section. This section introduces the reader to the importance of finding an oncologist and an oncology social worker.

The body text and the glossary are treated the same way to emphasize their equal importance.

The glossary pages are white for separation from the body text and to signify pure information.
APPENDIX A: Selected Spreads

Page 30
The diagram displays the role of the oncology social worker as a fulcrum to a patient's health-care needs. The diagram retains the circle shape with a nucleus to conceptually represent the cell and add to the continuity of the book.

Page 31
Introduces the Financial Assistance section. This section includes resources that provide financial assistance to patients.

### Financial Assistance

Receiving the best standard-of-care medical care can be very expensive, especially when insurance companies generally will not cover alternative and experimental therapies. Oncology social workers are trained to help patients with financial assistance.

Here is a list of organizations that can assist patients with insurance and other financial burdens.

**American Cancer Society**
- National Office: 1595 Clifton Road, NE Atlanta, GA 30329
  - 800-ACS-2345 (800-227-2345)
  - www.cancer.org

**National Association of Insurance Commissioners**
- 120 West 12th Street, Suite 1100
  - Kansas City, MO 64110-1925
  - 816-842-3600
  - www.naic.org

**Medicare, State Health Insurance Assistance Program**
- for your state call 800-638-4833
  - www.medicare.gov

### F G

**Feces** (also called bowel movements, or BMs): Feces are made of bacteria and fiber that is not digested in the body.

**Fibroadenoma** (Fibro-ah-deh-noh-mah): A benign (not cancerous) breast disease. Usually a fibroadenoma is a large tumor made of fibrous and glandular tissue.

**Fibrocystic disease** (Fibro-sis-tik dis-eez): Fibrocystic disease is not really a disease. It is a benign (not cancerous) condition of the breasts. Breasts that are fibrocystic have extra fibrous tissue and cyst-like spaces filled with fluid.

**Fine needle aspiration biopsy** (FY-nuh-nel-ahp-see-bye): A biopsy is a sample of cells taken from a person's body to look at under a microscope. Biopsies can help to tell a doctor if a person has cancer or if the cells are normal. When a person has a fine needle aspiration biopsy (FNA), a needle is inserted into a lump in the person's body and a sample of cells is removed (similar to giving blood). The needle used is smaller than the one used when a person gives blood.
APPENDIX A: Selected Spreads

Page 33
Introduces the Clinical Trials section. This section introduces the reader to clinical trials and provides a list of resources.

The word oncologist is printed in light blue to match the tab of the Health Care Team section.

Page 35
Introduces the Complementary Medicine section. This section introduces the reader to definitions and resources involved with complementary medicine.
This page introduces the Reference section. This section marks the end of the lowering horizon line. The reference section only contains additional lists of resources. The full page of sky blue represents the illumination that can come with seeking additional information.

This section is divided into five subsections.

Page 57
Introduces the reader to the Books section that provides a list of recommended books including a short summary of each. The text extends to the right side of the page and the type size is smaller throughout the Reference section. This helps the reader differentiate between the Reference section and the Cancer section.
APPENDIX A: Selected Spreads

Page 65
Introduces the reader to the Cancer Centers list, which includes National Cancer Institute sponsored centers from around the country.

Page 77
Introduces the reader to the National Organizations list, which includes explanations and contact information of the top national organizations that specialize in aspects of cancer.
APPENDIX A: Selected Spreads

Pages 83-86
Provide space for writing down new information or questions to ask your provider.
APPENDIX B: Completed Questionnaires
## Cancer: An Information Source Book

### Book Survey

**Directions:** Please answer the following questions concerning how effective the book *Cancer: An Information Source Book* communicates by circling a number from 1-5. 1=No, not at all. 5=Yes, a great deal.

<table>
<thead>
<tr>
<th>Question</th>
<th>Score</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Would this source book be useful to you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2) Do the colors establish a calming mood?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) Do the diagrams help to reinforce the information?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4) Do you find the anatomical illustrations useful?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5) Is the position of the glossary effective?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6) Did you learn anything new from this book?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7) Do you feel this book would assist you in finding more information?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8) Do you feel this book would help enhance the communication between you and your health care provider?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Do you have any suggestions for further improvement of this source book?  

- Please use this space for any additional comments:

- Are you:  
  - a cancer survivor  
  - a family member of a cancer survivor  
  - a health care professional. Specific occupation:  
  - ____________
Cancer: An Information Source Book

Book Survey

Directions: Please answer the following questions concerning how effective the book Cancer: An Information Source Book communicates by circling a number from 1-5. 1=No, not at all. 5=Yes, a great deal.

1) Would this source book be useful to you?
   Comments
   1 2 3 4 5

2) Do the colors establish a calming mood?
   Comments
   1 2 3 4 5

3) Do the diagrams help to reinforce the information?
   Comments
   1 2 3 4 5

4) Do you find the anatomical illustrations useful?
   Comments
   1 2 3 4 5

5) Is the position of the glossary effective?
   Comments
   1 2 3 4 5

6) Did you learn anything new from this book?
   Comments
   1 2 3 4 5

7) Do you feel this book would assist you in finding more information?
   Comments
   1 2 3 4 5

8) Do you feel this book would help enhance the communication between you and your health care provider?
   Comments
   1 2 3 4 5

Do you have any suggestions for further improvement of this source book?

Please use this space for any additional comments:

Are you:
☐ a cancer survivor
☐ a family member of a cancer survivor
☐ a health care professional. Specific occupation: Social Worker
Cancer: An Information Source Book

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1) Would this source book be useful to you?  
   Comments:  
   1 2 3 4 5

2) Do the colors establish a calming mood?  
   Comments:  
   1 2 3 4 5

3) Do the diagrams help to reinforce the information?  
   Comments:  
   1 2 3 4 5

4) Do you find the anatomical illustrations useful?  
   Comments: funny  
   1 2 3 4 5

5) Is the position of the glossary effective?  
   Comments: I find it a little cumbersome  
   1 2 3 4 5

6) Did you learn anything new from this book?  
   Comments:  
   1 2 3 4 5

7) Do you feel this book would assist you in finding more information?  
   Comments:  
   1 2 3 4 5

8) Do you feel this book would help enhance the communication between you and your health care provider?  
   Comments:  
   1 2 3 4 5

Do you have any suggestions for further improvement of this source book? No very nice

Please use this space for any additional comments:

Are you:
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Cancer: An Information Source Book

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   Comments

Do you have any suggestions for further improvement of this source book?

Hire a medical illustrator!

Please use this space for any additional comments:

Nice layout, excellent information

Are you:
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☐ a health care professional. Specific occupation: Medical Illustrator
Cancer: An Information Source Book

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Cancer: An Information Source Book

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   Comments
   1 2 3 4 5

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*Please use this space for any additional comments:*

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*We are:*  
- a cancer survivor  
- a health care professional
### Cancer: An Information Source Book

#### Book Survey

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<th>Comments</th>
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<td>5</td>
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<td>Comments</td>
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<td>2) Do the colors establish a calming mood?</td>
<td>5</td>
<td></td>
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<tr>
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</tbody>
</table>

Please use this space for any additional comments:

*The book was very nice and instructional.*

*By:*
- a cancer survivor
- a health care professional
# Cancer: An Information Source Book

## Book Survey

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1) Would this source book be useful to you?  
   Comments

2) Do the colors establish a calming mood?  
   Comments: Blue is very calming

3) Do the diagrams help to reinforce the information?  
   Comments

4) Do you find the anatomical illustrations useful?  
   Comments

5) Is the position of the glossary effective?  
   Comments

6) Did you learn anything new from this book?  
   Comments

7) Do you feel this book would assist you in finding more information?  
   Comments

8) Do you feel this book would help enhance the communication between you and your health care provider?  
   Comments

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ease use this space for any additional comments:

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### Cancer: An Information Source Book

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<tbody>
<tr>
<td>1) Would this source book be useful to you?</td>
<td>5</td>
<td>Very good</td>
</tr>
</tbody>
</table>
| 2) Do the colors establish a calming mood?                               | 5      | Very trustworthy
| 3) Do the diagrams help to reinforce the information?                    | 5      |                         |
| 4) Do you find the anatomical illustrations useful?                     | 5      |                          |
| 5) Is the position of the glossary effective?                           | 5      |                          |
| 6) Did you learn anything new from this book?                           | 5      | Good reference material   |
| 7) Do you feel this book would assist you in finding more information?  | 5      | Read good reference material |
| 8) Do you feel this book would help enhance the communication            | 5      |                          |
| between you and your health care provider?                              |        |                          |

**Please use this space for any additional comments:**

I would recommend calling The American Cancer Society + The National Cancer Institute + a specialized care group ex. 5kHz Cancer Foundation + a Colon Cancer Group Kenneth MD. I have both skin + colon cancer.