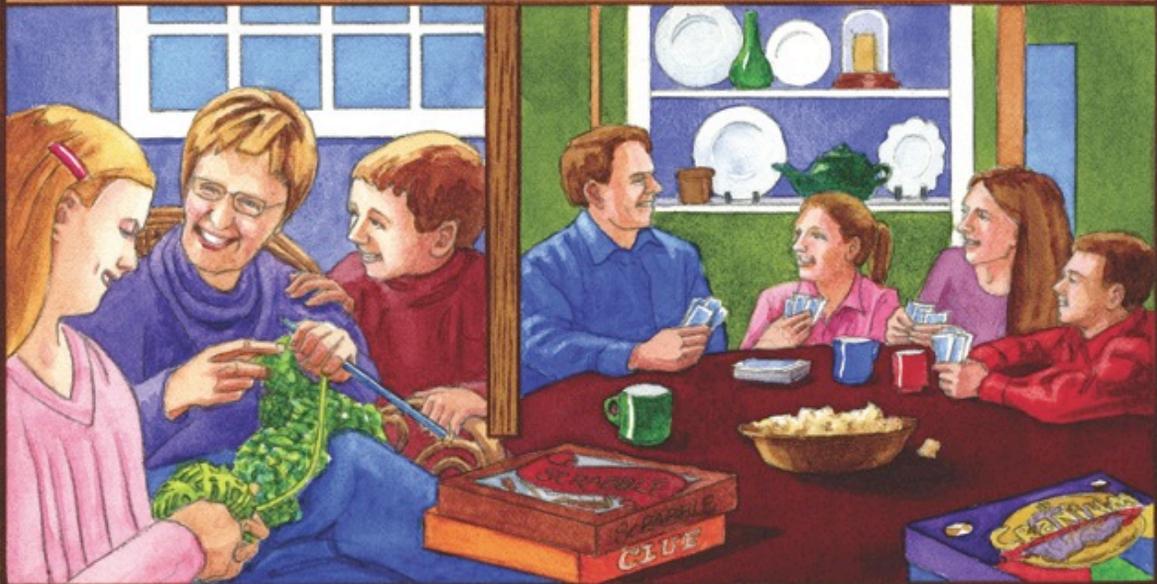


Understanding, Managing, and Living with Malignant Wounds

Sherry A. Clark



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Front cover by Mark Allison

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A Resource Guide for Patients and Caregivers

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Book cover and illustrations by Mark Allison. Mark began his medical illustration career at Rancho Los Amigos Hospital in Downey, CA, right after college. He has a degree in biology from Santa Clara University. After several years working at the hospital, Mark continued his education and expanded his skills into commercial art, illustration, design, and fine art. He is an award winning teacher of art and design for Linn Benton Community College. He also teaches for the community extension classes at Oregon State University, and continues his career as a freelance illustrator and designer. He may be contacted through his website: www.MarkAllison.wordpress.com

Author photo by Robert Durst.

Foreword

Cancer takes many faces, requires many responses, and challenges the patient and the care giver in many ways. While malignant wounds are uncommon, our knowledge of how to care for them is inadequate. At last, here is a handbook that not only helps the patient and the care provider to understand the basic issues, but also provides practical approaches to the many problems of skin that has been invaded by disease.

Sherry A. Clark wrote this gift of a book after being diagnosed with breast cancer in 1993 and suffering four separate recurrences. After surgery, radiation, and chemotherapy, sadly, Sherry was left with malignant wounds. In our work as family physicians, we have encountered other individuals who have had similar skin problems. Managing their symptoms and problems has been difficult, in part because we lacked clear and “common sense” educational materials. Now we have this excellent and helpful resource, a legacy from an amazing, eloquent author.

David H. Cutsforth, Jr. MD
David R. Grube MD

Preface

For a non-medically trained person, I thought that I knew a lot about cancer—breast cancer in particular. During the nineteen years since my first cancer diagnosis, I've gradually accumulated bits and pieces of information about the disease. I also have been very good at dodging the bullets of each recurrence (four), and took it for granted that I could do this forever. Imagine my surprise when weeping sores appeared on my chest and I was told that nothing could be done about them. I asked my oncologist for a name for this ugly thing, a brochure about care of it, or anything from which to begin understanding what was happening to my body. He called it cutaneous metastasis. But no brochure, no understanding, no proper care. Would I have to accept reduced quality of life, as well? No. Instead, I launched my own search for information.

Using lay and scientific search tools on the Internet, I began reading about breast cancer with cutaneous metastases. Published papers with that terminology mostly focused upon clinical trials and specifics about rodent genetics. Nothing practical was published about how a patient should actually manage these wounds so that one could avoid soiled pajamas in the morning or reduce odor so that one could enjoy the company of friends. Instead, there was brief mention of common materials that might bring relief: honey, yogurt, and dried plant material, for example, but not how they could be used in order to go about daily activities with confidence. I needed the how, but it was not where I could find it in either print or electronic version.

Week after week, month after month, I searched trusted, scholarly sites on the Internet for something that would give me a practical solution. I was sent to a wound care nurse, whose only suggestions were to gently debride in the shower using a washcloth and soap, and to keep the wound dry during the day. After three months of this (later learned to be incorrect) treatment, I required hospitalization for severe cellulitis. A hospital wound nurse with actual experience treating malignant wounds reversed the previous protocol. She showed me the correct dressings to use to keep the wound moist, what to expect, and a health products catalog from which to purchase suitable dressings as things progressed. Bless her! I also now had a new search term, *malignant wound*, for what was happening.

Armed with that catalog and medical insurance, I would be able to find dressings that wouldn't aggravate the situation or cause a new one. I continued my online search for almost two years. One day I came across the word *fungating* buried in the middle of a research paper about malignant wounds. A medical dictionary definition for *fungating* described what I saw on my chest!

Using *fungating* in my search string called up a host of papers previously unknown to me. Fortuitously, the first of these was about how to *manage* fungating wounds. The paper was written by a nurse in Ohio and had been published only a few weeks earlier.

Other papers I found were about specific dressings, details about exudate, and discussion about body image. I felt as though I'd won a big sweepstakes! Suddenly I had more to read than I had time.

My next prize discovery was written by a New Zealand nurse. His publication addressed an issue that was problematic for me at the time. My wound and periwound area had progressed to such a size that a common, wide elastic bandage was too small and not shaped properly to cover and hold in place the increasingly larger dressings I needed. The publication included a slideshow

uploaded onto the Internet that described the use of tube-shaped, elastic netting cut to fit various body areas to hold dressings in place without slippage. This had the added benefit of not requiring a second person to dress my wounds, improving my independence.

Thanks to nurses who published in their professional journals, I had resources from which I could gather not only an understanding of what was going on but of how to care for my wounds. These were the tools I would use to improve my quality of life. Imagine how much more I could have accomplished, with more comfort and confidence, had these resources been available at the onset of my wound development! I learned from the published literature that I was not alone with a cancer that creates malignant wounds. As a life-long educator, I had to share what I'd discovered. There was only one thing to do—a last lesson to teach. My discoveries must become a booklet, given to other malignant wound patients to guide them and restore quality to their lives.

This booklet, with its collection of information and color illustrations, is intended to help readers better understand malignant wound care management. Never more should patients or their caregivers lose precious time searching for what is going on or what they are supposed to do. I don't want patients, family, or friends to miss quality-of-life opportunities because of these wounds.

Three years have passed since my finding of the first nodule under the skin of my chest. In spite of time spent searching, I was determined not to let these wounds cause me to miss opportunities. I traveled with my husband to Asia (I even took a Korean cooking class) and to Europe (where I rode atop a mechanical elephant in Nantes, France). We traveled the east coast of North America, where in one day we were in eight different states. We spent a month in the UK and Ireland visiting areas my ancestors emigrated from long ago.

I went through four different chemotherapy treatments, understanding that none would cure, but hoping that one might slow down the progress of the wounds. None worked. I tried a topical cream (off-label use) in a clinical trial that didn't work for me, either. I tried to get into other clinical trials only to be turned away because I didn't have "enough" bulk tumor.

I hired a new oncologist. I learned to ask medical practitioners *before* they began to offer advice whether they knew the terms fungating, weeping malignant wound, etc. If they were unfamiliar with these terms, I excused myself and left to find someone who did know. There was no time to waste on well-intentioned practitioners with out-of-date or incorrect information.

I retired early and focused upon home and hobby projects. I made my daughter's wedding dress and enjoyed following her plans for a unique wedding ceremony. I focused upon bucket list projects around the home, some last trips, and finally writing this booklet.

Even a determined *me*, with well-managed wounds, is no match for cancer. Eventually, the toll of the invading cancer upon internal structures became evident. It was not something to be improved with different dressings or stronger medication. It was time to relinquish control of my health care needs to those far better equipped and trained. My husband and I phoned our local hospice service. This was one of the most difficult but the wisest decision we made as a couple.

My sincere hope is that *Understanding, Managing, and Living with Malignant Wounds* provides patients and their caregivers with the tools and confidence that bring quality at the end of life.

Dedication

*To my caring, loving, soul-mate, Bob.
I knew you were the one when you made me laugh.*

Acknowledgments

Talented and caring people supported my efforts to create this booklet. What began as an idea for a small brochure to fill a need for patients like me, evolved into multiple pages with color illustrations designed for a larger audience. Self-publishing aside, I did not develop this informative, final product without the guidance and help of many others.

My physicians and many nurses in clinics, hospitals, and hospice, are overdue a giant thank you for the treatment and care provided during my nineteen years experience with breast cancer. Arthur L. Clark put a check in my hand and told me to “Write the book!” I know patients, caregivers and their health-care team will forever be thanking him for kick-starting the project. Mark Allison was the teacher of the first art class I ever took who spoke like a scientist. When this project began, a few years later, I knew who could create the illustrations I envisioned. Thank you, Mark.

Editing draft after draft of a document, written by a non-writer, must be tantamount to giving oneself a root canal while going over a waterfall—or, something like that. For her outstanding, critical eye and multitude of suggestions from start to finish, I am forever indebted to Ella May Wulff. Struggling with health issues of her own and that of her family, her perseverance got this project to the print shop. I am forever appreciative of Lucy Himmelreich Noone for her last-minute proofreading and encouraging words when the project became overwhelming and my health was declining.

As the scope of this booklet grew, there became a need to ensure facts, availability of products, and many other items I could not have imagined. Therefore, I cast my net to a broad range of reviewers who responded with incredibly valuable input. These wonderful people include David Grube, MD; David Cutsforth, MD; Stephen Chui, MD; Shawn Foley, MD; Kelli Bergstrom, BSN, RN, CWOCN; Wayne Naylor, Senior Analyst at Cancer Control New Zealand, RN; Karen Daley, RN; Reenie Schwallie, RN, BSN, CHPIN; Robert Spiegel, RN, BSN, CHPN; Dawn Daniels, RN; and Emily Gilbert, Social Services, Benton Hospice Service.

Julie and Jessica, my wise, long-time friends whose varied support during this project is thanked from the bottom of my heart. I was blessed with encouraging words along the way from Carol, Gabriele, Jane, Kerry, Rick, Cliff, Diane, Ron and Kathy, Deron and Margo, members of *Rickett's circa '74*, and members of the *Order of the Holy Fungi Roundtable Group*.

Yards of thanks to Jan and Lou at JanniLou Creations who allow *Permission to Play* instructors LuAnn, Nancy, Virginia, and Kathi, to teach cancer survivors a new craft, each month, in their quilt shop. To Chris, Anika and all my Silica Sisters who stimulated my creative juices while working in my glass studio, I give you a perfectly fused thank you. To Chris, Eija, and others who offered transportation and humored me by fitting in a mocha or lunch in the process, I give you a delicious thank you.

For a fresh, clean house for four months I send a dust bunny-free thank you to Clean Endings, LLC., a local housecleaning service. In 2011, the owner was introduced to *Cleaning for a Reason* through the owner of The Clean Team, a supplier of household cleaning products. The employees and staff at Clean Endings quickly agreed that the gift of time for women battling cancer would be their “giving back to our community program”. See www.cleaningforareason.org for more information.

For assistance with future distribution of this booklet and its free, electronic availability I am grateful to Micky Shields, ED and the nurses and staff at Benton Hospice Service. For availability in iBook format, an iThanks goes to Kevin.

Introduction

The early sign of a malignant wound in the skin is frightening. The extent to which your wound will grow and spread is unknown. The amount of time you have left to be fully mobile and free of pain or other symptoms is unknown. *Understanding, Managing, and Living with Malignant Wounds* unfortunately cannot answer those unknowns. Instead, this booklet serves as a resource for the patient and caregiver whose normal routines and quality of life have been challenged by these wounds. The progress of a malignant wound from its earliest appearance to much later stages is assumed here to be managed by the patient and caregiver in the home.

This booklet begins with answers to questions asked by patients with malignant wounds. This is followed by a demonstration of how a malignant wound establishes itself in the skin, creating a wound bed. For illustration purposes, the location of this wound is the chest wall of a patient with a breast cancer recurrence to that area. Following this wound through time, one gets a clear picture of what is happening and learns the sensations the patient experiences as the wound develops. By providing an understanding of the process, the booklet lays the foundation for learning how to manage malignant wounds as they continue to grow and spread. Throughout the booklet, terms that may not be familiar to everyone are *italicized* and defined in sidebars.

The management of malignant wounds in the chest wall with proper products and sound practices makes their care in the home feasible. This is not always true for wounds that appear in locations the patient cannot see and reach. Some wounds may become more than the patient or caregiver is able or willing to maintain without assistance.

This booklet describes a variety of symptoms and symptom management practices. Contrary to more common healing-wound-care, where a dry wound bed promotes healing, malignant wound care requires a moist wound bed. Dressings needed to restore this optimal moisture environment are demonstrated by two sample wound bed treatments requiring different approaches.

Proper care of the wound bed and symptom-appropriate medication satisfy the physical needs of the patient, but the emotional and social impact of these wounds upon both patient and caregiver must not be underestimated. Wounds that are well managed provide quality time—free from discomfort or risk of embarrassment. This booklet should serve to free up the patient and caregiver to maximize quality time with loved ones. The booklet concludes with a more personal conversation with the author about her experience living with malignant wounds.

I encourage patients and caregivers to seek further information and care only from medical practitioners who have previous experience supervising malignant wounds, their symptoms, and complications. Poor or wrong advice can have serious repercussions. Here, the author speaks from experience.

A list of resources at the end includes sources the author used but may not be available to everyone. The author was fortunate to have access to special or subscription-only research and medical databases. The patient and caregiver are cautioned against taking advice from a source that lacks validity or peer review. Before accepting any finding on the Internet or print form, discuss the matter with your trusted, health care team.

Understanding Malignant Wounds

A small percentage of cancers will develop into *malignant wounds* in the skin. If they do, both the patient and *caregiver* need to know as much as possible about these difficult wounds so that they can better understand how to manage them and their complications.

What is a malignant wound?

A malignant wound is visible evidence that cancer cells from a *primary tumor* have *infiltrated* the skin. Over time, it may grow deeper into healthy underlying tissue layers. Unlike more common wounds, a malignant wound never heals. Despite its presence in skin, a malignant wound is not skin cancer *per se* but can arise from some kinds of melanoma as well as from other cancers.

What is the origin of a malignant wound?

The origin of a malignant wound is usually a primary tumor somewhere in the body. The route followed from a primary tumor to a malignant wound in the skin varies. Via one route, a primary tumor in or near the skin continues to grow and eventually becomes a malignant wound in the skin. A different route involves *metastasis*. Tumor cells detach from a primary tumor and travel to the skin through the blood, *lymph vessels* or between *tissue planes*. Once established in the skin, these metastasized cancer cells multiply, producing early signs of the malignant wounds they will become.

Do all malignant wounds look alike?

No. The early appearance of a malignant wound begins with one or more raised *nodules* under the skin's surface. These nodules eventually develop into shapes that resemble a crater or a cauliflower (Figure 1).

malignant wound: an injury to (skin) tissue due to invasive cancerous growth

caregiver: in the context of this booklet, caregiver is the person that provides the day-to-day care of the patient. Caregivers may be health professionals, family members, friends, social workers, or members of the clergy.

primary tumor: the original tumor

infiltrating cancer: cancer that has spread beyond the layer of tissue in which it developed and is growing into surrounding, healthy tissues. Also called invasive cancer.

metastasis: the spread of cancer from one part of the body to another

lymph vessel: a thin tube that carries lymph (lymphatic fluid) and white blood cells through the lymphatic system

tissue plane: where two different tissues meet and are usually joined by a thin connective tissue layer, for example where skin and muscle meet

nodule: a growth or lump that may be malignant (cancer) or benign (not cancer)

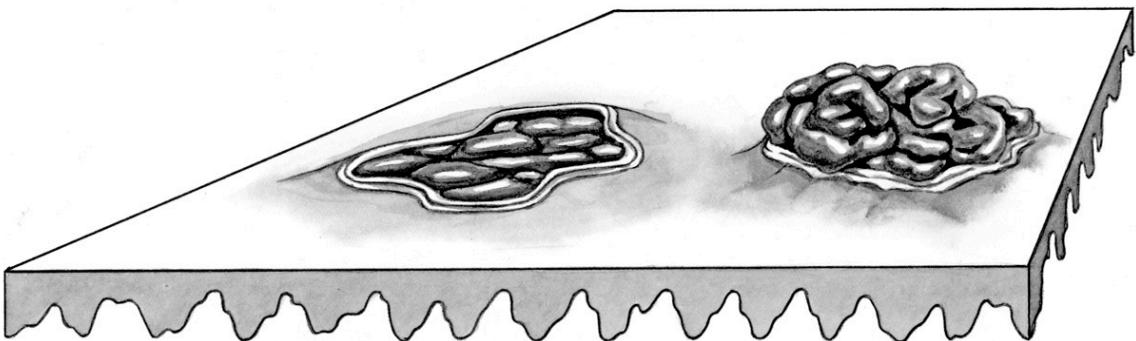


Figure 1. Ulcerating and fungating lesions

Some wounds resemble a crater (left) with high edges and a sunken center, commonly called an *ulcerating lesion*. Other wounds grow above the surface and resemble a cauliflower (right), commonly called a *fungating lesion*. Both types can occur in the same wound bed.

ulcerating lesion: a type of skin lesion where the surface cells have died and been cast off

fungating lesion: a type of skin lesion that is marked by breaks in the skin, cancerous outcroppings, and necrosis (death of living tissue)

wound bed: total area affected by wounds in the skin

Crater-like wounds, commonly called *ulcerating lesions*, have high edges with a sunken center. Cauliflower-like wounds, referred to as *fungating lesions*, look like clusters of raised nodules growing above the surface of the skin. Both ulcerating and fungating lesions can appear in the same *wound bed*.

Where do malignant wounds occur?

Malignant wounds occur in the skin. Because this is the largest organ of the body, there is potential for any part of the skin to develop a malignant wound. In women, the most common primary tumor that can lead to a malignant wound is a breast cancer that has also spread to the skin of the chest wall. In men, the most common primary tumor to invade skin is lung cancer. In general malignant wounds can occur to the skin of the head and neck, back, abdomen, groin, armpit, anus, and genitals from primary tumors anywhere in the body (Figure 2).

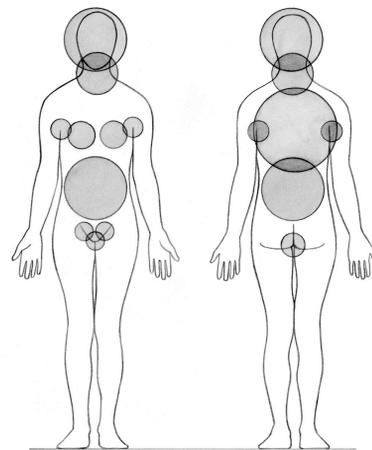


Figure 2. Common sites for malignant wounds

Primary tumors from any origin can lead to a malignant wound somewhere on the skin. The circled areas are the more common sites malignant wounds tend to appear.

Are malignant wounds easy to diagnose?

Not always. Sometimes the appearance of a malignant wound precedes symptoms of primary tumors. Seeing or feeling the raised nodule in the early stage of a malignant wound may be the first sign of an underlying cancer somewhere else in the body. Unfortunately, these early signs may be mistaken for a variety of benign skin conditions. This can confuse diagnosis and delay important care of these wounds and of the primary tumor.

How does a malignant wound progress over time?

Figure 3 represents a block of malignant wound tissue as it would appear in the chest wall of a patient whose primary tumor was a breast cancer. Beginning with normal tissue (Figure 3a), we follow this same block through time (Figures 3b, c, d). The illustration shows what can occur at the surface and beneath a malignant wound bed as the infiltrating cancer continues to grow. Early-stage nodules (Figure 3b) and ulcerating and fungating lesions (Figure 3c, d) are shown at the surface. As the nodules grow wider and deeper, the likelihood of disruption and damage to the surface and underlying

layers is demonstrated. The interval of time from Figure 3a to any subsequent stage is unpredictable, ranging from weeks to years.

Normal Tissue

Normal skin tissue (Figure 3a) includes a healthy, intact surface. Beneath this unbroken surface is an intricate network of vessels. In the absence of cancer, these blood vessels bring nutrients and oxygen to healthy cells while lymph vessels remove waste and excess fluid. Below the vessel networks is muscle tissue. Beneath this layer of muscle is bone tissue (a rib in our example). The organ tissue layer shown here is the lung. As we follow this tissue block through time, we shall see how the infiltration of cancer cells affects each layer, beginning with skin tissue.

Infiltration of Cancer

A wound bed is being established (Figure 3b). Often this is when a patient first realizes there is a problem. As mentioned earlier, a primary tumor may have gone undetected until it manifests itself in the form of a raised nodule under the intact skin surface. These nodules may be flesh-colored or red, and may be visible to the eye, or only detected with careful *palpation*. There is usually no pain at this phase. Sometimes the nodules are associated with, or preceded by, a rash. The *periwound* skin area may itch. Although it may appear normal to the unaided eye, the periwound skin may actually have been damaged by previous oncology treatments (radiation, surgery, chemotherapy).

Deeper Invasion

As the nodules continue to grow (Figure 3c), the once intact skin may be compromised. The surface area and depth of the wound bed increase in size, affecting underlying vessel networks and possibly muscle tissue. The continual breakdown of cells at the surface releases fluid and contributes to inflammation. If the skin is no longer intact, the wound weeps *exudate* onto the wound bed. Exudate contains water and toxic cellular materials that are irritating to the wound bed and periwound skin. This contributes to an environment where opportunistic microbes (bacteria, yeast) can grow.

Early on, the surface of a *weeping wound* grows pale in color because the cancer is diverting blood vessels for its own growth deeper into the wound. In time, wounds appear as a mixture of yellow, gray, or black colors. This is a sign of *necrosis*. The combined effects of exudate and necrotic tissue breakdown account for the foul odor associated with weeping wounds. The invading cancer also affects the integrity of vessel walls. This results in bleeding at or below the skin's surface. Leakage of blood from *capillaries* (Figure 3e) under the skin gives rise to a bruised appearance at the surface. Fragile tissue just

palpation: examine by pressing on the surface of the body to feel the organs or tissues underneath

periwound skin: the area surrounding the wound bed

exudate: a mass of cells and fluid that has seeped out of blood vessels or an organ, esp. in inflammation

weeping wound: a wound that discharges exudate

necrosis: the death of living tissues

capillary: the smallest type of blood vessel

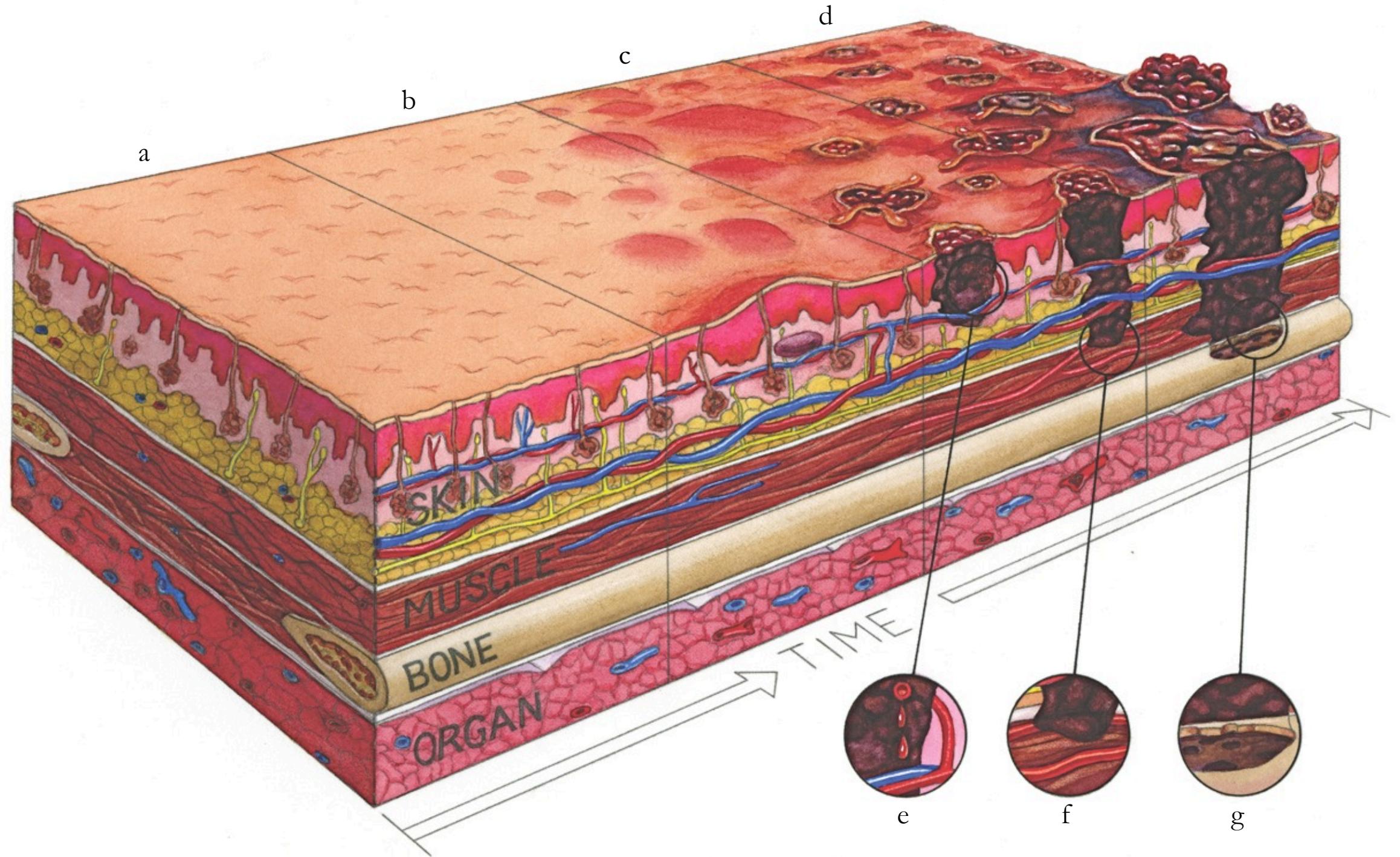


Figure 3. Malignant wound progression in the chest wall

Progressing of wound through time is shown from left to right.

- a. normal skin tissue;
- b. infiltration of cancer appears as early stage nodules (bumps) on skin, forming wound bed;
- c. cancer cells break through skin surface and weep, deeper invasion of tissues below;

- d. late stage wounds with ulcerating and fungating lesions at surface, very deep tissues affected;
- e. leaking vessels may create bruised appearance on the skin;
- f. invasion reaches deeper blood and lymph vessels and muscle tissue;
- g. eroding bone, leading to more systemic complications.

hemorrhage: in medicine, loss of blood from damaged blood vessels. A hemorrhage may be internal or external, and usually involves a lot of bleeding in a short time.

edema: swelling caused by excess fluid in body tissues

systemic: affecting the entire body

curative treatment: treatment and/or therapies designed to improve a patient's symptoms and cure the medical problem

palliative care: care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of palliative care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, supportive care, and symptom management.

beneath a necrotic, malignant wound can bleed easily. The cancer not only affects normal blood clotting factors but also weakens the walls of larger blood vessels. This can lead to *hemorrhaging*.

The rapid growth of tumors at this stage can disrupt or overwhelm the functioning of lymph vessels, too. The result is *edema* of the area, a source of pain and possibly reduced mobility. Deep invasion of cancer can begin to encroach upon muscle tissue, also causing pain and affecting mobility, among other discomforts.

Late Stage

Figure 3d illustrates continued growth into the chest wall. The surface of the malignant wound bed shows a variety of tumors at various stages of development. Beneath this visible surface chaos, the tumors create increasing risk to the patient. Not only is more muscle tissue involved (Figure 3f), with more restricted movement, swelling, and pain, but the tumor has now begun the slow process of eroding bone (Figure 3g). With deeper tissue involvement come more *systemic* complications. Again, the time frame from early stage to late stage can vary widely, depending upon the type of cancer and any primary tumor treatments.

What is the incidence of malignant wounds?

Malignant wounds are uncommon. In fact, only 5–10% of patients with internal, primary tumors develop malignant wounds. Depending upon the status of the primary tumor, malignant wounds and their care may not be the most debilitating consequence of the cancer. Only when the primary tumor is slow-growing or causes little discomfort does the care of the malignant wound become a primary factor in quality of life.

What can the patient and caregiver do?

When both the patient and caregiver understand what a malignant wound is, they can better work with their trusted health care team to manage these very complicated and devastating wounds. The next section of this booklet suggests how to manage these wounds in the home. The patient may be receiving *curative* treatment for a primary tumor from an oncologist while independently managing these wounds. When the decision has been made to end curative treatment, the patient transitions into *palliative* care. Palliative care is provided in professional facilities or can be set up in the home. The patient may be in palliative care for a long period of time.

When doctors, the patient, and family agree that the prognosis is

terminal, the patient may choose to enter into *hospice* care. Hospice is often thought to be appropriate only during the last few weeks of a person's life. Current hospice practices, however, prefer to support the patient, family, and caregiver for approximately the last six months of life. Although hospice services and supplies vary by region, staffing, and funding, the aim is improving patient quality of life by relieving pain and minimizing symptoms.

Regardless of patient prognosis or physical setting (home or care facility), managing malignant wounds is possible. In the following pages, wound symptoms, what to do about them, and what to watch for, are described with an emphasis upon minimizing discomfort and maximizing quality of life.

terminal: an illness that cannot be cured and will cause death

hospice care: a program that provides special care for people who are near the end of life (~6 months) and for their families, either at home, in freestanding facilities, or within hospitals

Managing Malignant Wounds

Understanding malignant wounds sets the foundation for management on a daily basis at home or in a care facility. Managing malignant wounds is different from the type of wound care with which most people are familiar. These wounds will not heal, and they continue to deteriorate. Managing, in this context, refers to successfully taking back a sense of control over the care of the patient's malignant wounds. It is not easy. It is not a quickly performed routine. It may require help from others. The reward, however, is more quality time. The pages that follow provide insight into what the patient and caregiver may expect and how best to cope.

moist wound healing: the gold standard of chronic wound care; involves the presence of a balanced moisture environment within the wound bed. Malignant wounds, however, will not heal.

Moist Wound Beds

Wound care practices that maintain a moist wound bed are preferred to manage malignant wounds, because they minimize or prevent complications (odor, exudate, bleeding). In the literature, *moist wound healing* is a common term for treating chronic wounds. Because malignant wounds do not heal, we will use the term *moist wound care*. The management practices are the same—maintaining a moist wound bed.

Assessment

A medical practitioner (e.g. wound care or hospice nurse) with previous malignant wound care experience determines the best protocol for the patient. They should first observe the wound bed and periwound skin and listen to the needs and concerns of the patient and caregiver. Likewise, the patient should be prepared at visits with questions to ask or concerns to resolve. Together they determine the optimal wear time for dressings according to the nature and volume of exudate, manufacturer's instructions, and patient's activity level. A list of alternatives should be discussed as well as complications to look for and how to correct them independently.

Keep notes on what works or does not. Periodic reassessment is necessary to accommodate the changing wound bed.

Moist Wound Care Protocol

Maintaining a balanced moisture environment is key to these types of wounds. The opposite is true for most other types of wounds the patient or caregiver may have encountered. Remember, malignant wounds will not heal, so drying out and scabbing over is not a goal.

It is possible that the patient simultaneously develops wounds in some areas that have different needs (one bleeds, another does not). Having a variety of dressing types on hand is wise. Saturated dressings and *blanched* skin are early signs of a wound that is too wet. To correct for this, more frequent dressing changes or more absorbent dressing layers may be needed. Very dry dressings and hard scabs on wounds are signs of a too-dry wound bed. Know how to restore the proper moisture content to avoid discomfort. Both too-wet and too-dry wound beds require restoration to an optimal moisture environment.

blanched: whitened or made pale

Dressing changes should be free of pain to the patient and free of trauma to the wound bed. A medical practitioner determines if pre-medication is advised to alleviate anxiety or pain at dressing changes. Reading the instructions for each dressing type, and following the recommended procedures, also contributes to eliminating pain and reducing trauma to the wound bed at each dressing change.

Specialized dressings can be found in wound care supply catalogs. On occasion, and to keep costs down, common products can be substituted for specialized wound dressings. Consult with your medical practitioner for cost-saving products that can be substituted for more expensive ones. To promote patient comfort, do not overlook minimizing bulkiness, which affects body shape and may discourage social interaction.

Restoring Optimal Moisture

Two different wound bed environments on the chest wall are illustrated in Figures 4 and 6. The management of each condition is determined by moisture status, signs of bleeding, the presence of foul odor, etc. Wound Bed A demonstrates wound dressings designed for a problematic wound bed that is very odorous and has moderate to heavy exudate but is not bleeding. Wound Bed B is dressed for minor odor and some bleeding but does have balanced moisture. By exploring combinations of dressing layers, the patient and caregiver can adapt to changes to the wound bed without sacrificing patient comfort. For clarity, wound dressing layers are separated into three categories: **primary**, **secondary**, and **tertiary**. Always apply fresh dressings to a clean wound bed. If a shower is not possible at dressing change time, a rinse with water or *saline solution* will soften dried exudate so that it can be removed with minimal damage. Note: gently cleaning with water or saline means no scrubbing or soap; just let the moistened exudate wash away. Do not pick at stubborn sections.

saline solution: used here, this is contact lens spray free of ocular lubricants or preservatives

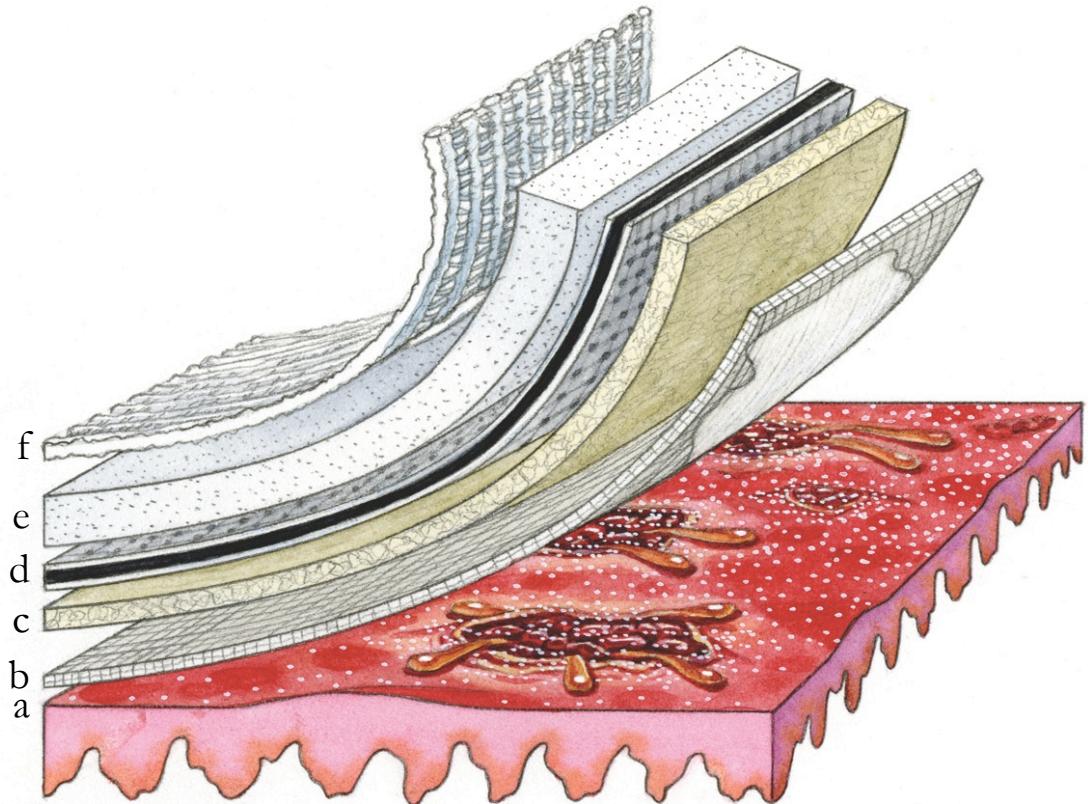


Figure 4. Example dressing layers: Wound Bed A

Bottom to top shows layering required to restore optimal moisture of this wound bed.

- Primary** a. The wound bed is very odorous, with moderate to heavy exudate, and no bleeding. Notice sprinkling of metronidazole powder directly on surface for odor control.
 b. Silicone mesh dressing with anti-bacterial cream smeared into the weave.
- Secondary** c. Alginate dressing for moderate to heavy exuding wounds.
 d. Activated carbon filter dressing to absorb odor.
 e. A highly absorptive dressing to capture excess exudate and prevent leakage.
- Tertiary** f. Elastic net, tubular bandage to keep dressings from slipping.

Wound Bed A

Status: very odorous, moderate to heavy exudate, no bleeding.

See Figure 4.

Primary

The primary layer is in direct contact with the weeping wounds. In this example, to control odor, notice a sprinkling of powder (*metronidazole*). Apply powder more liberally to the weeping areas. This powder can be used daily to keep odor in check. Anti-microbial lotions or gels are not an option in this example, because one shouldn't add more moisture to an already wet (moderate or heavy) wound bed. Noticeable odor improvement should be detected after a few days.

metronidazole: a drug that is used to treat infection and is being studied in the treatment of cancer.

Directly on top of the powder, for odor control, is an open-weave mineral oil coated and non-adherent silicone mesh dressing. This is soft and conforms to body shape. The open weave allows exudate to wick through to the absorbent secondary layer. The mineral oil coating helps maintain a proper moisture environment and prevents wound sticking, which could lead to unintentional *debridement* or bleeding. This silicone mesh is also beneficial because it encourages gentle, *autolytic debridement*, which is desirable. These dressings are easily cut to shape. Gauze is never advised as a primary layer because its fibers may adhere to the delicate wound bed.

Adding an additional *prophylactic* anti-microbial treatment to this mesh can be achieved by thinly smearing a silver-impregnated cream or gel into the open weave of the silicone mesh before applying it directly to the wound bed. Careful monitoring is required due to the addition of this moisture (anti-microbial cream) to an already moderate or heavy exudate wound bed. This is to prevent the wound bed from becoming too wet.

If advised by a medical practitioner, a *barrier film product* on the periwound skin can be applied at dressing changes to protect it from exudate leakage or abrasion from dressing layers. It is possible that the patient simultaneously develops wounds in some areas that have different needs (one bleeds, another does not). Having a variety of dressing types on hand is wise.

Secondary

Exudate moves away from the wound bed through the primary layer to these secondary layers. These absorptive layers collect the exudate from the weeping malignant wound. The dressing type, quantity, and frequency of changes require careful monitoring to insure that the moisture content of the wound bed is optimized. In this example, exudate flow is moderate to heavy and requires two different dressing types to prevent strikethrough to garments while maintaining a proper moisture environment. However, two absorptive layers also add significant bulk.

The secondary dressing closest to the silicone mesh of the primary layer is a dry, *alginate dressing* that can be cut to fit wound size and shape. An *activated charcoal dressing*, to trap odors, is added to this wound bed. These cannot be cut so size, so place them above the most offensive area but outside the alginate dressing. Activated charcoal dressings should not get saturated with exudate.

An additional, highly absorptive dressing completes the secondary layering. Any excess moisture passing through the alginate and carbon filter dressings is pulled away from the wound and is absorbed in this

debride: to remove of non-living tissue

autolytic debridement: using the body's own enzymes and moisture to break down and gently slough off necrotic tissue and exudate

prophylactic: in medicine, something that prevents or protects

barrier film product: a moisture-vapor permeable thin coating applied onto the surface of the skin

alginate dressing: made from seaweed; one of the secondary dressings for wounds that have moderate to heavy exudate

activated charcoal dressing: a dressing containing highly absorbent carbon

outer dressing. This helps prevent leakage onto periwound skin or passing through onto clothing or bedding. If these highly absorptive dressings prove too costly, other products (menstrual, incontinence, or gauze pads) can be substituted because these are not in direct contact with the wounds. Products using gels to trap moisture should not be cut because the gel can ooze onto the wound bed or out onto clothing or bedding.

Tertiary

The outer or tertiary layer should be non-adhesive and not composed of any material that would irritate periwound skin. Its purpose is to keep all dressing layers comfortably in place while the patient carries on with daily activities. The tertiary layer should not limit mobility or be so tight as to affect blood or lymph flow.

A convenient and highly adaptable solution for holding dressings against wounds on the chest wall consists of constructing a tank top from very stretchy elastic net tubular bandage (Figure 5). Sold in 25-yard units, one unit can make several dozen tank tops for the chest. Multiple sizes allow for covering everything from a finger to a large torso.

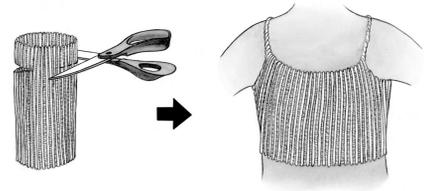


Figure 5. Elastic net tank top

Found online (keywords: “elastic net tubular bandage”) or ordered from pharmacies, the tubular bandage can be washed and reused many times. With practice, the patient and caregiver will learn how long to cut a length of tubing and where to clip it for shoulder straps. This should provide a comfortable fit and maximum control (to avoid slippage) of the layers beneath. Wide, elastic-wrap bandages or soft, cotton t-shirts are alternatives, or they can be used in combination with elastic netting to securely keep dressings in place.

Wound Bed B

Status: minor odor, balanced moisture, some bleeding.

See Figure 6.

Primary

The primary layer is in direct contact with the weeping wounds. In this example, to control odor, notice a sprinkling of powder (metronidazole). Apply more liberally to the weeping areas. Can be used daily to keep odor in check. Noticeable odor improvement should be detected after a few days.

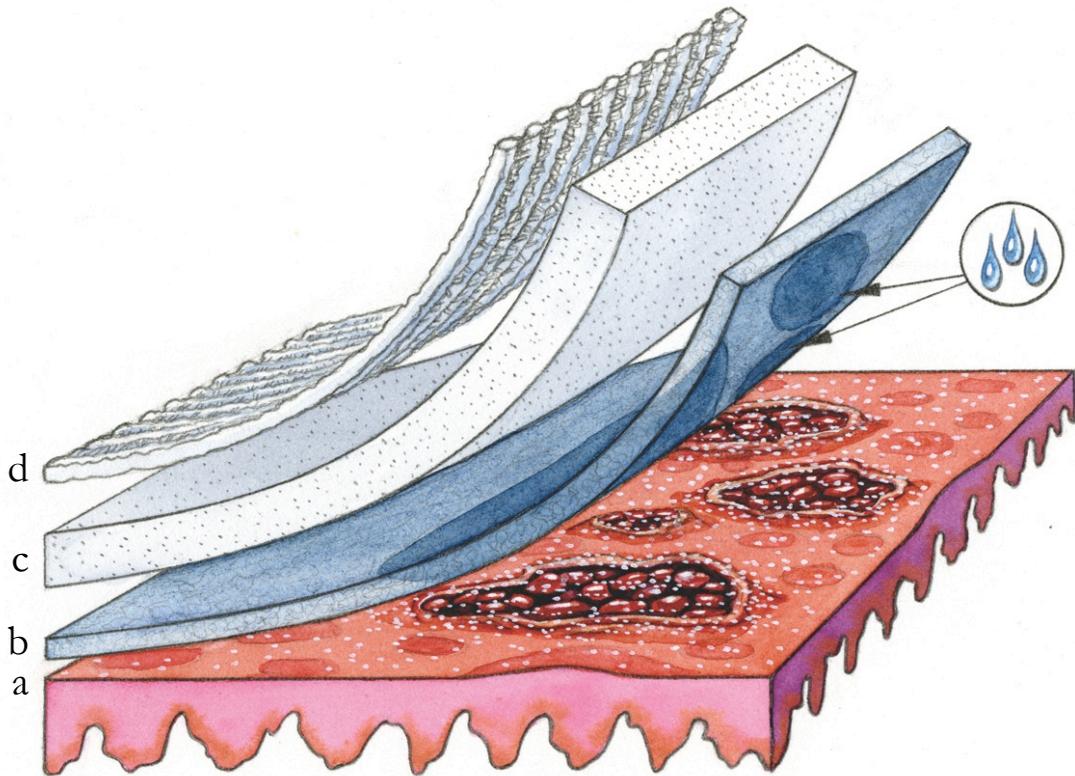


Figure 6. Example dressing layers: Wound Bed B

Bottom to top shows layering required to maintain optimal moisture of this wound bed and to stop minor bleeding.

- Primary**
- a.** The wound bed has minor odor, balanced moisture, and some bleeding. Notice sprinkling of metronidazole powder directly on surface for odor control.
 - b.** A silver-impregnated, hydrofiber dressing converted to a protective gel-like covering in the presence of moisture (exudate, water, or saline). Promotes clotting of minor bleeds.
- Secondary**
- c.** A highly absorptive dressing to capture excess exudate and prevent leakage.
- Tertiary**
- d.** Elastic net, tubular bandage to keep dressings from slipping.

Directly on top of the powder, the primary layer consists of a dry, *silver-impregnated, hydrofiber dressing* that can be cut to fit the wound size and body contours. Moisture (water, saline, or exudate) converts this dry, hydrofiber dressing into a wet, gel-like protective covering. The composition of this specialized hydrofiber dressing promotes blood clotting, which is advised for wounds with minor bleeding. The silver content also reduces odor-causing microbial growth.

silver-impregnated, hydrofiber dressing: a primary dressing that has silver ions added as an anti-microbial

Although a hydrofiber dressing is advised for bleeding wounds, caution should be exercised. Wound Bed B currently has balanced moisture. Without a steady supply of moisture (water, saline, or exudate), this hydrofiber dressing can become dry and hard and may adhere to the wound tissue. A hard dressing against a malignant wound is painful and can actually cause bleeding. Frequent

monitoring of moisture content may be necessary throughout the day. A spray of water or sterile saline solution can restore moisture to a dry hydrofiber dressing. At dressing time, a water or saline soak makes it easy to remove a too-dry hydrofiber dressing with minimal damage to tissue below. Do not attempt to remove an adhered hydrofiber dressing until it has been reconverted to a soft gel that easily falls away from the wound bed.

It is possible that the patient simultaneously develops wounds in some areas that have different needs (one bleeds, another does not). Having a variety of dressing types on hand is wise. If, while restoring Wound Bed B to optimal moisture environment, the wound bed becomes too moist, use the silicone mesh and alginate as discussed in example Wound Bed A, above. For isolated wounds that continue to bleed, small pieces of the silver impregnated hydrofiber can be applied directly to those areas. Continue to monitor the entire wound bed for balanced moisture.

A medical practitioner will advise the best methods to follow, what to watch for, and when to change a silver impregnated hydrofiber dressing. If advised, a barrier film product on the periwound skin can be applied at dressing changes to protect it from exudate leakage or abrasion from dressing layers.

Secondary

In this scenario, the secondary layer of Wound Bed B consists of one absorptive dressing, because exudate production is minimal and moisture of the wound bed is balanced. This single layer should be adequate to wick exudate from the wound bed and prevent leakage to clothing or bedding.

Tertiary

The outer or tertiary layer should be non-adhesive and not composed of any material that would irritate periwound skin. Its purpose is to keep all dressing layers comfortably in place while the patient carries on with daily activities. The tertiary layer should not limit mobility or be so tight as to affect blood or lymph flow.

A convenient and highly adaptable solution for holding dressings against wounds on the chest wall, consists of constructing a tank top from very stretchy elastic net tubular bandage (Figure 5). This tubular bandage comes in many widths for use all over the body. The abdomen range comes in three sizes. With practice, the patient and caregiver will learn how long to cut a length of netting and where to clip it for shoulder straps. This should provide a comfortable fit and maximum control (to avoid slippage) of the layers beneath. The tube tank can be washed and reused many times. Wide elastic-wrap

bandages or soft, cotton t-shirts are alternatives, or they can be used in combination with elastic netting to securely keep dressings in place.

Optimal Moisture Dressing Layers

If everything is going well, a common dressing layering to maintain a balanced moisture environment would include the following layers.

Primary

- Topical agent to keep odor in check
- Soft, non-adherent dressing (silicone mesh) with anti-bacterial cream smeared into weave

Secondary

- Alginate dressing
- Absorptive dressing with strikeproof barrier

Tertiary

- Elastic net tubular bandage

Signs and Symptoms

Pain

In Figure 3c and d, the continuing infiltration of cancer into vessels and deeper tissues was shown to cause many changes over time. Each of these changes contributes to the total pain the patient experiences. A medical practitioner helps the patient control pain with prescribed *analgesics* and may suggest non-prescriptive products or techniques.

The type of pain experienced depends upon many factors, including wound location, degree of tissue damage, nerve involvement, and the patient's previous experience with pain and pain medications. Each of these factors creates a different type of pain origin, intensity, duration, and sensation that may be difficult for the patient to convey to the practitioner. Adequate pain control includes information about the origin and possible migration of the pain. One method used to classify pain intensity uses a numeric rating scale from 0–10 with no pain (0) at the low end and severe pain (10) at the other. Pain duration can be described as *acute* or *chronic*. Location can be described as superficial or deep. Expressing pain sensation in terms such as cutting, burning, throbbing, stabbing, itching, tingling, stinging tells the practitioner more about the pain. Accurate pain description ensures that the practitioner can prescribe the proper medication. Pain relief contributes enormously to patient comfort.

analgesic: a drug that reduces pain. Analgesics include aspirin, acetaminophen, and ibuprofen.

acute pain: pain that comes on quickly, can be severe, but lasts a relatively short time

chronic pain: pain that can range from mild to severe, and persists or progresses over a long period of time

Causes/Sources of Pain

- Dressing changes
- Inappropriate dressings
- Exposure to air
- Pressure on nerves
- Inflammation
- Infection

How to Control Pain

Disturbing the wound bed at dressing changes can create pain and distress. A wound care practitioner with malignant wound care experience knows how to minimize pain during dressing changes. Depending upon wound bed conditions, some dressings may be left in place for long periods, thus minimizing wound disruption. Inappropriate dressings in contact with the wound bed (e.g. gauze; non-contouring) exacerbate the chaos at the surface. Dressings that adhere, harden, or in any way harm the delicate surface tissue must be carefully removed and replaced with a type that does not aggravate the situation. Pain caused by exposure to air can be minimized by temporarily covering the wound with a moist dressing during dressing changes. Water or a saline solution on a sterile, tight-weave pad placed on the wound while preparing new dressings may bring some relief. The patient may also benefit from *pre-medication* with an analgesic prior to removal of old dressings.

pre-medication: giving medication in anticipation of pain or anxiety of pain

long-acting: (a drug) maintaining its effects over a long period of time, being slowly absorbed and persisting in the tissues before being excreted

short-acting: (a drug) quickly effective, but requiring regularly repeated doses for long-term treatment, being rapidly absorbed, distributed in the body, and excreted

breakthrough pain: intense increases in pain that occur with rapid onset even when pain-control medication is being used. Breakthrough pain can occur spontaneously or in relation to a specific activity

Pain arising from pressure upon nerves, inflammation, and/or infection requires the skills of a medical practitioner, who works with the patient to develop an analgesic protocol that provides steady, *long-acting* relief as well as *short-acting* medicine for those times when there is *breakthrough pain* or anticipated pain (e.g. during dressing changes).

Effective control of pain from malignant wounds may involve a combination of appropriate analgesics, anti-inflammatories, and non-pharmacological products and techniques. Some patients find alternative pain relief therapies useful to reduce anxiety or the sensation of pain by creating a distraction. These therapies include: relaxation, music, massage, visualization, and aromatherapy.

Pain Warning Signs

If the pain changes, this may be a warning. Pain associated with redness, heat (including fever), or exudate could be sign of an infection. Pain that ceases to be kept under control, by either long-acting or short-acting medication, should be brought to your practitioner's immediate attention.

Exudate

Exudate is the fluid that weeps from a malignant wound that has progressed to the stage represented in Figure 3c. Management of malignant wounds requires maintaining a balanced, moist environment. Too much or too little moisture can lead to increased pain and complications. The release of exudate can make it difficult to maintain this balance. Exudate from malignant wounds contains substances that can irritate the wound bed and periwound skin.

Outer dressings that have become saturated may *striketrough* onto clothing, or, at night, bedding. This is a sign that dressing type is not adequate for current wound bed status. Proper management of exudate from the malignant wound contributes to patient comfort and well-being.

striketrough: the point at which absorbed fluid reaches the outer surface or edge of a dressing and leaks onto clothing

Causes/Sources of Exudate

- Fluid released from or around malignant cells

How to Control Exudate

Exudate is managed with dressings designed to match the volume of fluid released (light to heavy). Containing exudate requires advice from a medical practitioner familiar with weeping malignant wounds. There is a wide range of absorbent dressings available from medical suppliers. However, depending upon the status of the malignant wound, it may be difficult to find the perfect dressing to control exudate. A clever solution may involve *off-label use* of absorbent products (menstrual or incontinence pads) to achieve an appropriate level of absorbency. Off-label usage keeps costs down. To address striketrough, a different dressing type or an additional absorbent layer, may help match the interval of time between dressing changes.

off-label use: use of a product for something other than its intended use

A wound bed that is too wet or too dry may contribute to pain or lead to complications. If the tissue looks blanched, it is too wet. If surface exudate has dried or hardened above a weeping wound (like a scab), then the moisture content of that wound bed is too dry. Sometimes changing to a slightly different dressing for a few days restores proper moisture balance. It is important to recognize the appearance of *best* moisture environment, how to maintain it, and what to do if its status changes. It is also important to pay attention to periwound skin that may be irritated by exudate. Some practitioners recommend the use of barrier film products for periwound skin protection. Keeping absorbent dressings off of periwound skin is advised.

Exudate Warning signs

If there is a sudden change in volume or color of the exudate, consult your medical practitioner.

coagulate: to congeal; to clot

Bleeding

In addition to creating pain, dressing changes may also induce bleeding. The fragile tissue making up the wound bed can easily be disturbed, resulting in bleeding. Dressings that rub against, or adhere to, this tissue may cause bleeding either while being worn or when being removed. The infiltration of cancer may lead to erosion of blood vessels (Figure 3e), abnormally thin-walled blood vessels, or failure to *coagulate*. Sometimes the patient doesn't know until the next dressing change that there was a minor bleeding episode. The sight of blood on the dressing can be alarming to the patient and caregiver.

Causes/Sources of Bleeding

- Dressing changes
- Inappropriate dressings
- Vessel damage (erosion)
- Vessel abnormality (thin walls)
- Coagulation defect

How to Control Bleeding

There are several categories of bleeding. Their control varies depending upon the extent and cause of the bleeding. Minor bleeding may remedy itself or can be controlled by local pressure, ice packs, and/or alginate dressings placed directly against the bleeding wound.

Discuss preparation for moderate bleeding with your medical practitioner. It may be necessary to have appropriate dressings on hand. Depending upon the location and status of the malignant wound, trained medical staff may be required to control bleeding.

Concern about major bleeding should be discussed with your trusted health-care team.

Odor

For some patients, odor is more troubling than pain. It can also be the cause of depression and social isolation for the patient. With time, dressings become saturated with exudate and collect pieces of necrotic flesh and microbial waste products. Both exudate and necrotic tissue support the growth of microorganisms that produce odors that may be offensive to the patient and to anyone near them. Odor can also be a sign of a serious infection in the wound bed. With proper dressings and other products, odor can be minimized or even eliminated.

Causes/Sources of Odor

- Infrequent dressing changes
- Exudate (skin or saturated dressing)
- Necrotic tissue
- Infection

How to Control Odor

Determining the source of the odor is key to controlling it. The advice of the experienced medical practitioner includes which wound dressing type best suits the needs of the wound bed and periwound skin, as well as how often that dressing needs to be replaced. A saturated dressing may be a sign that more frequent dressing changes are needed. This is a good time to review the types of dressings being used.

Depending upon location and status of the malignant wound, gentle rinsing with water or saline solution removes most exudate and any loose necrotic tissue on the skin surface. Not all necrotic tissue in the malignant wound can or should be removed because the blood and lymph vessels below the wound are fragile and easily ruptured. If a shower is not possible at this time, a water or saline pre-soak softens dried exudate so that it can be removed with minimal damage. Note: gently cleaning with water or saline means no scrubbing or soap, just stand or sit and let the moistened exudate wash away. Do not pick at stubborn sections.

Cleaning the wound is the first step in controlling odor. Topical agents such as metronidazole 5% (available in powder or gel form) can reduce wound odor, but may take a few days to show results. If the wound is optimally moist, or too wet, the powder form is appropriate. If the wound is too dry, the gel form may be useful. Alternative topical agents include sugar paste, medical honey, and yogurt. Their use can be explained by an experienced medical practitioner familiar with applying these to the wound.

There are also dressings impregnated with anti-bacterial material (e.g. silver, iodine, medical honey). A medical practitioner can best determine if additional products (e.g. activated charcoal filter) or procedures will increase patient comfort and relief. As malignant wounds progress, different dressings for odor control may be added to, or taken away from, the various layers.

If preventing odor in the wound is insufficient, then absorbing or masking odor in the surroundings (home) may be necessary. In the home, charcoal, kitty litter, or coffee filters placed near the patient can help to mask or trap odors. Some patients also mask the odor by dabbing perfume or an essential oil onto the outermost dressing.

pruritis: itching. Severe itching may be a side effect of some cancer treatments and a symptom of some types of cancers.

Odor Warning Signs

Some patients may develop reactions to anti-microbial topical agents or to silver-impregnated dressings. Alternatives (silver versus iodine) should be discussed with the medical practitioner, with a sample alternative readily available should a problem arise.

A sudden change in odor should be brought to the attention of the medical practitioner.

If the source of bad odor is an infection, only a medical practitioner can determine if and which antibiotics may be required for control.

Itching

The sensation of itching in the periwound area can be a significant source of irritation and may interfere with social activities. The medical term for distressing itching is *pruritis*. For the patient with a malignant wound, this sensation may be localized or widespread. It may be so severe that the patient scratches uncontrollably, damaging the wound bed or periwound skin, even to the point of bleeding. Scratching that results in broken skin puts the patient at risk of infection.

Causes/Sources of Itching

- Excoriated (epidermis removed) skin due to contact with exudate
- Dehydrated or stretched skin
- Infection
- A sign of a more serious blood or organ disorder

How to Control Itching

Periwound area pruritis does not respond to antihistamines. If the cause of itching is irritation from exudate in contact with the skin, especially in the periwound area, then gentle washing with water or a saline spray helps stop the itching sensation. Barrier film products may prevent irritation from exudate leakage. Gentle patting or soft massage above the troublesome area can help stop the itch-scratch cycle. If the cause is dehydrated skin, first consult with a medical practitioner before using any product on periwound skin. Other methods that may be useful to reduce itching include distraction, music therapy, relaxation, and imagery techniques.

Only a medical practitioner can determine the cause of itching and offer alternatives when simple remedies fail. Infections and serious disorders may require prescribed medicine. If the cause is severe damage to the peripheral nerve supply, then alternative options may include cancer specific hormone therapy, chemotherapy, or TENS (Transcutaneous Electrical Nerve Stimulation).

Possible Side Effects and Complications

Cancer, malignant wounds, and their treatments assault on many fronts. Prescribed and non-prescribed medication to control some of the perviously listed symptoms bring with them a variety of side effects. As demonstrated in the previous pages, the malignant wounds affect many tissue structures and functions. The sum can lead to a host of side effects and complications that also require management. The following list demonstrates the breadth of complications that malignant wounds can inflict upon a patient:

- Swelling and inflammation
- Weakness and fatigue
- Interrupted sleep patterns
- Nausea
- Impaired mobility
- Shortness of breath
- Diarrhea or constipation
- Incontinence or urinary retention
- Impaired cognitive skills
- Lack of appetite
- *Tumor fever*
- *Cellulitis*
- Malignant-related *ascites*

These complications develop slowly over time despite a well managed wound bed. Managing these complications or their combinations requires the skills of the entire health care team, because treatments may be counterproductive. There is no simple fix-all as the wounds progress. Instead, be aware and watch for signs. Keep notes. Inform your health care team.

tumor fever: a fever associated with a tumor and believed to be associated with the release of pyrogens

cellulitis: a common, potentially serious bacterial skin infection

ascites: abnormal buildup of fluid in the abdomen that may cause swelling. In late-stage cancer, tumor cells may be found in the fluid in the abdomen

Home and Away Preparedness

The principles of basic wound care apply to both the patient and caregiver. Thorough hand washing before and after dressing changes is essential. Create a clean environment in which to assemble dressings. Take care to clean this area after dressing changes. Dispose of soiled, odorous dressings promptly. The sheer bulk of boxes of various types of dressings and supplies can pile up in the home, get in the way, and detract from a sense of normalcy. Instead, dressings and supplies should be stored so they are easily accessible and low stocks obvious (Figure 7).



Figure 7. Storing dressings

Over time, the vast amount of supplies needed in the home can become an eyesore. One solution is to store them in the closet with a rod-to-ceiling rack.

To encourage outings, put together a collection of extra dressings that may be needed while away from home, and keep these in the car or in an easy-to-carry bag. A change of clothing may also be appropriate in case of an accident. Simple preparations ahead of time encourage the patient and caregiver to relax and enjoy their time away from home.

Preparedness applies to managing medications, too. Dosages may change, and new medications may be introduced at various times to maintain patient comfort. Organizing this ever-changing regimen takes time, effort, and careful attention to detail. Keep a schedule of medications that includes dosage and time of day. Remember to keep it up to date. It is useful to have home pillboxes as well as well-labeled, additional pillboxes to carry along when the patient is away from home (e.g. afternoon meds when out with a friend). Modern cellphones have programmable alarms to insure one takes pills at the proper time.

Living with Malignant Wounds

As painful, odorous and messy as malignant wounds can be, it is possible to *live with* them. I have done so for over three years. It wasn't straightforward. I had no guide or manual to follow. In my home, I have shelves of country tour guides and stacks of operator manuals for everything from a desk fan to my overly complicated cell phone. But for wounds that were visible signs of my imminent death, there was nothing available. Surely I'm not the only one who's ever been diagnosed with this aspect of an advanced cancer. I'm special, but *not that* special.

I might not be able to stop my cancer's progression by learning about it in published sources, but I was certainly going to find out what these wounds were. I researched and took notes. Lots of notes. I found a common theme among articles in research and medical, online databases to which I was fortunately allowed access. Patients with poorly or incorrectly treated malignant wounds were showing up in hospitals. At the front-line, hospital nurses were tending to these patients. Many nurses were not prepared for what they encountered. Using their professional journals as the classroom, nurses began teaching their colleagues. But, who was going to teach the patients? Like a tourist in a strange land, patients needed a guidebook. A manual with illustrations and troubleshooting tips is valuable to the seamstress when the sewing machine fails. How is this any different for a patient who is isolated because of wound odor? With a good manual, one might be able to fix things and carry on. If anyone needs to fix something and carry on, it is another cancer patient like me, with malignant wounds.

That's when I decided to formally organize my reprints and various handwritten notes and set out to fill that gap. Thanks to a jump-start with in-kind donations and firm support of family and friends, I opened my laptop and began writing this booklet, for *you*.

Researching and writing the technical parts was an on-again, off-again three-years' journey. Along the way, I met many caring people. I wanted to share the technical details of exudate control, but they wanted to learn how I ordered supplies with my medical insurance. I spoke about moving from short-acting to long-acting analgesics, but they insisted I tell how I coped with odor on a long flight to Europe. Even as publication of this booklet drew near, I continued to be reminded to include a part about how I lived these past three years with devastating wounds. Those requests were not only from patients with malignant wounds. Some were from physicians treating cancer patients. Others were from cancer survivors or ones whose lives have been touched by cancer. They may be future malignant wound patients themselves. They may be future caregivers. They needed reassurance in the form of technical details alongside *my story* to believe one can *live with* malignant wounds.

After almost six years cancer-free, I found a small bump and, like all my previous findings over the past nineteen years, this was biopsied and found to be positive for cancer. I've always found that a poor use of the word *positive*. Now I was back in curative care, with two possible regimens to follow, should one not work. I would need a port installed for the delivery of nasty chemicals, and I would again lose my hair. Days after surgery, I flew to the Midwest to attend the baby shower of my expected twin nephews. I would be too sick to visit them after their birth, so this was as close as I could get. After the baby shower and while staying at another brother's home, I was busy mopping up damage caused by a severe water leak. The words from the discharging

nurse echoed in my ears, “Don’t do anything strenuous for several weeks.” She doesn’t know the Clarks. I just hoped the tube in my jugular was placed very securely.

I brought my laptop to the infusion center and either researched online or watched old Katharine Hepburn movies. Nodules continued to appear under the skin. There were so few, I could count them. I was gaining two new ones a week. It was time to try another chemo cocktail and resume counting. The nodules were winning, I was bald, and one of the older nodules above my sternum was behaving particularly oddly. It was time to let my body rest and rethink the battle plan. Meantime, we had an autumn trip to Europe for business and pleasure to organize. I needed to recover and figure out how to pack for a cold, wet Europe while bald and having issues with bumps on my chest. The one over the sternum now wept a yellow, thick fluid. I ordered extra camisoles to hold my foam prostheses and packed laundry soap so I could wash fouled camisoles each day. I filled a zippered pouch with all the supplies I had gathered at home or found in pharmacy sections of grocery stores to cope with that oozing liquid. I made sure I had one box of anything sterile and absorbent. But the scissors had to go in my TSA-approved pouch.

Off we went to the Netherlands, Belgium, and France. I borrowed a bike and retraced a few miles of the path to Delft I had trailblazed at age seventeen. I explored the former playing card capital of the world and lost all sense of time in a cooking store. Having taught Big Puppet workshops in my community, I couldn’t miss the amazing talents on display at Les Machines in Nantes, France. As a young reader, I had loved Jules Verne. Nantes was his hometown. Despite an icy wind and a soiled camisole, I climbed the iron, circular stairs to ride atop their life-sized mechanical elephant. Naturally, Les Machines’ mechanical animals are built in the style of Verne’s imagination. More nodules were breaking through the skin. Things were picking up speed. We stopped at a pharmacy (chemist) and looked at choices for absorbent dressings not found in the US. Nothing new there except the print on the box—we don’t read French.

After returning home, I learned about a clinical trial using chemotherapy and the off-label use of a topical cream. My previous chemotherapy disqualified me from the trial, but I was very interested in the cream part. I telephoned the researcher back East. Why not? What have I got to lose? Over the next few weeks, we developed a rapport. I would conduct the cream part of the trial and send her my data (which was to become anecdotal to her, not part of the trial). A baseline image of the nodules and unusual skin coloration was marked with a black, permanent ink pen on a large, clear plastic sheet placed above my chest. Each week, with the clean baseline image placed upon my chest, we marked changes, took a digital photo, and sent that to the researcher. The nodules were merging so quickly that it was next to impossible to draw anything useful. We stopped trying and gave up on the cream.

Odor reared its ugly head, and I visited a wound care nurse. I was told to use a soft washcloth in the shower and scrub away that pesky, hardened scab. This became a daily visit to hell. I was an emotional wreck after showering. Sometimes the wound bled. Each day, however, there was a new scab to scrub. I started using thin menstrual pads, stuffed down my camisole, to catch the smelly stuff and prevent my clothes from collecting it. A new business and pleasure trip was coming up. Now I had to pack for a longer time in stranger (to me) lands, because these wounds were coming along, too. It was going to look odd to TSA, but we were going to be traveling with six cans of contact lens spray just in case clean water for rinsing my wounds was not available. Six cans in two weeks was about right!

I don't know how many advanced cancer patients with malignant wounds have been to the DMZ in Korea, and safely (i.e. with armed guards) stepped about twenty feet into North Korea, but count me in that number. I am probably the only one in this wound group who managed to get an impromptu, one-on-one lesson at a Korean cooking school. To get to that lesson, I had to navigate without understanding any Korean. I had to take mass transportation, alone, and get off as close to the school as possible. Weeping wounds or not, I wanted to learn how to make Bimimbap. Make sure you count me in with the weeping wound crowd who ventured into enormous lava tubes at Jeju Island. It was peak cherry blossom season in Japan, so include me in the tally for those who climbed the stairs of Himeji Castle and stood in awe of the temples and shrines in Nara. However, it was time to really focus on the odorous and heavier flow from my wounds. They were a nuisance and starting to interfere with my foreign adventures. We returned home determined to find a better way to cope with the wounds.

We learned, however, that day-to-day management of these wounds is not a skill set of most oncologists. My wounds would not heal. They were getting worse. I had tried unsuccessfully to get through the day without smelling awful or constantly changing my clothes. I found a different oncologist who *only* saw advanced breast cancer patients. But, as luck would have it, a few weeks before I was to begin a new chemotherapy protocol, I developed a severe case of cellulitis and was hospitalized. In the hospital, a team of surgeons tried to get me to consent to a skin graft that would "remove all the cancer" and I'd be fine. That simply wasn't true, and the attending oncologist, ironically my former one, told them so in front of me. Just before I was discharged, a wound care nurse paid me a visit. From her, I learned I should not have been scrubbing the open wounds all those months. I also learned about better products for absorption of the fluid and prevention of infection. Between the surgeons and the wound care nurse, I had an odd combination of mistrust and trust of the medical community. I had to pay more attention and definitely do more research.

I took every possible opportunity to search for information about wounds associated with advanced cancer. The articles published by medical researchers, naturally, did not have helpful information about absorbent dressings or controlling odor. I was looking for any clue that might lead me to what I needed for daily care. While the new chemotherapy regimen was underway, I came across the term *fungating*. Like all other unknown words I was finding, I looked up the definition. Fungating described me. This was what I had on the skin of my chest. A new set of searches with that term uncovered brand new articles by different authors (mostly nurses). A brilliant and useful guide was Kelli Bergstrom's article (see Resources). I now had a guidebook. I also saw pictures of others with these wounds. Emotionally, I was not sure I could face any further advancement. My husband and I talked a lot about what was to come. We talked with family and friends. My future was horrific and cruel.

I continued researching. The wounds had progressed to such a size that the wide sports bandage we used to keep dressings in place was no longer working. That's when I came across Wayne Naylor's teaching video (for nurses) using elastic net tubing to secure dressings. Another brilliant discovery, and just in time for my needs. The new chemotherapy was not slowing down the progression of the wounds in my skin. It was time to transition from curative to palliative care. If I was going to face the future that I'd seen in Bergstrom's article, I needed to take charge, form a plan, and prioritize my life. My oncologist supported my decision to stop curative care, but continued to guide pain management. For wound care management (odor, bleeding, leakage), I was on my own.

Helping plan our daughter's wedding took my mind off the chaos taking place on my chest. Personally, I think battling 30 yards of tulle is more difficult than managing weeping wounds! Our son has worked at dozens of weddings and took on tasks that were beyond my skills and energy level. Each time a problem with planning came up, he assured me that regardless of any oops on wedding day, everyone would have a great time. We had an oops when \$100 of helium balloons escaped from an open van during setup. Watching the limo drive away with the happy couple was something I never thought I'd witness when first diagnosed with cancer nineteen years ago. My son was right, everyone had lots of fun.

The complications of, and medications for, advanced cancer were slowing me down. Before it was no longer an option, I had one more trip to take. Would it be Africa or UK/Ireland? I had been to six of seven continents. Should I get that seventh one and have a proud claim? Should I use the information I'd been gathering about my ancestral roots and travel around UK/Ireland? Given the condition of my wounds and now knowing more about serious complications, I chose the latter. Packing for a month away from home with a very large mass of weeping wounds on my chest required much planning and anticipation of problems. I humored myself by saying that all the space I was taking up with dressings and related supplies, I would fill with mementoes. So I packed a lot!

There seemed to be a lot of mold in those castles and cottages of my ancient land. I thought I'd picked up an infection in my lungs, because breathing became difficult. True, I was a bit out of shape, but it was so difficult to climb stairs that I frequently let others in our group go while I stayed on one level—often complete with gift shop. It was not on my travel itinerary, but I had a ride in an ambulance to a London ER because breathing had become seriously difficult. American and British English sound different inside an ambulance. I was about to be pricked with a little lancet by an EMT when I told him my blood type, "B positive." To this he asked, "When was that diagnosed?" Diagnosed? That's an odd way to ask when I learned my blood type. Did he really need to know *when* I learned my blood type? We both stared at each other trying to decipher what the other had said. Finally, I replied, "I learned it in high school biology class." This really surprised him. His surprise just confused me. My finger was pricked regardless. A few minutes later, the other EMT solved the riddle we had created. The first EMT thought I was referring to positive for hepatitis B. Silly English language. On we went to the ER, but no scan was done. I left to go pack for the next day's flight.

Back home, a scan revealed that my breathing problem was not from mold infection from a quaint cottage in the Cotswolds. Instead, I had pleural effusion and the beginnings of bone erosion. Not so glamorous. Time to reassess, again. This time, the decision was made to transition from palliative to hospice care. We were going to need the support of a knowledgeable team. We phoned our local hospice service, and almost overnight, the burden of managing all that these wounds required was lessened. True, it meant relinquishing some of the control I had so carefully organized. But it gave me back time to focus on the quality of my final months of living. That was more than a fair trade. It allowed me to write this resource guide.

This is the background story of how I have lived with my malignant wounds. Cancer survivors, caregivers, and others want assurance that managed malignant wounds won't rob them of living. Perhaps I have demonstrated that it is possible to squeeze as much quality out of a life as possible. That squeezing will be accomplished in different ways by different people. You now know *my story*. Go out there and live yours!

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Notes

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Sherry A. Clark, a retired educator, lives in Oregon with her family. During her twenty years of teaching, she combined her love for the sciences with the introduction of computers in schools and taught dozens of classes at middle school, high school, and university levels. This included a year as an exchange teacher in Auckland, New Zealand, where her family learned all things Kiwi. Beginning at age six-months, she is a long-time traveler who managed to set foot on six of seven continents. Quilting and glass fusing are favorite hobbies. She is also a breast cancer survivor with four recurrences. Her recent recurrence, untreatable, developed into malignant wounds. She came out of retirement to offer this booklet as her last lesson: to help and encourage others with malignant wounds to improve the quality at their end of life.