⁂

“You have no room, time or energy
for a single negative thought.”

⁂

MAN
TO
MAN

A Practical Guide
For Male Caregivers
When Breast Cancer
Strikes Their Loved Ones

By Carl Morgan

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ABOUT THE AUTHOR

Carl Morgan, author/publisher of *Man to Man*, has been a lifelong journalist, retiring in 1992 as Editor of The Windsor Star. Although he previously produced four non-fiction coffee table books, *Man to Man* is the first dealing with a specific medical matter as devastating as breast cancer.

As a labour of love, the research and writing absorbed hundreds of hours over a nine-month period. He and his wife, Gloria, are confident that the investment of time and energy will be of immeasurable value, benefit and comfort to other men who are suddenly faced with the reality of having their partners deal with a life-threatening disease called Breast Cancer.

IT'S FREE: Because of the generous financial support of many individuals and institutions, Caregivers Unlimited is distributing *Man to Man* free of charge to those who need it. The only cost will be normal mailing and handling expenses.

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WORDS OF APPRECIATION

Although most of the material for this guidebook was drawn directly from my own personal experiences, enriched by discussions with other men who shared similar challenges when their wives were diagnosed with breast cancer, I could not have completed it without the unselfish support of many other people familiar with cancer treatment generally, and breast cancer specifically.

I owe them an enormous debt of gratitude and take this opportunity to acknowledge their guidance.

While it is often unwise to spotlight a few individuals over all others, it would be even worse if I didn't applaud three very special people for their outstanding efforts and support:

Carol Derbyshire, Executive Director of Hospice of Windsor and Essex County Inc. Jumped into the breach at a crucial time and voluntarily "adopted" the project. She offered the help of staff members, issued tax receipts, opened a special file to receive contributions, and was always there to listen and offer sound advice.

Shelley Markland of Wellspring London and Region, along with Carol Burnham-Cook of Willow Breast Cancer Support & Resource Services, Toronto, worked untold hours on their own time, reading the raw manuscript material, fine-tuning it as they went along. They also offered encouragement as well as wise and important suggestions when they felt something wasn't the way it out to be. There were many others:

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Windsor Regional Cancer Centre: Nancy Gibbons, Administrative Co-ordinator, Cancer Centre Foundation;

Canadian Cancer Society: Nathalie Noel, Community Outreach Co-ordinator, Southwestern Region;

HELP US TO HELP OTHERS

Publishing and distributing *Man to Man* was made possible entirely through generous contributions from more than 150 friends, relatives, associates, service clubs, fraternal organizations and other institutions.

Because of the grassroots response to a three-month letter-writing campaign which generated about $25,000, we were able to publish 12,000 copies and distribute them free of charge throughout Ontario.

If you have found this guidebook to be of value to you, other members of your family, friends or colleagues, and if you feel that such a unique publication is worth perpetuating, you are invited to contribute to a second printing.

It's as simple as writing a cheque to:

CAREGIVERS UNLIMITED
12402 Riverside Drive
Tecumseh, ON N8N 1A3

All contributions will be acknowledged. However, only those of $20 or more will receive a charitable receipt suitable for tax purposes.

For more information phone 519-735-6188 or email cmorgan155@cogeco.ca

Carl Morgan
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Hospice of Windsor and Essex County Inc: Staff members Pauline Boyle, Jamie Henderson, Linda Power;

Marty Gervais, Windsor Star columnist; Wayne Stevens, 800 CKLW and 580 CKWW; Anne Faubert, volunteer worker with the Canadian Cancer Society; Paul Gignac, constant positive supporter, and voluntary fund-raiser; Jim Moore, Cary Wheeler, Ralph Johnson, all primary male caregivers whose wives were treated for breast cancer. They openly shared their personal experiences in extended interviews.

Others who read and edited the manuscripts included: Dr. Kenneth M. Schneider, Program Lead, Department of Radiation Oncology – WRCC; Interim Chief, Department of Oncology WRCC/Windsor Regional Hospital; Dr. James Laird, surgeon; Dr. Sharon Doyle, family physician; Dr. Steve Radin, retired surgeon; Dr. Raymond Larocque, retired surgeon; Tim and Wanda Henderson, lay readers; Marcia Hogan, former oncology nurse; Janet Spiers and Joanne McGuire, social workers at the Windsor Regional Cancer Centre; Pauline Boyle, information liaison, Hospice of Windsor and Essex County Inc.; Dr. Hakam Abu-Zahra, medical oncologist, Windsor Regional Cancer Centre.

KUDOS FOR THE KIDS

Often, when a family member is struggling with a life-threatening illness, attention is focused on the patient and spouse. The children, who offer great warmth, understanding and comfort, are frequently overlooked.

For that reason, at this time, we thank our children profoundly for their support over the long, anxious months of their mother's illness: Jocelyn and husband Paul; Scott and wife Tracy; daughter Julie. All were there for their mother all the way, every day.

DEDICATION

It is the ultimate, bittersweet irony that if my wife, Gloria, had not been diagnosed with breast cancer in December of 2001, this guidebook would not exist as it does today. If could not have been done without the first-hand, deeply personal experiences I shared with my wife of 46 years as she struggled through months of significant physical, mental and emotional pain, anxiety and discomfort. There were also extended and terribly frustrating bouts of extreme fatigue.

Today I applaud the inner strength that Gloria drew upon to get her through the difficult periods – one day at a time.

This is also perhaps the right moment for a personal confession.

In the early days, after I finally managed to fully grasp what she was enduring and what else was to come, I wished that I could take her place. I was certain that I had a higher pain threshold than she did.

I was wrong. In the end, Gloria showed the tough stuff she is made of: her extraordinary patience … her unbending resolve … her incomparable resilience. Eventually I did a complete turn-around, knowing that I could not have accepted the physical discomfort and mental anguish as stoically as she had.

Though we still have occasional, almost surrealistic flashbacks of some of those anxious weeks as she faced each new hurdle, she has stubbornly battled back and today is as fresh, vivacious, kind and generous, as she was in the days before she discovered that awful lump in her breast.

For these reasons and too many others to catalogue here, I want to dedicate this slender volume of hope and hope to Gloria, my wife.

Julie Morgan (In memory of Graham Hibbert)
Carmen Doyle (In memory of Frances Slater)
Joe and Pat Passa
Hugh and Jacky Naldert (In memory of Sue Stewart)
Alexa Posliff
Bev Lounsbury
Jerry and Helen Slavik
Deborah Jessop (In memory of Jean Pascoe)
George and Nancy Plantus
Dr. Carl and Barbara Montcalm
Mike and Joanne DiMaio (In memory of Wilma and Joe Piercell)
Joan Rieveley (In memory of Mom and Dad, John & Hilda Shepherd)
Bill Bishop (In memory of wife, Doreen Bishop)
Dr. Steve and Dorothy Radin
Rheta Baker
Dr. Monique Verhaegen
John and Susan Yablonsky (In memory of Mother, Florence Dault)
Joe and Caterina Greco
Anil and Vijaya Chitte (In memory of Brother, Ramesh P. Doshi of Mumbai/Bombay, India)
Leon and Sandra Paroian
Katherine Roth and Maurice O’Callaghan (In memory of Cheryl DiPenta)
Frank and Kathleen Gignac (In memory of Linda Fiott Monforton)
Russ and Winnie Sawtuk (In memory of Mother Lena Dutka)
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Terry and Julie Lawrence (In memory of parents Ed and Flo Katt, Reg and Van Lawrence)
Alexander and Lorraine Zonjic
Mike and Ann Smith
Sheila Mosley
David and Kathleen Estok (In memory of mother, Mary Estok)

FINANCIAL SUPPORT

Researching and writing material for a guidebook such as this, is not a particularly difficult task. It merely demands extreme commitment over a nine-month period.

The real trick is coming up with the money to pay the production costs. Neither my bank account nor those of any relatives or friends were equal to the task. Furthermore, I didn't know any organization, institution or foundation well enough to ask them to absorb the full cost.

There was only one other option, albeit a risky one. Appeal directly to friends, relatives and acquaintances through a letter-writing campaign. Much to my everlasting gratitude, the response was overwhelming.

As this guidebook was heading to the printer, the organization I had created under the name of Caregivers Unlimited, had received in excess of $25,500 – more than enough to print and distribute 12,000 copies.

More than 150 individuals and organizations contributed and I want to recognize them for their tremendous generosity. Contributions ranged from $10 to $3,000, but for practical space considerations, only those who gave $100 or more are acknowledged.

There are four categories: SILVER: $100 or more; GOLD: $500 or more; PLATINUM: $1,000 or more; PLATINUM PLUS: $3,000 or more.

SILVER - $100 OR MORE

Jeff Baker (In memory of Moe Smith)
Doug and Debbie Pickthall
John and Teresa Whiteside
Paul and Jocelyn Gignac (In memory of our grandparents)
Scott and Tracy Morgan (In memory of John Watt)

Carl Morgan Photo

Once chemo treatment begins, it is probable that your wife will lose all or most of her hair. The impact can be lessened if she is prepared in advance by deciding whether she prefers a hairpiece, hats or scarves. Gloria selected a hairpiece that suited her best.

INTRODUCTION:
MEN AS CAREGIVERS

According to the Gage Canadian Dictionary, a caregiver is "a person who takes care of someone else, whether for payment or not."

This guidebook is a collection of relevant information, designed to serve as a quick resource for men who are called upon to become primary caregivers to their loved ones who have been diagnosed with breast cancer.

Although it was conceived with thoughts of male partners in mind, it will also be useful for brothers, sons and fathers who must support sisters, mothers and daughters. It is composed of personal anecdotes drawn from my own experiences, enriched by vignettes offered by other men who walked the same bumpy road.

All of the material has been researched, written and edited with the greatest of care, then critiqued by a variety of professionals. None of it is presented as medical advice. Nothing said or implied is intended to replace or supplant treatment by physicians or other members of a medical team.

I decided to produce this book after my own wife was diagnosed with breast cancer and I was faced with the daunting task of doing my research-on-the-run. I soon realized that though there is more than enough material for and about women (as there should be), there is little that talks to men; nothing to guide men, or explain what their wives are experiencing physically, psychologically and emotionally. Nor is there anything to alert men as to what they should expect in a given set of circumstances, or how they should prepare themselves to respond to unexpected and often emotionally draining situations.

In short, I decided that what most men don't know would fill a book. This is a start. But only a start.

information on the disease and its treatments.

Willow provides:

- Current information about diagnosis, treatments, side effects and social issues.
- Emotional support through trained volunteers who have had breast cancer.
- Training for support group facilitators, links to a network of other breast cancer support groups.

Willow is located at 785 Queen Street East, Toronto M4M 1H5; toll free telephone 1-888-778-3100; 416-778-500; Fax 416-778-8070; email info@willow.org TTY 877-778-2009.

willow

BREAST CANCER SUPPORT CANADA

WILLOW BREAST CANCER SUPPORT & RESOURCE SERVICES

Willow Founded in 1994

Willow Breast Cancer Support & Resource Services, is a survivor directed, non-profit charity that provides information and emotional support to individuals diagnosed with breast cancer, their families and caregivers.

Founded in 1994, Willow is committed to serving a broad constituency including rural and urban communities across Canada. It also serves people with disabilities.

Willow ensures that breast cancer information and support are accessible to everyone through a variety of services including a Canada-wide toll-free line, a comprehensive resource centre and service, an interactive website, training workshops, presentations to health care professionals concerning psychosocial needs of their patients and a support network program for self-help survivor groups.

After contacting Willow for assistance, those with breast cancer, family or friends, will be connected to another person who has experienced breast cancer and has access to relevant

---

Why now?

Until recently, there was little need for such a guidebook because it was rare for men to assume the role of caregivers. Changes began when the Canadian medical system came under increasing pressure from senior governments to put the brakes on spiralling health costs, particularly in hospitals and at the home-care level.

The move was on for more relatives to paper over the cracks in the system, to take on many of the tasks once handled by professionals. Chief among those relatives (insofar as breast cancer is concerned), are the men in the family. Like it or not, ready or not, men have no choice but to accept this new responsibility. Some men slip into their new role with ease; others do not, and still others cannot because they are neither equipped nor trained to do so.

This guidebook is intended to shine a light into the dark corners of understanding.

A LEARNING EXPERIENCE

Before I began writing Man to Man, I was perplexed, as are so many others people, about why there were not always straightforward answers to straightforward questions.

Now I know. Treating cancer, as I have come to understand it, is a horrendously complex matter. There are few shortcuts, no straight lines from A to B. Indeed, the opposite is true. Doctors are constantly searching for solutions in a maddening maze of unknowns and maybes.

Instead of wondering why doctors sometimes cannot find the right combination of treatments to cure, or at least impede the spread of cancer, now my greatest wonder is that they get it right as often as they do.

A CAUTION

Although I have attempted to keep the content as general as possible to serve the widest possible audience, I know that not all of the information will be right for everyone. You are encouraged to make your own assessment of the material, ignore that which does not apply to you, and make appropriate modifications so that they shoe fits and you are comfortable in moving forward.

A CHALLENGE

While I have tried desperately to address the most obvious situations that men might face, I know that this single publication cannot possibly cover every eventuality.

I pass the torch to the adventurous and caring reader to pick up where I left off and produce a sequel. Do your own research, and back-fill the ruts and potholes which I left behind. The contribution you make will be of immense importance to those who will follow.

I hope that those of you who take the trouble to study these pages carefully will gain some measure of insight into the intellectual, human and emotional challenges ahead.

include Wellspring at Sunnybrook and Women’s College Health Sciences Centre; Wellspring Halton Peel in Oakville and Wellspring Niagara in Thorold.

Wellspring users are patients and caregivers who are either referred by healthcare providers or pay a visit and decide to become involved in programs and services of their own choosing.

Wellspring is concerned with the overall supportive needs of cancer patients and their families. Its aims are to:

- Meet the social, emotional and spiritual needs of cancer patients and their families;
- Help those who are living with cancer to acquire skills and develop strategies to cope with the disease;
- Provide a form for professionals and students to gain a better understanding of the non-medical dimensions of the disease and its effects on individuals and families;
- Develop Wellspring as a model which can be replicate in other communities.

Wellspring London and Region is located in central London at 231 Hyman Street. N6A 1N6. It can be reached at 519-438-7379; fax – (this needs updating); email: feedback.wellspring @rogers.com; For other Wellspring locations, refer to www.wellspring.ca

Hours of operation: Monday through Friday 9 am to 4pm and some evenings.

children. This is the first Hospice Village in North America.

Hospice is not about dying, it's about living. Its philosophy is that people with life-threatening illnesses such as cancer, HIV/AIDS, A.L.S. (Lou Gehrig's disease), multiple sclerosis, renal kidney failure etc., all have the right to live with joy, dignity and the absence of pain.

Although support comes from the Ontario Ministry of Health and the United Way, 55 percent of the operating budget is generated by fund-raising programs, most of which are organized by volunteers who raise more than $800,000 a year.

Hospice facilities are open to everyone, and a doctor's referral is not necessary. There are no fees for service. Hospice is located at 6038 Empress St., Windsor ON N8T 1B5 and can be contacted by phone at 519-974-7111.

Website: www.hospicewindsoressex.com

WELLSPRING
London and Region

WELLSPRING IN FIVE LOCATIONS

Wellspring London and Region is a non-profit, community-based, non-residential centre for individuals and their families who are living with cancer. Wellspring provides support programs, information and services directed at the development of self-help skills and coping strategies. All programs and services are offered at no cost.

The London Centre is one of five Ontario Wellspring sites,which had their beginning in Toronto in 1991 with the opening of the Coach House on Wellesley Street. Other sites

BREAST CANCER 101

There are more than 100 types of diseases we call cancer[1]. They can attack almost every part of the body. Breast cancer is among those most dreaded by women because it assaults her whole being, her femininity, and can lead to her death.

In 2002, according to the national Cancer Institute, roughly 20,500 Canadian women were diagnosed with breast cancer. Of those, 6,600 were in Ontario. The Canadian estimates for 2003 ran as high as 31,200 with up to 8,000 in Ontario[2]. Since breast cancer is not a "contagious" disease, reasons for those increases puzzle researchers. Some blame it on the environment, lifestyles and dietary habits – or a combination of all three.

After lung cancer, breast cancer kills more women than any other. It is followed by colorectal, pancreatic and ovarian cancers.

While the bleak news is that more Canadian women are diagnosed with breast cancer each year – the good news is that the death rate is dropping, principally because of the improved treatment and earlier diagnosis.

(Breast cancer also affects men. About 140 Canadian males are diagnosed with the disease each year. Of that number, 40 will die.)

If your partner has been diagnosed with breast cancer, there are different paths that can be taken.

(a) Some women will undergo a lumpectomy (breast conserving surgery), to have the invasive lump and any affected lymph nodes removed. This is usually followed by radiation and possibly chemotherapy.

(b) Others will have the lump as well as lymph nodes removed through a mastectomy. Mastectomy refers to the removal of the affected breast.[3] An oncologist will then decide on post-surgical treatments including chemotherapy and/or radiation or hormonal therapies.

If mastectomy is chosen, the patient can decide whether she wants breast reconstruction. If she does, then she must decide whether she wants the reconstruction at the time of the surgery, or later when she feels stronger mentally and physically.

There are different views on the wisdom of having the reconstruction completed at the time of the mastectomy. One school of thought cautions that the procedure (which some people teasingly refer to as a “free tummy tuck” is major surgery and “increases the magnitude” of the original breast removal itself.

The decision should be made only after the implications have been discussed thoroughly with the surgeon.

While some women who elect a lumpectomy followed by radiation and/or chemo, are often back of their feet mere weeks after treatment ends, others require a much longer recovery period. Reasons for the difference are varied and generally speaking no two women respond exactly the same way.

For many, it is a lonely road, haunted by the thought: Will *“IT”* come back?

As the caregiver, you won’t be able to dispel such thoughts but a confident, reassuring presence will help lighten the burden.

---

[1] Cancer: Living Well with Cancer. One of a series of fact sheets produced by Living Well with Cancer Information Centre. Telephone 1.877.909.5592; email info@livingwellwithcancer.com

[2] 8,000 us the number of new cases of breast cancer estimated for 2003 in Ontario, for females. It appears on page 24 of Canadian Cancer Statistics in Table 3 “Estimated New Cases for Major Cancer Sites by Gender and Province, Canada, 2004”

[3] Some women choose to have the second, healthy breast removed as a precaution against cancer surfacing there. Although this is referred to as a “prophylactic” procedure in medical terms, it is better known to patients and ordinary people as a double or bilateral mastectomy.

the hospice
The Hospice of Windsor and Essex County Inc.
L'Hospice de Windsor-Essex Inc.

HOSPICE REDEFINING ITSELF

The Hospice of Windsor and Essex County Inc., is the oldest and largest community-based hospice in Canada. It offers support for physical, emotional and spiritual pain. Its mission is “to support, educate and empower those affected by, or caring for, someone with a life-threatening illness.” Patients and families are served by a multi-disciplinary team of nurses, a pain management physician, social workers, pastoral care personnel and trained volunteers. It has a staff of 34 full-time and 900 part-time volunteers.

Over the years, Hospice has evolved dramatically and redefined its approach to caring for patients and families. Now, the hospice team becomes involved at the time of diagnosis rather than only at the terminal stage.

A newly constructed 20,000 square foot Wellness Centre provides education, counselling and health-promoting activities to patients and families, including women living with breast cancer. The Centre is a haven for those who are in palliative care, as well as those on the road to wellness.

Since the inception of Hospice in 1979, more than 30,000 people have received help. As patient load continues to increase (from 275 in 1994 to 900 a year), the organization is creating a Hospice Village, adding four houses to its present site. One house will become the pain management clinic; two will offer 24-hour residential care for patients and the fourth will be dedicated to

CANADIAN CANCER SOCIETY

The Canadian Cancer Society (CCS) is a national organization of volunteers whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer.

In partnership with the national Cancer Institute of Canada, the Canadian Cancer Society achieves its mission through research, education, patient services and advocacy for healthy public policies.

The Canadian Cancer Society is a non-profit organization, funded by donations from the public and money raised through its fund-raising activities in communities across Canada. It is the largest charitable financial supporter of cancer research in the country and would be able to offer these services or finance important research without the generous help of volunteers and donors.

Because of the generosity of its donors as well as the work of volunteers and staff, the Canadian Cancer Society is leading the way in the fight against cancer.

The Canadian Cancer Society provides:

- Reliable information about all cancers, treatment, early detection and resources available.
- Emotional support groups as well as one-to-one and telephone-based supports from others who have had similar experiences.
- Transportation assistance in getting to and from cancer-related care appointments.
- Practical support for people at cancer treatment centres, clinics and lodges

Contact the Canadian Cancer Society's cancer information specialists at www.cancer.ca or phone 1-888-939-3333.

THE ENEMY WITHIN

It was in December, 2001, about 20 days before Christmas that I got "the word".

Gloria, my wife of 46 years, and I wee at dinner when she reminded me that she had been to see Dr. Sharon Doyle, her family physician, about a lump in her right breast.

There was a pause as I waited for the other shoe to drop.

"Sharon said: 'It's cancer, Gloria… We need to move quickly'".

Dr. Doyle set up a next-day mammogram and asked my wife is she had any preference for a surgeon. Gloria named Dr. James Laird, a man with a long-standing reputation as a knowledgeable and skilled surgeon. He was also a family friend which we counted as a plus as we braced ourselves for whatever was coming down the road.

Dr. Laird confirmed Dr. Doyle's diagnosis and said he had already booked an operating room. He then listed my wife's options: She could have a lumpectomy (breast conserving surgery); a mastectomy to remove the affected breast – or she could choose to do nothing, and he would cancel the operating room.

The choice was entirely her own, but time was of the essence.

Our oldest daughter, Jocelyn, was with us and while it's probably not accurate to say that we had a full and frank family "consultation", there was a hasty discussion, a few meaningful glances and mumbled words. The options were weighed and then my wife asked Dr. Laird the defining question:

"If your wife was in my situation, what would you do?"

"A lumpectomy." he said without hesitation.

In that heart-beat moment, I joined the growing ranks of primary male caregivers. As with so many other men, I knew absolutely nothing about this enemy in our lives. If it's possible, I knew even less about the treatment…about surgery … about chemotherapy… about radiation. Certainly I couldn't begin to imagine the long, bumpy road ahead.

I was hopelessly out of my element.

THE SEARCH BEGINS

Because I am a voracious reader, I began pouring through pamphlets, booklets, books, and searched the Internet to bring myself up to speed.

The search was both illuminating and frustrating, mostly because of the mind-bending amount of information that I had to absorb. We put the brakes on many things we once did as a matter of routine so that we could focus all of our attention and energies in completely new directions.

Dr. Laird excised a wedge of breast and was confident that he had removed all cancerous tissue, leaving a "clear field." He also removed 20 lymph nodes (glands) from the armpit (axilla), 10 of which were cancerous.

This meant that after surgery, Gloria would begin a regimen of four cycles of chemo followed by five weeks of radiation, five times a week.

Depending on the patient, chemotherapy can be a difficult treatment. In Gloria's case, it caused nausea, headaches, fatigue – and loss of hair.

FULL TOXIC BOMBARDMENT

It's important to understand that Gloria's experience is not necessarily mirrored in every breast cancer situation. What your own wife, partner, sister, aunt or mother experiences will depend

It is not an exaggeration to say that I was in awe of the number of such organizations in existence, as well as the enormous cadre of staff members and volunteers who make the system work.

Since it was not necessary nor prudent for me to try dealing with them all, I limited the number to four, listed below in alphabetical order.

Canadian Cancer Society; Hospice of Windsor and Essex County Inc.; Wellspring London and Region and Willow Breast Cancer Support& Resource Services in Toronto

As *Man to Man* took shape, and as the final sentences were being written I decided that those four agencies should receive recognition for the incredibly valuable assistance they provided to me.

Coming to that decision was not intended to arbitrarily exclude others. Although it would be nice to list every organization, hospital or clinic serving cancer patients and survivors in Ontario, the sheer numbers make it impractical. I can only hope that those who do not share the spotlight will at least bask in its reflection.

While the visions, the mandates, the goals and the mission statements for each organization differ marginally one from the other, there are some important commonalities:

They are generally self-sustaining; staff members as well as volunteers are totally committed to the single goal of helping people with cancer deal with the vagaries of the devastating disease and subsequent treatments. They are invariably caring and comforting. Many of them are breast cancer survivors themselves.

EPILOGUE

Many months ago, when I tapped out the first few words for the introduction to this guidebook, I had only a vague idea of where it was going, or how it would get there.

That's not an unusual experience for writers who feel deep within themselves that they have a story to tell. They might know in a general sense how and where it will begin but not necessarily how or where it will end. When that happens, writers also know almost intuitively that as the creative juices begin to flow, the story they want to tell will unfold as it should, often taking on a life of its own. Along the way, the writer becomes the conduit, sometimes leading, sometimes following, until the story ends where it is supposed to.

An over-simplification perhaps, but that was roughly the way *Man to Man* moved from conception , through birth, adolescence and finally emerged, mature and in full bloom.

As I admitted in the introduction on Page 8, other than a few serendipitous bits of knowledge which picked up while caring for my wife, I knew zero about either breast cancer or being a caregiver.

Still, in choosing to write this guidebook, I triggered a challenge for myself and was determined to press ahead.

However, because I knew nothing of any substance about the disease and its impact on the lives of those who are stricken, I had to find other, reliable sources on information. The search for those wellsprings of knowledge took me down many unfamiliar paths and opened a whole series of new doors. I learned that there are countless organizations across the province dedicated exclusively to caring for and comforting those people whose lives have been turned inside-out by the onset of cancer.

---

largely on how their bodies react to the treatments. Some will have a relatively easier time of it, others will have more difficulty.

Radiation therapy, we had been told, is less intrusive than chemotherapy, but it an cause a skin reaction similar to a sunburn. Some people experience a mild itch while others have greater discomfort. In Gloria's case, the burn was at the upper range of severe and had to be treated with medications applied to the skin. It also caused the skin under the fold of her breast to split.

What is not always spelled out in published material or in talks with physicians, is that each of these three – surgery, chemo and radiation – is really a major assault on the body. Any one of them is enough to rock a strong woman off her feet. One knowledgeable person bluntly described the combination of chemo and radiation as a "full toxic bombardment".

In our case, Gloria's own determination and stamina were enough to carry both of us over the psychological and physical humps and hollows in the days that followed. After a few weeks of treatment, the radiation burns were healed. In time her hair began growing back and the soreness in the armpit had diminished.

The most persistent and long-lasting after-effect from her treatments was intermittent bouts of fatigue that ranged from mild to extreme. These caused considerable frustration for a personal who had always been active, vivacious and virtually tireless.

THE DAY YOUR LIFE TURNED ON ITS AXIS

You're a Canadian male, on the wrong side of 50, with a tube of flab around the middle as mute testimony to the irrevocable passage of time. You're married, with two, maybe three children. You hold a steady job and enjoy a reasonable salary. You're self employed, or work in a factory. Or perhaps you're a farmer, a miner, a dedicated teacher or nine-to-fie accountant. You enjoy Saturday night hockey, a round of golf, a beer with the boys, winter vacations in Sun Country.

You are what demographers label a "typical Canadian". You have a few bucks in the bank, your RRSPs are where they should be. You might have two cars and a wheelbarrow in the garage; you vote in every election. You curse both the cold winters and hot summers.

Life is good. Make that, "was good".

Overnight that good life turned on its axis when your wife said she a "lump" on a breast. More troublesome is that the area under the armpit seemed swollen. A talk with her physician adds to the concern when the doctor says: "There are 'strong suspicions' you have cancer."

Before offering a definitive diagnosis, further tests are ordered, but your gut instinct has already given you the answer.

Suddenly, you are catapulted into a baffling new world; a world not of your choosing. You have been conscripted into the ranks of primary male caregivers.

Your first reaction is of stunned silence, and then your emotions switch into overdrive as your mind ramps up in a titanic effort to make sense of everything.

Unlike many of our female counterparts, most men have probably spent less than 20 minutes in their entire lives actually

families. Canadian Cancer Society and Health Canada. 3rd ed., Toronto. 2002

Nutrition and Breast Cancer: What you need to know. Canadian Cancer Society. Rev.ed., Toronto. 2002

Understanding Breast Cancer Treatment: a guide for patients. National Institute of Health, National Cancer Institute, Washington, D.C., 1998

Radiation Therapy and You: A guide to self help during treatment. Canadian Cancer Society, Rev.ed., Toronto 2002

Chemotherapy and You: A guide to self help during treatment. Canadian Cancer Society, Rev.ed., Toronto 2002

Sexuality and Cancer: For the woman who has cancer and her partner. Leslie R. Schover. American Cancer Society, New York, N.Y., 1996

NOTE: There are scores of other books, pamphlets and brochures worth reading. Many are available free of charge in libraries of cancer clinics, hospitals and other cancer-oriented organizations and institutions. Generally speaking, virtually every publication will provide you with fresh insights and information crucial to your search for material that will help you understand what your partner is going through today and what she is likely to face tomorrow.

For more information or assistance, please see the four organizations listed on pages 52-57.

IF KNOWLEDGE EQUALS POWER

If knowledge equals power, then there is plenty of power at your fingertips on the subject of breast cancer. The trick is deciding what you want or need to know. In your search for answers to questions you haven't even thought about yet, you'll find there's a small mountain of useful material published under a wide range of titles.

Following is a selection which we found to be particularly helpful.

Number One Choice:

Questions and Answers on Breast Cancer: A guide for women and their physicians. This booklet is based on Canadian Clinical Practices Guidelines, as published in the Canadian Medical Association Journal and distributed by the Canadian Cancer Society's Cancer Information Service; the Canadian Breast Cancer Foundation and Willow Breast Cancer Support & Resource Services, Toronto. Available online at www.cma.ca or www.hc-sc.gc.ca/hppb/ahi/breastcancer/publications.htm

Other worthy titles include:

Breast Cancer and You: Edited by Helen Hatton. 2nd ed. Amgen, Mississauga, ON 1999

Lumpectomy: What you need to know. Canadian Cancer Society; Rev.ed, Toronto 2002

Mastectomy: What you need to know. Canadian Cancer Society; Rev.ed, Toronto 2002

Looking Ahead: A handbook of survivorship issues; Lakeridge Health Corporation. Bowmanville, ON, 2002

Helping Yourself: A workbook for people living with Cancer, by Alistair J. Cunningham. Ontario Cancer Institute, Princess Margaret Hospital, Toronto, 1989

Pain Relief: Information for people with cancer, and their

thinking about breast cancer. The topic is not on the male radarscope.

In the following weeks, you will come face-to-face with *more* things you *don't* know than things you *do* know.

UNDERSTANDING WHAT'S AHEAD

You'll begin by doing the obvious – search for whatever information you can find about this stubbornly vile thing called breast cancer. You will find countless Internet sites, dozens of pamphlets, handbooks and guidebooks tell you more than you ever wanted to know about breast cancer generally, and specifically, about such things as lumpectomies vs mastectomies; lymph nodes and lymphedema; shunts and ports; loss of hair; about nausea and fatigue; about x-rays and ultrasounds; about chemotherapy and radiation therapy; hormone treatment or maybe a drug called tamoxifen.

In time, disjointed bits and pieces will tumble into place creating a rough imagine of things to come. Even so, much will remain unclear. Don't beat yourself up – even the medical profession has not yet unravelled the many mysteries of breast cancer.

At the risk of sounding repetitious, it is good to realize that the role of the primary caregiver is a crucial one. While it can be baffling, confounding, disconcerting and draining, it can also be satisfying as you begin to understand the many tasks ahead and gird yourself to face those challenges.

One of the truly important aspects of your role as primary caregiver is that your wife needs to know and accept, without doubt, that you will be there for her over the long haul. Make no mistake, it will be a long haul.

On the flip side, however, is the knowledge that with the right information, motivation, drive, patience, understanding and sheer determination, you can make a difference, and good things will happen.

Since there is nothing you can do about yesterday or tomorrow, think of each morning as the dawn of a brand new day.

It is the first day of the rest of your life.

TUNING OUT

Early on, your will discover that there are many hurdles in your search for information about the care and treatment of breast cancer. There are literally millions of words at your fingertips, but getting what you need quickly is the trick.

Don’t be surprised if your wife, already under stress, soon reaches saturation and says that she just can’t handle any more information. She simply “tunes out”.

This is a normal, human reaction. For her, Task One is to concentrate her strength and energy on the present and deal with her medical problems one at a time.

That’s when you accept the challenge of learning whatever needs to be known about the present and the future. You will become your own information sponge, trying to anticipate what’s coming next, preparing your wife and family, and acting in her best interest. It is important to understand that patients and caregivers need different amounts of information relating to the diagnosis and treatment of breast cancer.

Your wife has every right to “tune out”; you enjoy no such luxury.

possible cancer occurrence.

However, some oncologists avoid using the term “double mastectomy”. They argue that the removal of a healthy breast is considered a “prophylactic” procedure and is not part of the cancer treatment per se.

In these pages, you will find a number of references to “double or bilateral mastectomy”. While this runs counter to some medical thinking, I felt that “double mastectomy” is best understood by the general public – those people most likely to read and receive guidance from this guidebook.

RADIATION THERAPY: As you search a variety of sources for information concerning breast cancer you will find references to a treatment which people tend to simply “radiation” as in: “after chemotherapy she will undergo radiation treatment…”

You will also find references to radiotherapy, x-ray and even irradiation. However, medical professionals consider “radiation therapy” the most appropriate term.

For the sake of simplicity, I have generally used the term “radiation therapy” in the first reference and then contracted that to “radiation” in subsequent references.

Radiation therapy covers a spectrum of treatments delivered by an external radiation source, or by radioactive sources placed within body tissue/cavities. Radiation impairs cancer cell growth by stopping those cells from multiplying while allowing normal tissues to heal. Some radiation side effects are considered acute or chronic. The acute effects include skin reaction and breast tenderness which generally heal within a few weeks. Chronic effects including scar tissue, breast firmness and skin colour changes generally last longer.

always been healthy and physically active. Even after recovering from surgery, she would tire more quickly than she was used to and couldn't lift things that she once handled easily. I had to learn to deal with this reality."

Today, Dianne Moore is once again a woman on the fast track. She has resumed her busy professional and family life as well as her community involvement through Rotary. She counsels other newly diagnosed women, helping each to cope with the fear she once faced. She has also spearheaded The Power of Women, a network of local women raising funds for a digital mammography machine. Dianne has also become a breast cancer activist and has served as a consumer reviewer on Canadian and U.S. panels reviewing proposals for funding new breast cancer research.

Except for the fear of recurrence that every survivor feels, life couldn't be better. Moore emphasizes that he and his wife have drawn closer together. "We came to terms with our own mortality and the realization that life is not going to go on forever. So let's do the things we want to do while we have the health to do them."

TERMINOLOGY DIFFERENCES

As medical science evolves, so does the language. This can lead to confusion between medical professionals and Ordinary Joe and Jane. Consequently, I felt it is useful to clarify two of the differences.

DOUBLE OR BILATERAL MASTECTOMY: Double mastectomy is a terms that ordinary people generally use when referring to a woman having both breasts surgically removed. This occurs when doctors determine that the one affected breast should be removed, and the patient decides to have the other, healthy breast removed at the same time. Those patients who do so, consider this to be a reasonable precaution against a second

GETTING ANSWERS TO YOUR QUESTIONS

As you work your way through stacks of books, booklets and pamphlets, offering all sorts of information and advice, you'll identify at least one common refrain:

"When you meet with your doctor(s), don't be afraid to ask questions and take a notebook to jot down the answers." Some sources even suggest you take a tape recorder.

That all sounds like good, practical advice, but it doesn't always work out as well as you might hope. While most doctors are forthcoming and ready to share any relevant information, others react negatively, and will tell you so.

Whenever possible, have at least one other companion with you, and if possible, two. So much unfamiliar medical jargon will flow your way, that it is difficult for one person to absorb it.

After discussion with the doctors, it is smart to compare memory notes with your companion(s) immediately after the interview. Different people will hear different things but collectively, they can offer a reasonable summary of who said what to whom.

Why is note-taking discouraged by some medical staff? One professional suggests that there are not always clear, definitive answers to specific concerns. Another suggests that in today's litigious society, some doctors are wary of legal actions and would rather not have their responses come back to haunt them.

One cancer worker offers two excellent suggestions:

1. If you have questions (especially if they tend to be confrontational), don't ask them until the end of that day's treatment. At the beginning you are "the patient" and will be treated as such. Later, you are your own person and free to ask and have a right to know.

2. Prepare a written list of questions for yourself as memory joggers, and provide copies to the doctor, the attending nurse and anyone else who might be involved. The doctor then has a chance to review them and respond without being dismissive. Also, if you feel a question has not been answered satisfactorily, you can refer back to your list, and ask the doctor to review question number…

***

When you run into glitches in the medical system (as you surely will do), it is useful to reflect on the comments of Dr. Kenneth Schneider, senior oncologist at the Windsor Regional Cancer Centre:

“Frustration can occur when a loved one is ill and the expedient care they require is less than ideal. The health care team constantly deals with large numbers of patients, many with similar concerns.

Being human in a health care system which is stretched beyond its means, creates the potential for disruptions in the smooth delivery of the required care. This challenge is faced by health care providers, not on a daily, but on an hourly basis.”

whole new dimension. I was numb and so was Dianne, but our children (all of whom live four hours away), were totally supportive. From the days we got the diagnosis to a couple of weeks after surgery at least one of them was with us all the time.”

“After the diagnosis, our surgeon presented us with two options – a lumpectomy or a bilateral (double) mastectomy. When she explained the odds of the cancer returning with either procedure, we agreed that the safer route was with a bilateral followed by full reconstruction.”

BECOMING AN ADVOCATE

“I learned that as well as providing your wife with emotional and physical support, you have to become an advocate,” Moore says. “You have to ask questions. Sometimes you have to get the medical jargon translated into plain English.”

That lesson was reinforced early on. Just a few days after the shock of diagnosis, his wife received a letter telling her that the blood samples she had submitted for genetic testing had been discarded without being tested. Because neither her mother nor her sisters had had breast cancer, she was not considered a “primary candidate” for genetic testing.

“It was a tense time,” Moore says, “when I met with the author of the letter and told her of my wife’s diagnosis. She agreed to take new samples and promised that she would personally ensure they were tested. The tests came back negative for BRCA-1 and BRCA-2, the two genes associated with breast cancer. However, the geneticist explained that there is still much to be learned about genetics and breast cancer. The incidence of cancer in my wife’s family indicates there could well be other genetic “markers” that have not yet be identified.”

“I learned a lot in the weeks that followed. My wife had

PARTNERS WITH A NEW CHALLENGE

Jim and Dianne Moore have been partners in a technology consulting business for 17 years. Now they are closer partners in an entirely different undertaking making sure that Dianne, who has emerged from a bilateral (double) mastectomy with flying colours, hangs on to her renewed joy in living life to its fullest.

Jim Moore, whose friends agree is someone who is rarely rattled, recalls that it was backing 2000 when his wife was diagnosed with breast cancer and he became her primary caregiver.

Moore says, “As a man who had enjoyed more than 30 years of marriage to a woman who was the central support person of our family, I was faced with an instant reversal of roles. Like many men, I had been deeply immersed in my work. Suddenly, work didn’t seem to important and it was largely put on hold while I helped Dianne with her ordeal.”

His wife had gone for an annual mammogram in February, 2000 and received a clean bill. However, because six aunts and several cousins had had breast cancer, she decided to undergo genetic testing.

BIOPSY CONFIRMS CANCER

She gave the requisite blood samples in early summer and was waiting to hear results when, she sensed that her right breast “just didn’t feel right”. She saw a doctor who said there probably wasn’t anything to worry about, but recommended an ultrasound. The results showed there was “something there” and a biopsy confirmed a cancerous growth.

“The news hit like a ton of bricks,” Jim Moore said. “Even with the family history, when it’s your own wife, it takes on a

BUILDING A SUPPORT TEAM

When word spreads about your wife’s plight, phone and door bells will chime as relatives and friends call to express their sympathies and offer support.

The most common message will be: “If there is *anything* I can do, just let me know. *Anything* at all.”

And they mean it. Catalogue their names and phone numbers, thank them and *promise* that you’ll call them back as soon as you sort our your greatest needs and priorities. Keep that promise. It will set your wife’s and your own mind at ease especially if you still have a full-time job or run your own business, particularly if your work takes you out of town.

You could need help for any number of reasons; when your wife feels a wave of nausea just as you’re leaving for work; when she has a blinding headache, or needs something to quench an insatiable thirst. Then there are those days when you simply need an extra pair of hands just to get the kids ready for school.

Friends can also sit with your wife when she is experiencing pain or nausea, drive her to appointments, help with meals or run errands.

Your list of available “Samaritans” should contain more names than you think you will need because some might not be available when your need is greatest. If possible, enlist the support of one or two nurses. Their professional experiences are priceless.

Give everyone:

- Your phone number at work;
- Your cell phone or pager;
- Whatever they need to contact you in a hurry;
- Leave a clearly, timely set of instructions from the family physician, surgeon or oncologist;
- Be sure to pin this list near the telephone.

Committed volunteers are priceless. They really DO want to help, and the one thing that volunteers cannot abide is NOT being asked to do something. Be sure to assign specific tasks and don't forget to say "thank you" and mean it. Even better, take a few moments to write a "thank you" note. Don't fret about the legibility of your script, the thought is the important part. It will do wonders for you and for your support team.

If you have to travel out of town, consider asking one of the volunteers to be the "team leader" – something willing and capable of organizing things in your absence.

A CARD, A FLOWER, A HUG

It happens to all of us. We have one of those days when nothing goes right. We feel down, gloomy, blah or melancholy. Then the mail brings an unexpected note from an old friend; the local flower shop drops off a bouquet, or someone offers a hug and a warm, happy smile. The sun comes out and things change for the better. They just do.

Think for a minute how much any of these thoughtful gestures will mean to your partner, particularly on those days when nausea sets in, or she runs out of energy before noon, or when a splitting headache sends her to a darkened bedroom in the middle of dinner.

In the end, it's not the size of the bow or the candy box, it's the act of "doing" that really matters.

Reach to Recovery is delivered by experienced volunteers who have survived breast cancer. They have been "there and back" and offer encouragement and emotional support after diagnosis, before surgery, in the hospital, at home, or any time during treatment.

They also demonstrate exercises to help speed up mobility in the arm next to the breast where surgery took place. There is a tendency for that arm and the armpit to stiffen after surgery.

KEEPING A DIARY

As basic as it might sound, it is important to keep a daily diary. Even if you didn't start at Day One, start now and try to reconstruct everything you can recall and go on from there.

In the weeks and months of treatment, so many things will happen and so many instructions will be given, that your mind will go into information overload. Dates, times, places, names and figures will become a tangled mass of medical jargon. Unless you have total recall, you simply won't be able to remember important things without reference to diary entries.

Your diary should also contain little anecdotes, things that will trigger memories of related events that otherwise disappear with the passage of time.

their private lives private; others are energized and benefit from being able to share a coffee and their own experiences with other women who have jumped through the same hoops. For them, it is a therapeutic exercise to exchange information, to know that they are "not alone" as they fight their way back to good health and the "new normal."

In the end, however, the decision to join with others or not, is your wife's to make. Much of it depends on timing; how well she feels both mentally and physically. Today might be the wrong day, tomorrow might be right. If you are not personally aware of any such groups, a list of helpful organizations and resources available can be found on pages 52-57.

Many women feel that they learn more incidental and relevant information about treatment, the side effects, the pluses and minuses and other practical tips from "soulmates" than thy do from the professionals who treated them.

Even if your wife is reluctant at first, don't surrender. You might consider enlisting the assistance of other women who have participated in group support practice. You can also contact experienced social workers at cancer treatment centres servicing your region.

REACH TO RECOVERY

The Canadian Cancer Society offers four emotional support programs: Living with Cancer (group support): CancerConnection (telephone-based support); CanSurmount and Reach to Recovery. The latter two are one-on-one programs.

Reach to Recovery is designed specifically for breast cancer patients. Since not all units of the Canadian Cancer Society offer identical programs, contact the Unit serving your region and find out what services are available.

CAREGIVERS AS ADVOCATES

Cary Wheeler's wife, Trish, underwent a bilateral (double) mastectomy followed by chemotherapy and radiation. He sums it up well when he says that his emotions ran from a sense of total helplessness and frustration to one of fear of physically hurting his wife while carrying out some of his new "home nursing" duties.

Wheeler says that when he learned his wife had cancer, he had only the vaguest notion of what "caregiver" meant and what was expected of him. At no time did any professional offer him even the most basic overview of the things he would face in the months ahead.

"Thinking back", he says, "if we were starting all over again – God forbid– I would want, right from the get-go, a full and frank discussion with a trained professional of what could or might happen. I would want to know the good, the bad and the unthinkable. I didn't get any of that, so every day there was the potential for a completely unexpected surprise.

Wanting that depth of information comes naturally to Wheeler, who runs a successful printing company. He says he can't manage his business unless he sees the full picture, and he needed someone to sketch the same kind of scenario for him about his wife and her prognosis.

Because his wife had both breasts and seven lymph nodes removed, she left hospital after than 40 hours with four tubes still connected to her upper torso. The tubes drain body fluids that collect around the surgical sites, and have to be drained or "milked" to prevent blockage and backup.

Wheeler is a fast study. Even though he didn't know what was coming next, he accepted the role of caregiver, which included serving as an advocate. That meant speaking for his wife when she was not able to do so herself. His first challenge came when the hospital wanted to discharger Trish only 13 hours after surgery.

"My wife went into surgery at 7 o'clock at night and they tried to discharge her at 8 the next morning!

Over my dead body! I told them that was outrageous! She had been heavily sedated and was still 'out of it' I said I wasn't taking her home in that condition and they had better arrange to keep her for at least another 24 hours."

After a lot of huffing and puffing, hospital staff saw it his way.

HAIRCUT = $10,000

When his wife started her chemo treatments, she was told that she would lose her hair. Wheeler decided to have his own head shaved bald and use it to raise money through pledges from friends, relatives and business acquaintances. He came within a hair's breadth of raising $10,000 which he donated to the Windsor Regional Cancer Centre.

Wheeler ran into other moments of frustration, particularly when his wife was suffering from nausea and sores in her mouth. He called an emergency number for assistance. It happened twice. The first time, the nurse showed up promptly and treated Trish which gave her some relief. The second time, a nurse arrived and asked:

"Why am I here?" When told, she asked Wheeler if he had a syringe. He said "no" and she had to drive to an all-night drug store, bought one, and returned to provide treatment.

While most patients and their caregivers maintain they are generally satisfied with the quality of home nursing care they

The Community Care Access Centre plays a role in deciding the level of care. If you are not satisfied with their judgement, you can consider supplemental "private pay" care through the VON. You might have to pay that cost yourself, or you might have a health care plan that covers the cost. There are different options, and you will have to decide how much care you feel your wife needs, and how it can be paid.

WHEN TREATMENT ENDS

For some women, the end of regular "institutional" attention with the diminished support of friends, can lead to an emotional downer.

Where once your partner saw her chemo team two or three times a month, followed by regular visits for radiation treatment or blood tests, suddenly there is a vacuum. Everything that has to be done is done. This can lead to a touch of loneliness and melancholy.

If you sense that something "different" is happening in the post-treatment days, discuss it with your spouse and urge her to talk to her physician, or a social worker experienced in counselling cancer patients.

THE VALUE OF GROUP SUPPORT

When your wife is back on her feet and regaining her strength, you might want to raise the subject of networking through a group support system with other breast cancer patients/survivors.

This can be a sensitive subject. Some women prefer to keep

HOME NURSING OR NOT – YOUR CALL

Following surgery, breast cancer patients are frequently assigned a nurse to make home care visits as needed. However, do *NOT* assume that it will happen automatically, you might have to intervene on your spouse's behalf.

As caregiver, there are certain tasks that you will be expected to perform while your wife is recuperating at home. If you are not comfortable doing so without assistance, you might wish to have a nurse examine your wife, oversee what you are doing, or assist with the tasks.

Basically, there are three stages when a nurse might be requested:

1. PRE-SURGERY: Generally it is the surgeon who makes arrangements for home nursing care. During pre-surgery discussions, ask your surgeon if a nurse will be assigned to visit your wife. If the answer is "no", explain that you are not comfortable with the idea of "going alone" and would like professional assistance. It is covered under OHIP.
2. POST-SURGERY: As you and your partner are preparing to leave the hospital after surgery, ask the discharging nurse if a request for home nursing care has been made. If not, check back with your surgeon or family physician.
3. CONTINUING CARE: if you are caring for your spouse at home and are uncomfortable with that role, speak to your surgeon or family physician, explain your concern and as for assistance.

received, that is not always so and Wheeler remains baffled by the breakdown in service.

"It is simply beyond me why they would not equip nurses with everything they need, especially when I described her situation and my concerns over the phone. I don't believe there should have been any confusion or misunderstanding," he says.

At the time of writing, Trish was back on her feet and turning up regularly for work at the print shop. In 2003, she competed in a dragon boat race held on the Detroit River.

JUST "BE THERE"

Being a caregiver is not synonymous with being a cheer leader, though words of encouragement, support and congratulations are always welcome, and be an important part of the healing process.

But there is also a need for quiet times; times to let the body and mind mend themselves. As your partner dozes, background music can be comforting, as can be the sound of familiar voices on radio or television.

In the end, though, one of the greatest benefits is nothing more than your quiet presence. Just "being there" is a powerful prescription.

Another reminder for those who think that once the outward signs have all but disappeared, that there is no longer a need to "be there". Nothing could be further from the truth. The pain and the hurt might not be evident but there can often be a longing for love and attention.

The solution is relatively simple: a backrub or foot massage in the event will boost morale wonderfully. Some women take particular delight in a manicure or pedicure. Simple things that speak volumes.

PACING YOURSELF

Let's accept for the purposes of discussion, that by their very nature, women tend to be better caregivers than men. Girls learn at their mother's knee how to care for sick siblings, fathers, grandfathers and the like, while boys go about doing what boys have always done.

It should be no surprise that men can be overwhelmed by the tasks they inherit as unskilled caregivers. Beside taking care of a spouse who is hurting from surgery, nauseated by chemo or burned by radiation, men must also achieve a balance in domestic chores. For some, this is not a great challenge, for others it can be intimidating.

The first thing is to find the vacuum cleaner, dishwasher, clothes dryer, toaster and microwave. While there's more than a little jailhouse humour in that, it is true nonetheless – at least for some men.

For those who have not been "house-broken", it is necessary to pace yourself by moving to your own drum-beat and reasonable work schedules. Trying to be all things to all people all the time is not a healthy way to go.

It is much better to set priorities, with your wife's needs as Number One. Then parcel the rest of your day to cover as much ground as possible in a reasonable amount of time and leave time for R&R.

It's not a grievous sin to leave what is not done until tomorrow. There's always another tomorrow.

IN FOR THE LONG HAUL

Amidst all the emotional turmoil of dealing with the care and treatment of your wife, it is easy to forget that the end of the road, long and difficult as it has been, might not yet be in sight.

Well-meaning friends and relatives continue to pepper you with friendly but unanswerable questions such as:

"Did they get *IT* all?"

The truth is, you don't know, and neither does your medical team. Your surgeon will tell you that he or she did as much as was humanly possible; the oncologists know they did everything within their power. The reality is that no one truly knows "if they got *IT* all."

So the anxious wait begins. When the initial treatment is finished, your wife will revisit the hospital or cancer treatment centre for a series of examinations to determine whether there are any signs that a tumor has returned.

This pins-and-needles process (usually every six months) will continue for up to five years before anyone will give an optimistic thumbs up. Even then, there are no guarantees.

Meanwhile, you and your wife have the opportunity to begin piecing your lives back together. A word of caution: Some breast cancer patients are anxious to celebrate, and even take a well-earned vacation overseas. Others choose not to, for reasons that are private, and properly, their own.

Some men feel it will do their wives good to "get away for a while". Nut no one should presume to know exactly what your wife really wants. It's best to ask. In the end, give your wife all the time and space she needs before making the decision; which is hers to make.

In such circumstances, an understanding caregiver should be at the top of his game. Don't make assumptions based on the way your partner looks. With the magic of makeup, she might appear to be strong enough to do the laundry and vacuuming – or (heaven forbid) the inevitable dusting.

Look beyond the cosmetic mask and remind yourself what your partner endured and know that she could still be coping with the after effects.

UNREALISTIC EXPECTATIONS

Believe it or not, there are men who assume that once the surgery and subsequent treatments are finished, there is no reason that their wives/partners simply can't hop out of bed, put on a pot of coffee, slip a couple of slices of bread into the toaster, feed the kids and get on with their lives as though nothing had really happened.

Truth is, it could take many months for a cancer patient to get over the trauma. Her energy levels might continue to sag, her emotional resources are low, and in many cases, she never really stops thinking about what might be around the corner tomorrow or next year.

Caregivers should be ready and willing to do *whatever it takes* to help their partners work their way through what might well be a long a difficult period to full recovery.

TALKING TO YOUR CHILDREN

As difficult as it is for an adult to understand that a loved one has just been diagnosed with breast cancer, consider the confusion faced by children in the family, no matter what age.

Dealing with the concerns faced by your offspring can be a challenge and parents who are often caught up in the emotion of the moment should consider seeking the advice, support or direction of professionals such as social workers, doctors, nurses, religious leaders, or school teachers.

Also, do whatever you can to shed light on the subject by encouraging your children to talk openly about cancer and express their feelings freely. There is nothing so unsettling as knowing that "something bad" is happening, without understanding what is is.

Build in more family time, particularly where younger children are involved. Make sure they understand that the did NOT cause the cancer; explain that cancer is not contagious, and above all, that it is normal to be worried, angry or sad.

LUMPECTOMY VS MASTECTOMY

Some patients feel they have to make snap decisions about whether they want a lumpectomy (breast conserving surgery) or a mastectomy, involving surgical removal of the affected breast. One school of thought suggests that in some circumstances, there might *seem* to be a psychological urgency to decide quickly, even though there might not be a medical urgency to do so. By delaying the decision, breast cancer patients can take a little time to weight the options and ramifications.

In earlier years, the available information was more contradictory than is the case today. Medical people were divided on the question of whether a mastectomy really did provide greater protection than a lumpectomy.

The debate was resolved in 2002 when the New England Journal of Medicine reported that 20 years of patient follow-up study offers “powerful confirmation” that eliminating just the lump can save as many lives as removal of the entire breast.

An important caveat is that the lumpectomy *must* be followed by radiation.

To learn more, you can turn to the Internet and search:

“*Lumpectomy Study, New England Journal of Medicine*”.

If you feel it necessary, copies of the study can be made available to your partner’s physician and surgeon.

TRAVEL INSURANCE

It doesn’t take long to realize that many things once taken for granted have, or will, change for those living with breast cancer.

Insurance is one of them. Particularly travel insurance. It’s something most of us don’t think about until we begin making inquiries.

If your partner is planning a trip for a change of scenery, or just to celebrate the end of treatments, she should carefully investigate whatever travel insurance she is considering buying and make certain that what she is getting is what she really wants and needs.

The reality is that it may be difficult to get certain types of travel insurance – *even for situations unrelated to cancer!!*

EXAMPLE: An acquaintance had purchased an “annual” out-of-province plan with coverage limited to 17 days per trip. When she began planning for a 21 day European trip, she assumed all

LOSS OF ENERGY, LOSS OF VITALITY

A potential long-term effect of radiation therapy can be an enormous loss of energy, an overwhelming, bone-weary fatigue. One study suggests that between 60 and 75 percent of more than 300 women who received radiation treatment reported decreased stamina that lasted from two to ten years.

One of the difficulties in treating fatigue is that its cause is not well known and could result from a variety of factors including nutrition, anemia, drug interaction, tumor activity, lack of exercise, depression and changing sleep patterns. Studies are underway to identify the contributing factors.

As with so many side effects, no two women necessarily respond the same way. Some experience no fatigue, others experience it intermittently and still others wrestle with it everyday.

If your wife is suffering from what you feel could be chronic fatigue, it should not be ignored. Let her physician know so that he/she can search for remedies. Keep a diary indicating when the fatigue was first noticed; is it growing progressively worse; does it occur more at certain times of the day.

One woman said her experience was like hitting a “wall of fatigue”. She said it is “indescribable because you can’t point to a place in your body and say: ‘see, here it is!’” In a sense it should not come as a great surprise because during treatment the woman’s body is seriously at war with cancer and she needs all of her energy resources to fight the disease.

Caregivers need to understand that for a woman who prides herself in having raised a family, tended a home and cared for a husband, or perhaps held a full-time position in the outside work place; a woman who has been assertive, active and dynamic – this woman can be deeply frustrated as she now discovers that even the least physical effort can leave her drained.

RADIATION THERAPY THE GOOD, THE BAD AND THE LOUSY

Radiation therapy is often, though not always, an essential part of breast cancer treatment. Its purpose is to kill cancer cells still lurking in specifically targeted parts of the body after surgery. Hence it is considered a “local” treatment and is often combined with chemotherapy to deliver a one-two punch.

Once your partner’s radiation therapy schedule has been established, the regimen of treatment is intense; five days a week ranging from 3.5 to 6 weeks. Oncologists are reluctant to break the treatment schedule except for unusual and compelling reasons.

Resource material often suggests that one of the side effects can be compared to a “mild” sunburn and the patient might experience a slight tingling or itching sensation.

There are exceptions. It could be as painful as a severe sunburn including skin discolouration and peeling. There might also be skin damage around the breast requiring separate treatment.

Sometimes these side effects do not manifest themselves until days or weeks AFTER the treatment is finished and your wife is no longer in direct contact with the radiation oncologist. It is important that the radiation oncologist reviews the possible side effects in order to alleviate these concerns and prescribe treatments as required.

If that does not occur, your wife should discuss it with her family physician or surgeon.

Although the term “radiation therapy” as used here is technically correct, it is also commonly referred to simply as “radiation”.

she had to do was ask her insurance provider to “top up” her coverage for an extra four days.

The insurance company rep asked a few medical questions, but when the word “cancer” popped up, the woman was stunned to learn that the insurance company refused to top-up her plan. She was in a minor rage, feeling humiliated and stigmatized.

CAUTION: A cancer patient /survivor should not gamble on the change that nothing will happen if she takes the trip without prior insurance approval. It could work like this: she might suffer something completely unrelated to cancer (a broken leg, for instance). When she returns to Canada with her medical receipts in hand, the insurance company might say: “Sorry, even your basic 17-day coverage is null and void because of the pre-existing cancer.”

The reasons are illogical, the circumstances might be rare, but they do exist. Read the fine print, and ask. Some travel insurance companies might provide full coverage – as long as she gets a letter from her doctor stating she is well enough to travel. But check first and make certain before you board that plane or boat.

DISABILITY INSURANCE

In the days after your wife has been diagnosed with breast cancer, the last thing on your mind is her disability insurance. Especially the fine print.

Be careful. You could find yourself in a frustrating fight over what you believe she is entitled to vs what your insurance company feels is her due.

This is especially true of people who businesses where husband and wife share the work and are comfortable in the belief that their disability insurance coverage will be there when they need it most.

Don’t count on it.

A friend tells about a couple who operate their own restaurant. When the wife was diagnosed with breast cancer, she underwent surgery and received chemotherapy. Several weeks into the program she was feeling reasonably well and decided she would try returning to work to help out during the lunch time rush.

That was Mistake Number One. Mistake Number Two was notifying her insurance company. She felt she was playing the game honestly and assumed that her disability payments would continue, but on a reduced pro-rated basis calculated on the number of hours she worked each week.

Wrong! After considerable tooing-and- froing, the insurance company ruled that because she was well enough to return to work, they wouldn’t recognize her disability claim at all, except for a small, one-time settlement payment.

Still smarting from the rebuffs, the woman’s husband cautions that one of the first things to do is to dig out your insurance policy, go through it with a fine tooth comb; discuss it with your agent as well as someone in authority at the insurance company.

Until you have all the answers in black and white, your partner should *not even think* about returning to work – even on a temporary, part-time basis. You could find yourself holding a very large and very empty bag.

treatments, Maggie’s energy levels dropped and the need for rest was paramount. It was here that her husband’s familiarity around the kitchen came into play.

“I’ve always done some of the cooking, so I just added shopping to my chores,” he said.

“It’s silly to suggest there are any “upsides” to a cancer diagnosis,, but as with many other couples, the Johnsons have pulled closer together. They’ve faced their own mortality and the need to make the best of whatever time they have together.

On the downside, he believes there are too many potential glitches in the medical care system and that greater efforts must be made to fine-tune and speed up medical reports and actions. “The waiting itself is hell when your wife is dealing with a life threatening disease like this…”

CHANGING BEDS, CHANGING ROOMS

In the days following surgery, and later during chemo and radiation, your wife might have difficult sleeping soundly. There could be several reasons, including a subconscious concern about keeping you awake during a restless night.

Don’t be afraid to talk about it. While it might be more comfortable for her to know you are nearby, it is more important that she enjoys a full night’s sleep while her body is under repair.

One option is to consider sleeping apart, possibly in separate rooms. You both win. You will sleep better and wake up feeling more refreshed; she will sleep more soundly, knowing that she can roll, toss or turn through the night. Her doctor might prescribe a mild sedative at bedtime.

LIKE AN UNWANTED HOUSE GUEST

Back in 1995, Maggie Johnson, then a social worker at Windsor and Essex County Hospice Inc. noticed a lump in her breast and breathed a sigh of relief when a biopsy showed that it was benign. Seven years later, another lump developed, and she was optimistic that it too would be benign.

It wasn't. She was diagnosed with breast cancer and after meeting with her doctors, opted for a lumpectomy followed by chemo and radiation.

Her husband, Ralph, a university philosophy professor, recalls that when he got the news, "The shock was something I could never have been prepared for." It was simply what he calls "the horror" of it. He likens it to "an unwanted house guest who just won't leave."

A BALANCING ACT

His mind was trying to simultaneously process two vastly different situations: (a) his wife was dealing with a life-threatening illness and there was much she should be doing to help her; (b) he had a full-time job, dealing with a classroom full of students.

"Teaching philosophy is something I've done for 36 years and on a good day, it would be a walk in the park. Then I realized that my attention was divided and I really wasn't focusing on my work the way I should have."

He argues that in moments of crisis, the mind is not always able to process information as quickly as is normal.

The reality of his wife's illness also brought about a dramatic change in their priorities.

"Today there is always an ominous, unpredictable threat hanging over us," Ralph Johnson says. "After the early chemo

PORTS, DOMES OR SHUNTS

It's round, about the size of a small grape, and resembles a tadpole with a short, thin plastic "tail" called a venous catheter. It's known variously as a port, a dome or shunt. But by any name, to women undergoing post-surgery treatment, its value is difficult to exaggerate.

The port (developed by Windsor surgeon Dr. James Laird in the 1970's), is surgically implanted under the skin, either in the chest wall or an arm. The plastic "tail" is fed into a major vein, at a point where the vein enters the heart.

Its purpose is two-fold: Instead of injecting chemo cocktails into a vein or using a vein to draw blood for testing, the technician simply slides the needle through a thin membrane of skin directly into the catheter with no more sensation than a mild pinch.

Ports are implanted using only a local anesthetic sometime after surgery. The timing decision rests with the oncologists and usually takes place before chemotherapy begins.

Before development of the port, chemotherapy and blood work were done by traditional means using the woman's veins, which are often fragile and brittle. At times, technicians were not able to find a "good" vein. Also, since chemo drugs are highly toxic, they can cause a painful inflammation reaction if a vein breaks or leaks.

Although ports are now frequently used, your partner might not have one implanted. She should ask her physician if insertion of a port is possible or necessary. If the answer is "yes", arrange to have it done.

WIGS, SCARVES AND HATS

While breast cancer treatment can be full of surprises and uncertainty, one thing patients can count on is that, once chemotherapy treatment begins, she will probably lose most – or all – of her hair

That's the downside; the upside is that inevitably it grows back, sometimes softer and more vibrant than before.

Some women manage to escape without hair loss, but the majority are well advised to prepare for it, physically and psychologically.

My wife was told she could expect her hair to begin falling out in three weeks. It started almost three weeks to the day.

However, she was prepared: She had accepted it as an inevitability and had her natural hair cut short. She felt that she could handle the psychological impact more easily if it didn't tumble into the bathroom sink in massive clumps.

She learned that "real" hair wigs are warmer than synthetic, and are far more expensive. They also require as much care and attention as her own natural hair.

Eventually she found a woman who was understanding, sympathetic and enjoyed a sense of humour. The woman also agreed to wash and take care of the hairpiece during treatment.

Facing the loss of hair is not, by any measure, a fun thing to anticipate but some women can enjoy the experience of trying on styles and colours perhaps wildly different from her own.

There are other options. Your partner might favour colourful scarves or attractive (even flamboyant) hats. The choice is a personal one but it is important that she begins thinking and planning before her energy levels drop and the first signs of hair loss show up on her pillow one morning.

SEXUALITY AND YOU

An important concern about the impact of breast cancer surgery that troubles some couples is how loss of a breast will affect their intimacy.

It is not always an easy discussion to open, however, reports indicate that couples do come to grips with it in their own time on their own terms. Counselling is also available and there are helpful information brochures on the subject.

Retired surgeon Dr. Steve Radin says at least one of the hurdles can be dealt with right in the surgeon's office. He recalls that whenever he was preparing for a lumpectomy or mastectomy, he explained to both partners exactly where the surgery would be, and described the visual and physical results.

"Men are not always involved in these discussions and they should be. That way there will be fewer surprises, and both can accept the future more comfortably," Dr. Radin says.

AN UNQUENCHABLE THIRST

Mid-way through chemo treatments, my wife developed a terrible thirst and her mouth felt dry as desert sand. We tried the obvious: ice cold water, crushed ice cubes, orange juice, cranberry juice, iced tea and even thin slices of juicy apples. They all worked but only for a time.

Then, one day she developed a craving for watermelon. Big juicy, ice cold slices of the ripe, red fruit – sweet but not fattening.

Presto! Of all the home-based remedies, watermelon worked best.

CAUTION: If there are any dietary concerns (diabetes comes to mind), ask your doctor before experimenting on your own.