

Lives affected by cancer...

women speak



Canadian Cosmetic,  
Toiletry & Fragrance Association  
**FOUNDATION**

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# Foreword

My spirit was broken the evening a doctor and two interns appeared in my hospital room and delivered the news that would change my life forever: “You have cancer. You have no chance for survival.” It was September. “We doubt you’ll see the New Year,” the doctor said.

I felt as though someone had jabbed a dagger through my very core. But my shock and disbelief fueled my determination to defy the odds and discover what I have since referred to as “the other side of cancer”.

I was 30 years old. Just two years prior, I had lost my mother to a painful death from malignant melanoma. Knowing how she had suffered, it broke my heart to call my father and sister to give them the grim news. But my father’s words encouraged me: “whatever it takes, we’re here for you and we’re going to face this head on”. In that moment, I knew my cancer journey was not destined to be a solitary one.

As I endured a gamut of nauseating and aggressive treatments including surgery, chemo and radiation that resulted in severe nerve damage to my spinal cord and legs, the support and encouragement I received from a vast network of family, friends and committed health professionals became the very life force that energized and propelled me forward, to wellness and recovery.

Today, more than 20 years later, I am thankful that the stage IV, small-cell ovarian cancer that threatened my life is gone from my body; but every morning, as I put on the leg braces and prosthetic that enable me to walk – albeit with a cane – **I am reminded that cancer will always be a part of my life.**

In 1992, as a Board Member of the Canadian Cosmetic, Toiletry and Fragrance Association (CCTFA), I was part of the Operations Committee that worked to establish the CCTFA Foundation to support women with cancer and to deliver Look Good Feel Better. I was one of the program’s first volunteers, and now, almost two decades later as the Foundation’s Executive Director, I can say with conviction that my work is more than a career – quite literally, it’s my calling. It couldn’t be more meaningful for me to be involved in our enhanced vision to foster greater awareness and understanding of, and support for, the psychosocial needs of people living with cancer, at every stage of their journey. I believe this report, “Lives affected by cancer...800 women speak”, is the first step in achieving our vision of a future where patient-centered care is the norm.

My own journey is in many ways mirrored by the findings of this report. **The tremendous ability women have for remaining positive through our most trying times is evident throughout the statistics.** I attribute my own triumph over cancer largely to my determination to remain optimistic throughout the journey. Each woman's cancer experience is as intense and unique as she is, but all women living with cancer wish to surround themselves with people, resources and medical care that can focus on the possibility and the return to one's own individual definition of a "normal life".

It is my personal hope that by sharing the findings of this report, society will become more informed and better equipped to help women face the many and diverse psychosocial challenges that are inherent with a cancer diagnosis and subsequent treatment.

I believe this report will provide all stakeholders interested in supporting whole-person cancer care with insight that quantifies what we have learned from our work with more than 100,000 women who attended Look Good Feel Better workshops – **We are simply not meant to face cancer alone.**

Determined to provide women with cancer, and their caregivers, access to the psychosocial supports they need at each step of their journey, the CCTFA Foundation is using these findings to establish a new program – **Facing Cancer Together.**

As we deepen our commitment to foster better understanding of the emotional and social needs of women with cancer, and work to ensure that effective supports are in place, I add my voice to those of the 814 women who shared their experiences with us so that we may bring you this report.



**Sherry Abbott**

*Executive Director,*

*Canadian Cosmetic, Toiletry & Fragrance Association Foundation*

# Executive Summary

## MISSION

Foster greater awareness and understanding of, and support for, the psychosocial needs of people living with cancer, at every stage of their journey.

As cancer survivorship rates continue to improve, society is challenged to better understand the long term cancer journey. A greater awareness of the lifelong requirements of the whole person – emotional, social and physical – needs to be understood and addressed. It is within this context that person-centred cancer care has emerged as a critical area of focus for research, clinical practice, advocacy and service.

In support of our mission to foster greater awareness and understanding of, and support for, the psychosocial needs of people living with cancer, at every stage of their journey, the Canadian Cosmetic, Toiletry and Fragrance Association Foundation (CCTFA Foundation) has committed to a series of collaborative projects. Inspired by the experiences of our Look Good Feel Better program – an initiative that has supported over 100,000 women living with cancer to improve their self-image and emotional well-being – the CCTFA Foundation has reached out to over 800 women across Canada to learn more about their experiences living with cancer and how best to support them throughout their journey. It is our hope this report will elucidate the issues, challenges and opportunities for planning, development and delivery of care and support services for women with cancer.

Through both an online survey and face-to-face interviews, women candidly expressed their thoughts on the impact of their diagnosis and treatment on their lives and those of their loved ones. This work reinforced our fundamental understanding that a diagnosis of cancer has a significant and lifelong impact on a woman's emotional, psychological, social, spiritual and functional well-being and quality of life.

Overwhelmingly, the women told us that although cancer is a life altering event that has both positive and negative repercussions, **they are determined:**

- > Determined to be positive and optimistic
- > Determined to be actively involved in their healing
- > Determined to return “life to normal”

Survey respondents also told us that the most useful supports were those that emphasized an individualized approach and reinforced a positive outlook. The women clearly told us that they are looking for active versus passive involvement in their healing. They are determined to feel in control and empowered and want their support networks to embody and reflect this sentiment.

Getting back to normal is an important part of the healing process and a key step in a woman’s cancer journey. “Getting back to normal” carries different connotations – some women will re-evaluate their priorities, some may decide to shape a new future that includes more time with family and friends, a less stressful existence or more involvement in their community. To realize these goals, cancer survivors face additional complications that are physical (e.g. fatigue, disfigurement), emotional (e.g. anxiety, fear) and societal (e.g. misconceptions about the impact of cancer). To overcome these challenges, a network of support must be available for women who are currently undergoing treatment as well as survivors. It is especially important for women to connect to someone who understands what they are going through and the participants in our survey clearly saw a role for themselves in the sharing of their experiences and coaching others through the emotional and social hurdles they had successfully navigated throughout their journey.

This report is just one contribution to a better understanding of, and response to, the psychosocial needs of women with cancer. It illuminates both the challenges and the opportunities for health and social service providers, policy makers, researchers, cancer organizations and support service providers – anyone concerned about women and cancer – to help women living with cancer have a better experience and return to fulfilling lives.

While the voices of our participants shed light on their experiences, concerns and priorities, more research must be undertaken to understand the short and long-term psychosocial impact of cancer on the individual, the family and society. As medical and pharmacological research continues to find new treatment modalities and preventative strategies, it is our duty as a caring society to not only recognize but actively work to ensure the emotional, social and physical well-being of individuals with cancer and other life-threatening diseases.

Building on 20 years of experience with our Look Good Feel Better program and the CCTFA Foundation’s commitment to providing innovative supports to women living with cancer, we are actively engaging stakeholders in our Facing Cancer Together initiative. This multi-phased program will include an online community for women living with cancer, source new support networks, provide guidance and information and advocate on behalf of women across Canada.

As we move forward we recommend that stakeholders actively work together to **support the psychosocial needs of women living with cancer**, through the following actions:

Facilitate the dissemination and uptake of **person-centred cancer care** through broad engagement of stakeholders to provide individualized supports, targeted at health and well-being and focused on the needs identified in this report.

- > Foster collaborative partnerships to promote knowledge dissemination across sectors and industries
- > Support the Canadian Partnership Against Cancer “Cancer Journey” working group strategic initiatives

Promote vehicles that facilitate the sharing of the cancer journey experience and the supports needed to **achieve the “new normal”** among women living with cancer.

- > Identify a library of resources for women living with cancer to access and share
- > Facilitate opportunities for women newly diagnosed with cancer to communicate with cancer survivors and share their experiences and challenges
- > Support social networks and web-based sharing
- > Develop support programs that focus on nutritional, fitness and lifestyle

Develop tools and resources for **family/friend caregivers** to increase their knowledge and understanding of the psychosocial impact of cancer and to provide support for the invaluable role they play in providing a person-centred approach to cancer care.

- > Reach out to family/friend caregivers through a targeted survey to gain a better understanding of the issues and supports they need
- > Explore ways to support and implement the Canadian Caregiver Coalition’s national Caregiving Strategy that includes five key elements

Engage employers and insurers in consultations on the development of innovative strategies and **programs to assist women** living with cancer in their goal of reintegration to their former roles.

- > Leverage the work of the Canadian Breast Cancer Network “Breast Cancer: Economic Impact and Labour Force Re-entry. Canadian Breast Cancer Network” and explore best practices and other options

Support **research** into the psychosocial impacts on cancer patients to inform evidence based solutions and policy development.

- > Encourage the Canadian Institutes of Health Research — Institute of Cancer Research — to reinforce psychosocial support systems throughout their research priority areas
- > Facilitate knowledge dissemination and exchange through a variety of vehicles (social networking/print/conference/media) to maximize update and application of research





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# Introduction

Today, there are almost half a million women living with cancer in Canada, both patients and survivors.<sup>i</sup> In 2010, an estimated 83,900 more women will be newly diagnosed.<sup>ii</sup> The good news is that the cancer survival rate in Canada has doubled since the 1960s; today, 62% of people diagnosed with cancer will survive.<sup>iii</sup> This continuous improvement in survival rates has stimulated a new emphasis on understanding the 'long-term cancer journey' and challenged society to acquire a greater awareness of the needs of the whole person and the necessary supports for emotional and social needs of cancer patients, in addition to the physical ones.

It is within this context that 'person-centred cancer care' has emerged as a critical area of focus for research, clinical practice, advocacy and service. There is a growing awareness and understanding of the impact of cancer on the emotional, social and functional aspects of a person's life at every point in their cancer journey, from diagnosis through treatment and survival, or end-of-life. In fact, the Canadian Association of Psychosocial Oncology defines psychosocial oncology as "a specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs that can improve quality of life for people affected by cancer".<sup>iv</sup>

Much has happened over the past two decades to advance understanding of and support for the psychosocial needs of people living with cancer. Psychosocial oncology, dedicated to a whole-person approach to cancer care, is increasingly recognized in health care as a critical part of clinical care.<sup>v</sup> In 2004, the Canadian Strategy for Cancer Control

took the important step of recognizing emotional distress, a significant aspect of a woman's cancer experience, as the "sixth vital sign" – in addition to temperature, respiration, heart rate, blood pressure and pain – for assessing a person's health and well-being.<sup>vi</sup> Clinical practice guidelines have been developed in Canada to support assessment of psychosocial needs in adult cancer patients. The Canadian Partnership Against Cancer's<sup>vii</sup> initiatives to support survivorship and 'person-centred cancer care' are two examples of work underway to assist individuals through their cancer journey, specifically in the areas of psychological challenges and stress. Yet much remains to be done to better understand the psychosocial needs of individuals diagnosed with cancer and the necessary supports for the patient and their families through diagnosis and treatment to living with cancer, stages of recovery and to end-of-life care.

## Why this report

Over the past 20 years, the Canadian Cosmetic, Toiletry and Fragrance Association Foundation (CCTFA Foundation) has provided emotional and social support to more than 100,000 women with cancer through the Look Good Feel Better program. In that time, we have learned a great deal from women about their cancer experience, their psychosocial needs and the type of support they want during their cancer journey. The CCTFA Foundation is committed to continuing this important work and expanding our focus to foster better societal understanding of and support for psychosocial needs of women living with cancer. Our goal is to work with partners to ensure that women have the emotional and social support they need by gaining a deeper understanding of what women experience throughout their cancer journey, the specific challenges they face and how best to support them.

Based on a pan-Canadian survey of over 800 women, this report captures and conveys women's psychosocial needs and experiences throughout their cancer journey. We anticipate that this report will animate the issues and challenges and contribute to better knowledge, understanding and action to ensure that all women with cancer in Canada have access to the psychosocial support they need.

It is our hope this report will inform and inspire health and social service professionals, government policy and decision makers, and research, non-profit and private sector organizations, and others who play a role in identifying, planning, developing, delivering or funding care and support services for women with cancer.

## About The Canadian Cosmetic, Toiletry and Fragrance Foundation

The Canadian Cosmetic, Toiletry and Fragrance (CCTFA) Foundation is the charitable foundation of Canada's personal care products industry association. Our mission is to foster greater awareness and understanding of, and support for, the psychosocial needs of people living with cancer, at every stage of their journey. In 1992, the Foundation acted upon a commitment to support women with cancer by launching Look Good Feel Better. This innovative program embraces the concept that an improved self-image can help lift women's spirits and nurture hope, helping them face their illness with greater confidence. The benefits of the program go well beyond beauty. Look Good Feel Better is Canada's only cancer charity dedicated to empowering women to manage the effects that cancer and its treatment have on their appearance, and often on their morale. Since its inception, Look Good Feel Better has helped more than 100,000 Canadian women face cancer with more confidence, courage and hope.

Building on our strong history of providing innovative supports to women living with cancer, the CCTFA Foundation has expanded its commitment through the launch of a new program, Facing Cancer Together. This multi-faceted approach to supporting the psychosocial needs of women living with cancer includes a web-based virtual community *facingcancer.ca* — developed in partnership with Shoppers Drug Mart — for women, their families and their friends to connect, confide, share, learn and find support.

## About The Report

### Lives affected by cancer...

**800 women speak** is based on a March 2010 national survey of over 800 women commissioned by the Canadian Cosmetic, Toiletry and Fragrance Association Foundation. Details on the research methodology are included at the end of the report. The report is also available in PDF format at [www.cctfafoundation.ca](http://www.cctfafoundation.ca).

# Psychosocial Support – An Unmet Need

## **Women feel their needs for psychosocial support are not being met.**

Cancer affects much more than the body. A cancer diagnosis can have a significant impact on a woman's emotional, psychological, social, spiritual and functional, well-being, and her quality of life.<sup>viii</sup> Specific challenges a woman faces are the presence of debilitating fears, anxiety and fatigue, and financial pressures due to an inability to work or additional expenses related to her cancer treatment.<sup>ix</sup> These emotional, social and practical consequences, for both the patient and family, extend well beyond treatment and must be addressed as a function of daily living. While it is generally accepted that support is required to cope better, feel better and enjoy better quality of life, too many women do not have the support they need. Age and family status, income, location, culture and ethnicity can all pose barriers to accessing the emotional and social support a woman needs.

According to our survey, just over **one-half** of the respondents identified that they felt supported during their cancer journey.

## **Needs continue well beyond treatment, but women feel less supported as time goes on.**

Increased survival rates mean that more women are living well beyond the treatment and rehabilitation phases of their cancer journey and will need support as they find their way back to a 'new normal' or chart a new path in a life irrevocably changed by cancer. The psychosocial effects of a cancer diagnosis have profound impacts on a woman and her family for months and years after recovery, but for many women the availability and access to supports does not reflect this reality.

In our survey, the number of women who identified that they felt supported five years and more after their cancer diagnosis fell by almost half.

“ You can't just close the door and walk out.  
You'll never be who you were. ”

### Gaps in societal understanding of women's experiences impact access to support.

The more social, emotional and functional support women have, the better they do when they have cancer.<sup>x</sup> But societal misconceptions and assumptions, and a basic lack of understanding about the profound and lasting impact of a cancer diagnosis, can all contribute to a woman going without the support she needs to manage the challenges she faces on a daily basis. While it is difficult for someone to understand such a life-changing experience unless they have been through it themselves, this knowledge gap has a profound impact on women and the support, or lack of it, they experience during their cancer journey.

**57%** of women surveyed experienced the misconception that “if they don’t look sick, they must feel fine”. (n = 814)

**86%** of survey respondents strongly agree that cancer is a life-changing experience that they can never forget. However, more than a third of women in our study encountered society’s misconception that “life goes back to normal once they are cancer-free”. (n = 814)

“I don’t think you can imagine the feelings unless you have walked in the shoes. ”

“It really changes how a woman feels about herself on the inside, not whole anymore. ”

“People don’t understand how isolating it can be, how much emotion and fear there is at times. ”

## Psychosocial Support – An Unmet Need

### Age, culture, income and geography can also pose barriers to accessing support.

During the “*Rebalancing the Delivery of Cancer Care*” workshops<sup>xi</sup> held in May 2008, participants expressed concern about appropriateness and access to support and services for marginalized social groups. These included but were not limited to: culturally appropriate services for minority groups, language barriers, age-appropriate services, access and culturally appropriate resources for aboriginals and geographically challenging areas. Our survey also identified income as a factor in accessing support,

Less than half, **48%** (n = 584) of the women surveyed with a household income under \$75,000 identified that they felt supported.

Compared to **63%** (n = 230) of those with a household income over \$75,000.

### Some women find it difficult to ask for support.

Society’s understanding of cancer has increased over the past decade, but the stigma of cancer endures. Our survey participants shared their feelings that “*having cancer acts as a barrier to making positive and meaningful connections with people around them*” and that they often feel “*isolated and disconnected*”. These feelings of isolation and seclusion may impact a woman’s ability to seek out and ask for the support they need. Fear of being treated differently because of their cancer can stop women from asking for the help they need; one study found that 59% kept information about their cancer closely guarded to avoid being treated differently.<sup>xii</sup> In addition to social isolation, women in our survey reported that they have difficulty seeking support because they do not want to be a burden or worry to others.

Of the **242 women** who said they found it difficult to ask for support, financial support (30%) and emotional support (19%) were the top two types of support they needed but found difficult to request.

**One-quarter** of survey respondents had experienced a societal misconception that if a woman with cancer needed help, she would ask for it. (n = 814)

“ I feel pressure to act as though I am feeling positive when often I just don’t. ”

# The Importance of Psychosocial Support

Research confirms the importance of social and emotional support for individuals who have experienced serious illnesses, including cancer. Cancer patients and their families who have access to psychosocial support to manage stress, depression, loss of control, anger, sadness, isolation etc. experience improved quality of life.<sup>xiii</sup> Among women with breast cancer, emotional support delivers psychosocial benefits, including better adjustment to cancer and fewer symptoms of psychological distress.<sup>xiv</sup> The participants in our survey confirmed this.

## A network of support has a positive impact.

The women in our survey who reported having access to a network of support said they felt more optimistic and determined about their cancer experience and themselves. They were more likely to feel that cancer has had a positive impact in their lives, and that they were doing better at meeting their own self-expectations.

**37%** of women surveyed who accessed a network of support through 10 or more sources said that cancer had positively changed who they are; only 19% of women who had one or two support resources responded in kind. (n = 814)

Of the **300 women** who had large networks (10 or more supports) only 10% said they were not meeting their self-expectations. For the 154 women who said they had limited networks (one or two supports), 26% told us they were not meeting their self-expectations.

## Women look to their family and friends for support.

Support networks can be comprised of various types of individuals/groups who provide a wide range of assistance for women living with cancer. These sources can include friends, family, healthcare professionals, colleagues, organized workshops and support groups, internet sites, spiritual counselors/leaders and employee assistance programs. Our survey showed that women accessed a wide range of supports for their emotional, social and physical needs.

**77%** of women surveyed turned to family for support followed by their friends (74%). (n = 814)

Participants indicated they accessed their oncologist (59%), family doctor (58%) and nurse (24%) for support with fewer accessing a mental health professional such as psychotherapist (16%) or social worker (14%). (n = 814)

## The Importance of Psychosocial Support

**73%** of respondents accessed the internet and cancer related websites for support, **48%** obtained information through books and only **15%** accessed a support group. (n = 814)

“ Be there. Don't say let me know if I can help, but reach out and do something – cook a meal or clean the house, or get groceries. ”

### Lifestyle and psychosocial supports are very important.

According to Michael Zevon, PhD, Chair of Psychosocial Oncology at the National Comprehensive Cancer Network, cancer patients experience “waves of impact” as they deal with an onslaught of concerns about their health, finances, employment and family responsibilities. When treatment results in a visible change to their bodies—as often occurs with breast cancer diagnosis—women experience an additional wave of impact around feelings of sexuality and attractiveness. Given this ‘wave of impact’ it is not surprising that the women in our survey identified a wide range of much-needed supports.

Nutrition, fitness and lifestyle were the most strongly needed types of support, with **37%** of respondents indicating these to be the “type of support they need most”. (n = 814)

Emotional and psychological supports also identified as very important with **36%** of women indicating they wanted “everyone around me to help me continue living as normally as possible” and **34%** needing “support of the ‘whole me’ not just my cancer”. (n = 814)

Social acceptance and companionship were identified as supports needed, **24%** of women said they wanted “emotional support” and **27%** desire “someone in whom I can confide”. (n = 814)

“ I wanted people to look at me in a positive way. Not ‘poor you.’ I loved people who would laugh. ”

“ The first thing I did was go out a buy Lance Armstrong's book and a spinning bike. ”



### Supports vary in their usefulness.

Given the diverse impact of cancer with its 'waves of impact', and the unique journey each woman and her family experience, not all resources were equally useful. The women we interviewed had accessed a wide variety of resources and those deemed most helpful were the ones that rose above being clinical and delivered on two key needs: "a positive outlook" and "personalized support".

### Family caregivers provide the most useful support.

According to our survey respondents, friends and family are not only the most accessed support, but also the most useful. Often referred to as a "family caregiver"<sup>1</sup>, their emotional support, understanding and compassion enable a woman living with cancer to do so with dignity and participate more fully in society. The women in our survey identified traits they valued in family caregivers, including "positive and supportive", "good listeners", "offer help" and "provide love – even when not asked". It is not surprising given the high needs for emotional and social support that family, friends and spouses/partners are a critical part of their support network.

“ Love them, support them and let them know how important they are to you. That cancer hasn't changed who they are to you. ”

— Advice from a woman living with cancer to a family caregiver.

### The healthcare team provides information relevant to their treatment.

The healthcare team is comprised of a number of professionals who work collaboratively to provide quality care and support the cancer patient through their diagnosis and treatment. Members of the team often include the oncologist, nurse, and family physician. The goal of the healthcare team is to provide person-centred care which emphasizes the overall well-being of the cancer patient – including attention to psychological, social, spiritual, informational, practical, physical and emotional needs – rather than focusing solely on treating the tumour or the disease site.<sup>xv</sup> This concept is still relatively new to the healthcare field as evidenced by the survey respondents' comments on dealing with their healthcare team:

**73%** of women surveyed felt that the doctors they dealt with gave them the information they needed to make the right treatment decision. (n = 814)

In terms of emotional support, nurses rated higher with **64%** of respondents rating them favorably compared with 52% for doctors. (n = 407)

**A key challenge identified by the women we surveyed, when dealing with both doctors and nurses was the need for addressing the "whole person" (their emotions, personal values and realities) rather than only considering the medical facts.**

<sup>1</sup> "Family caregivers" provide care and assistance for spouses, children, parents and other extended family members and friends who are in need of support because of age, disabling medical conditions, chronic injury, long-term illness or disability.

## The Importance of Psychosocial Support

“ I told my oncologist, radiologist, etc that I want to get all of you in one room and talk to ME and ME. I had to assimilate it myself. ”

“ My oncologist went through all the statistics and then closed the book and said: ‘Tell me who you are’. From there he could deduce my fears, concern, anxieties. It wasn’t clinical anymore. ”

### **Mental health professionals are not frequently accessed for support.**

The stigma of mental health in our society often poses a barrier to seeking support and counseling. According to research, “many [cancer] patients who report high levels of distress are not taking advantage of available psychosocial professionals”.<sup>xvi</sup> This attitude was reflected in our data as only 16% women surveyed indicated they had accessed a psychologist, a psychiatrist or therapist-type person for support and only 9% found the experience to be among the most useful.

### **Group environments are one method of accessing necessary supports.**

The findings of a 2007 study in which cancer support groups were reviewed revealed that participants preferred activity-based interaction over passive activities such as group discussion.<sup>xvii</sup> The women who participated in our survey told us that support groups that are effective are ones that provide positive reinforcement and personalized support. One example is Wellspring, a Canadian network of community-based centres that provide support, education and coping skills to cancer patients and their families. They provide a range of customized services including group support, one-on-one programs, child care, transportation and bereavement counselling.

**only 16%** of the 814 women surveyed identified accessing a support group as one of their resource networks and only 7% indicated that it was a useful support.

“ At [support group] we were not talking about misery. We were sharing the good stories. I walked out of there and I felt human again. It taught me to get up, do things and act like it is a normal day. I knew that this is how I want my treatment plan to go. ”

### **The internet is valuable for information and practical tips.**

Canada ranks as the 12th country in the world for Internet usage with 28.0 million users, 84% of the total population. 54% of Canadians connect to the Internet using a type of high-speed connection, and 48% of Internet users connect at least three times per day.<sup>xviii</sup> Of our survey population, 594 (73%) said they used the internet as a support tool for the cancer journey.

**86%** of women who have turned to the internet for support in their cancer journey are using it for accessing medical information. (n = 594)

**49%** of women who have turned to the internet for support indicated they used the internet for life information and/or practical tips on living with cancer. (n = 594)

**21%** of women said the internet was one of the most helpful support resources, which may be a reflection on the progression of the technology and the recent inclusion of online social networks that allow for sharing of experiences. (n = 594)

The five internet sites considered most useful by our respondents were:

1. Canadian Cancer Society ([www.cancer.ca](http://www.cancer.ca))
2. Canadian Breast Cancer Foundation ([www.cbfc.org](http://www.cbfc.org))
3. Cancer.com ([www.cancer.com](http://www.cancer.com))
4. Health Canada ([www.hc-sc.gc.ca](http://www.hc-sc.gc.ca))
5. Look Good Feel Better ([www.lgfb.ca](http://www.lgfb.ca))

# The Profound and Lifelong Impact of Cancer

A cancer diagnosis has profound impact on the emotional, social and physical well-being of patients and families throughout the continuum from diagnosis, treatment, recurrent disease, palliative care and survivorship. The participants in our survey reinforced this reality and shared their experiences and challenges with us.

**86%** of women surveyed said that cancer is a life-changing experience they can never forget and 42% said that life never goes back to normal. (n = 814)

“ There is life pre-cancer and life post-cancer. ”

## Fatigue affects every aspect of daily life.

For many women, fatigue is constant, and has lingering effects for months and sometimes years. Fatigue can be mental as well as physical, which can make returning to work and meeting other responsibilities difficult—for some women, impossible.<sup>xix</sup> A study of cancer patients found that 78% reported fatigue as the most common cancer-related symptom, as well as the most severe. The study also revealed that 71% of patients said that it interfered with their ability to function, with the greatest impact on their ability to work.<sup>xx</sup>

**40%** of women surveyed ranked fatigue as their top concern. (n = 814)

“ I just don't know how to function the way that I did. ”

## Cancer brings new fears and anxieties.

At many different times during the cancer journey, women may be fearful and anxious. Numerous events can cause fear including the initial cancer diagnosis, the reoccurrence of cancer, fear of treatment and its lasting effects, being a burden on family, not being able to return to work or dying. All these fears impact the health and wellness of women who are already coping with a traumatic disease.

**70%** of women surveyed feared recurrence of their cancer most. (n = 814)

**40%** of cancer survivors live in constant fear that their cancer will recur. (n = 523)

**45%** of women who currently have cancer identified fears about the future, personal finances (37%) and being a burden on others (35%). (n = 291)

The long-term effect of cancer treatment was a fear shared by both women who currently have as well as those who have had cancer.

#### Changes in appearance affect emotional well-being.

Temporary and permanent physical changes—hair loss, weight gain, removal of a breast or reproductive organs, disfiguring surgery and scarring—have a huge impact on a woman. In a study on the effects of cancer on quality of life and appearance, 84% of women were concerned by the changes to their appearance after treatment, and 83% felt the changes had an impact on their quality of life in the areas of emotional, spiritual and psychological well-being, sexuality and appearance, social interactions and their profession.<sup>xxi</sup>

In our survey population, **17%** of women were concerned about a physical disfigurement and ranked this fear in the top 20. (n = 814)

“ I always look tired and sick now, no matter what I do. ”

“ I need support accepting that I’m going to look this way for the rest of my life, and somehow be OK with my disfigurement. ”

#### Sexuality is impacted by both physical and psychosocial effects of cancer.

Sexuality is a complex characteristic that involves the physical, psychological, interpersonal, and behavioural aspects of a person. A diagnosis of cancer impacts all these. Physical impacts include loss of function due to the effects of cancer therapies, fatigue and pain. Unlike the physical side effects of cancer treatment, sexual problems are also caused by the psychosocial impact of cancer including depression, changes in body image after surgery, and stress. These lasting effects may not resolve within the first year or two of cancer-free survival, but can linger for years and potentially interfere with a woman’s desire to return to a normal life. Sexual dysfunction affects up to 90% of women treated for breast cancer.<sup>xxii</sup> In a study of the impact of cancer on sexuality and intimacy, 79% of spouses and partners of women with cancer said that sex and intimacy either lessened or stopped altogether. The study also noted that changes to sexuality were associated with self-blame, rejection, sadness, anger and lack of sexual fulfillment for both partners.<sup>xxiii</sup>

## The Profound and Lifelong Impact of Cancer

According to our survey, sexual attractiveness and fear of intimacy were less of a concern among women who have had cancer in the past (13%, n = 523) than it was for those who currently have it (19%, n = 291), and are of highest concern among women with breast cancer (20%).

“ With breast cancer I lost a breast – my sexuality and femininity was affected. My mastectomy has negatively affected my sexual relationship with my husband. ”

“ My disfigurement and inability to look sexy are permanent. ”

### Financial challenges cause stress and anxiety.

Having a diagnosis of cancer can have a negative financial impact. Although the majority of treatment and medical costs are covered by Medicare, there are unexpected expenses such as the cost of transportation to and from treatment, over-the-counter medications, child care, home care, and medical devices or supplies. Depending upon the provincial health plan, these costs may not be covered by health insurance and must be paid out of pocket. Individuals with cancer also experience the challenge of daily living expenses (food, housing, etc.) if the individual or caregiver needs to stop working. A 2010 national study of women with breast cancer revealed that 80% of women experienced financial impact because of their cancer, with an average drop of just under \$12,000 in annual household income. According to the study, more than one-quarter of women took on debt to manage during their illness and treatment, 44% used their savings and 20% had to leave their jobs due to the effects of cancer on their ability to work. The study also identified that 69% of women suffer stress and anxiety due to the financial burden of cancer, and 40% feel that the financial consequences of cancer have had or will have a long-term effect on their health.<sup>xxiv</sup>

Among the women we surveyed **one-third** indicated that personal finances were a concern for them. (n = 814)

**22%** rated financial support as one of their top support needs during their cancer journey, for both women undergoing active treatment and survivors. (n = 814)

“ I have to travel over 500 miles to get my radiation treatments and I’m almost at the point that I can’t afford it. ”

# A Life Changing Experience... Getting Back to “Normal”

Overwhelmingly, the women we surveyed told us that although cancer is a life changing event that they can never forget, they have experienced a strong desire to focus on a positive outlook for life and living and a need to return life to “normal”. Throughout the survey and interviews, our participants expressed their candid thoughts on how cancer has changed their lives, their priorities and aspirations, the challenges they face in achieving a new normal and the unique experience of returning to work.

**54%** of women surveyed said that cancer had both a positive and negative effect of them. (n = 814)

The positive impacts of cancer were **“appreciate life more”** (42%) and **“cherish/have closer relationships with family”** (24%) and that a cancer **“changed their life/routine/priorities”** (20%). (n = 439)

Among those women who have felt that cancer has had a negative effect, the top two negative impacts were **“a fear that the cancer might come back”** (19%) and **“anger”** (18%). (n = 439)

“ I am more aware now of how I go through things.  
I’m more of a positive person. I am not going to get stuck. I move on. ”

“ Learned to accept what cannot be changed.  
Live each day to the fullest; and one day at a time! ”

## A Life Changing Experience ... Getting Back to “Normal”

### Living each day the way they always have.

A diagnosis of cancer brings life altering changes—physically, emotionally and socially — and life for a woman with cancer can never go back to “normal”. Given this reality, over 700 women in our survey told us that when they were diagnosed with cancer they wanted to “keep moving forward”. To support this optimistic outlook and desire to look to the future, 82 % (667 women) told us they “don’t want to be treated differently because of their cancer”.

**Over 63%** of respondents said they wanted to achieve a “normal” life with key priorities including “maintaining independence” , “not looking sick” and “not being a burden on their family” and “finding a balance in life”. (n = 814)

**59%** of women strongly agreed with the statement “I just want to feel human again”. (n = 814)

“ It was time to get busy living or get busy dying.  
I am going to hurt if I do nothing and I am going to hurt if I do something,  
so I chose the latter. ”

### Getting ‘back to normal’ shaping a new future

Getting back to normal can mean many things to different individuals; some women will re-evaluate their priorities, some may decide to shape a new future that includes more time with family and friends, a less stressful existence or more involvement in their community. However it is defined, getting back to normal is an important part of the healing process and a key step in a woman’s cancer journey. The majority of women who participated in our survey clearly expressed this goal as one of their top priorities, but also shared the challenges and barriers they face in attaining it. Although this goal is a reasonable one, cancer survivors face additional complications that are physical (e.g. fatigue, disfigurement), emotional (e.g. anxiety, fear) and societal (misconceptions about the impact of cancer). To overcome these challenges, a network of support must be available for women who are currently undergoing treatment as well as survivors. Unfortunately, our respondents told us this was not the case.

Almost half of the women surveyed, **45%** told us they were not able to “get comfortable with the new normal”. (n = 814)

**56%** of respondents (both single and married) indicated a challenge with resuming intimate or sexual relationships. (n = 814)



“ When you come out of treatment you are not really ready to reintegrate...emotionally, physically. ”

“ I need emotional support dealing with the new normal of my life. ”

### **The transition of returning to work.**

Returning to or maintaining a workplace attachment for a woman living with cancer has both emotional and practical implications. Keeping a job and workplace relationships can provide supportive encouragement and a sense of normalcy for a woman undergoing active treatment/rehabilitation. For survivors returning to work, this can mark the transition from being a patient to re-entering normal life, and result in a restored sense of identity and social interaction. For both the cancer patient and survivor, employment brings practical financial benefits that are often necessary for health and well-being.

Numerous studies have explored the challenges of returning to work for women living with cancer. A 2002 US study identified 38% of women felt that their treatment experience had a negative impact on their work life, leaving them less productive than before and unable to maintain their workload. A number of participants in the study also felt that they were treated differently by their boss or co-workers, and that their career opportunities were diminished.<sup>xxv</sup> A 2009 study of Canadian women with breast cancer revealed that 45% of them found they had a reduced ability to work: 19% reported the effects of chemotherapy caused difficulty in doing their job. The report also showed that 43% of women reported that their employer made arrangements to accommodate their needs, and 20% said that a gradual return to work made the transition easier.<sup>xxvi</sup> The participants in our qualitative focus groups reinforced these findings and shared their challenges with poignant stories:

- One participant pushed herself in her career to maintain the image that she upheld in her own mind and in the minds of her colleagues: “I keep working throughout my treatment. Why shouldn't I?”
- One woman brought her “all clear” reports to her boss when she returned to work as she knew they wondered if she would ever be normal again.

“ I need support on how to transition back into work life successfully. ”

# What Women Say They Need

The women in our survey identified many things that are important to them through their cancer journey: moving on, maintaining a positive and optimistic attitude, finding a new path and balance and not being treated differently because of cancer. They clearly told us that they are looking for active versus passive involvement in their healing. They are determined to feel in control and empowered and want their support networks to embody and reflect this sentiment.

## **Women living with cancer need to be recognized as a whole person.**

For each woman living with cancer, their journey is unique. Instead of being treated as a “malignant tumour” or “cancer statistic”, women want to be recognized and treated as a whole person—physical, mental, emotional and spiritual—and have access to care and support that address their psychological and social as well as physical needs.

**50%** of women surveyed strongly agreed with the statement “I need someone who can help heal the whole me (mind, body and spirit), not just my cancer.” (n = 814)

**44%** strongly agreed with the statement “I wish I could have a person—not statistics—to help me make treatment decisions.” (n = 814)

**38%** agreed that “There needs to be more flexibility in treatment plans to better align treatment with individual priorities.” (n = 814)

“ We need a place or service focused on ‘How can I help you get through this?’. Healthcare only cares about their little piece of me: my cancer. But who is looking after me, the whole person? ”

“ [The doctors] were trying to get me to a baseline where everybody else was and I was working to goals way above that. ”

Considerable advances in our understanding and recognition of patients as “whole” have been made over the past decade with the introduction of patient-centred care and client-centred care models. The Canadian Partnership Against Cancer is currently working with a diverse group of stakeholders to advance the concept of person-centred care that “recognizes that these needs—informational, emotional, spiritual, practical, psychological, physical, and social—are as important as the individual’s illness, and are in fact central to the health and well-being of the whole person and their family.” The person-centred care concept considers an individual’s needs “within the social context in which they live and including their persona and familial relationships to shape access to resources, support and information”.<sup>xxvii</sup>

### **Women living with cancer need opportunities to share their experience and positively impact others.**

According to the US National Survey of Health and Well-being, cancer survivors show resilience in the areas of social relationships, spirituality and personal growth.<sup>xxviii</sup> Our survey participants consistently reinforced that the experience of cancer can have both positive and negative impacts. Our respondents shared how the bonds and relationships with their family and friends grew stronger and how they found internal strength and determination. Conversely they shared their fears, concerns and challenges in a candid and open manner.

**24%** of women surveyed reported closer relationships with their family. (n = 814)

Despite the challenges of their cancer experience, **85%** said that all things considered, cancer has had a positive or at least a positive and negative effect on them. (n = 814)

**87%** said they had made positive changes to their lifestyle including: eating healthier, reducing stress and exercising more. (n = 814)

“ My relationship with my daughter is even closer than before cancer. ”

## What Women Say They Need

“ Everyone’s journey is specific and individual but it is all about how you cope with what you’re given. ”

The journey of a cancer patient is unprecedented. There is no road map or directions, but there are networks of support and caring on which women living with cancer can rely. It is especially important for women to connect to someone who understands what they are going through: a third of women (n = 404) in the US “Quality of Life and Appearance” study said that talking with other cancer patients is very important to coping.<sup>xxix</sup> Throughout the literature reviewed for this report, the need for women to connect, talk and have access to peer support was consistently reinforced. The women in our survey clearly saw a role for themselves in the sharing of their experiences and coaching others through the emotional and social hurdles they had successfully navigated throughout their journey.

**One-third** of women surveyed said that having a positive impact on the people around them was a top priority. (n = 814)

**18%** said the same about making a positive contribution in their community. (n = 814)

“ I preach it to everyone now. You just have to start living. ”

“ [Cancer] made me stronger mentally, made me a more positive person and to be an inspiration to people. ”

### Women living with cancer need support for their family as well as for themselves.

Women are often the primary caregiver for their immediate and extended family and the impact of cancer can have broad ranging effects on the family unit. The women who participated in our survey identified family as the number one source of support for themselves and consistently shared their concerns about “being a burden on their loved ones” and “being a worry to them”. Family/friends play a crucial role in ensuring physical and emotional well-being of a woman living with cancer and provide a wide range of supports on a daily basis. These supports may include: providing emotional support and someone to confide in, listening without judgment, taking on the household chores, sourcing information, offering physical aide or just being there for love and hugs.

**Over one-quarter** of the women surveyed expressed a need for family and friends to stay positive and optimistic. (n = 814)

“Not being a burden on their family” was identified as one of the top 10 needs of women through their cancer journey.

**26%** of participants with immediate families told us they want to be able to care for their family. (n = 171)

“ As a mother, I am the main caregiver of my family. When I’m not able to care for them, everyone suffers. ”

“ The woman is generally the caregiver and generally runs the household. Those responsibilities don’t go away just because she has cancer. ”

“ My family members cook meals and clean the house for me. They make me laugh and give me lots of love. ”

Family/friend caregivers embrace their role in supporting their loved one, even though that role can be lengthy. However, there are consequences to caring and many family and friends have experienced firsthand the financial, emotional, physical and mental burden that accompanies caregiving, especially when balancing care responsibilities with paid employment. Supports often do not include the family/friend caregiver or do not provide for their unique needs. The women in our survey clearly expressed concern about the health and well-being of family/friends and identified a desire for targeted supports to address the family caregivers’ needs.

# The Way Forward

It is clear from the research and the opinions and thoughts expressed by the 814 women who participated in our survey that while they are determined to face their cancer diagnosis head on, they need emotional and social support to achieve their goals. Unfortunately, access to these psychosocial supports is often limited or non-existent. This deficit is not only evident with women undergoing treatment and recovery, but also in the stages of survivorship and/or end of life.

We heard that greater priority must be placed on treating the whole person and facilitating access to psychosocial support networks and reaching out to marginalized populations. Increased emphasis must be placed on individualization and empowerment as each woman's cancer journey is unique and the support networks they access and leverage reflect this distinctiveness. Family caregivers—family and friends who play such a crucial role in providing emotional, physical and social support—must be recognized and have access to user-friendly information and other supports to sustain their role. While the voices of our participants shed light on their experiences, concerns and priorities, more research must be undertaken to understand the short- and long-term psychosocial impact of cancer on the individual, the family and society. As medical and pharmacological research continues to find new treatment modalities and preventative strategies, it is our duty as a caring society to not only recognize but actively work to ensure the emotional, social and physical well-being of individuals with cancer and other life threatening diseases.

This report is just one contribution to a better understanding of, and response to, the psychosocial needs of women during their cancer journey. It illuminates both the challenges and opportunities for health and social service providers, policy makers, researchers, cancer organizations and support service providers—anyone concerned about women and cancer—to help them have a better experience and return to fulfilling lives.

As part of the Canadian Cosmetic, Toiletry and Fragrance Association (CCTFA) Foundation's commitment to providing innovative supports to women living with cancer, we will actively engage stakeholders in our *Facing Cancer Together* initiative. This multi-phased program will not only include a virtual community for women living with cancer, but will source new support networks, provide guidance and information and advocate on behalf of women across Canada. As a first step in our journey to support women living with cancer with their psychosocial needs, we propose the following recommendations.

Facilitate the dissemination and uptake of **person-centred cancer care** through broad engagement of stakeholders to provide individualized supports, targeted at health and well-being and focused on the needs identified in this report.

- > Foster collaborative partners to promote knowledge dissemination across sectors and industry
- > Support the Canadian Partnership Against Cancer's "Cancer Journey" working group strategic initiatives

Promote vehicles that facilitate the sharing of the cancer journey experience and the supports needed to **achieve the “new normal”** among women living with cancer.

- > Identify a library of resources for women living with cancer to access and share
- > Facilitate opportunities for women newly diagnosed with cancer to communicate with cancer survivors and share their experiences and challenges
- > Support social networks and web-based sharing
- > Develop support programs that focus on nutritional, fitness and lifestyle

Develop tools and resources for **family/friend caregivers** to increase their knowledge and understanding of the psychosocial impact of cancer and to provide support for the invaluable role they play in providing a person-centred approach to cancer care.

- > Reach out to family / friend caregivers through a targeted survey to gain a better understanding of the issues and supports they need
- > Explore ways to support and implement the Canadian Caregiver Coalition’s national Caregiving Strategy that includes five key elements:
  - Safeguarding the health and well-being of family caregivers and increasing the flexibility and availability of respite care
  - Minimizing excessive financial burden placed on family caregivers
  - Enabling access to user friendly information and education
  - Creating flexible workplace environments that respect caregiving obligations
  - Investing in research on family caregiving as a foundation for evidence-informed decision making

Engage employers and insurers in consultations on the development of innovative strategies and programs to **assist women living with cancer** in their goal of reintegration to their former roles.

- > Leverage the work of the Canadian Breast Cancer Network “Breast Cancer: Economic Impact and Labour Force Re-entry. Canadian Breast Cancer Network” and explore best practices and other options

Support **research** into the psychosocial impacts on cancer patients to inform evidence based solutions and policy development.

- > Encourage the — Institute of Cancer Research — to reinforce psychosocial support systems throughout their research priority areas
- > Facilitate knowledge dissemination and exchange through a variety of vehicles (social networking/ print/conference/media) to maximize update and application of research

# Research Methodology

The CCFTA Foundation commissioned Strategic Navigator to conduct a study of Canadian women with the goals of gaining insight into their psychosocial needs and experiences while living with cancer. The study featured qualitative in-depth interviews which then informed the development of a quantitative survey instrument. The primary purpose of the in-depth interviews was to develop a depth of understanding about the connections between a woman's cancer, the many facets of her life and her emotional, spiritual and physical state. The interviews were 90 minutes in length, and were conducted in person in environments chosen by respondents to provide comfort and familiarity. The quantitative component included a national online survey (in English and French) that resulted in responses from 814 women, ranging in ages from 18 to 69, who currently have or have had cancer. Fieldwork was conducted in January and February 2010. A literature review was conducted as background for this report.

## **Note on reading the tables**

Figures may not add up to 100% due to acceptance of multiple answers or the response "don't know/refused".

## **Definition of psychosocial**

Throughout this work, the team used the definition of psychosocial as defined by the Canadian Association of Psychosocial Oncology "*the social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer, from prevention through bereavement*".



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