FLORENCE AND JOSEPH APPLEMAN EDUCATIONAL BOOKLET SERIES

Facing Ovarian Cancer as a Jewish Woman





The publication of this booklet was made possible with generous support from

The Gorlin Family Foundation

The Stephanie Sussman and Ann Nadrich Memorial Fund



Facing Ovarian Cancer as a Jewish Woman

TABLE OF CONTENTS

Get to Know Sharsheret
You Are Not Alone
Ovarian Cancer Genetics
Privacy and Confidentiality
Community Support7
Being Single9
Relationships and Marriage10
Fertility and Pregnancy11
Parenting
Spirituality and Well-Being
Prayer and Meditation14
Celebrating Holidays15
Working During Treatment
Using the Ritual Bath17
Holistic, Complementary, and Integrative Medicine
Survivorship19
How Can Sharsheret Help Me?
Resource Directory

GET TO KNOW SHARSHERET

Sharsheret supports young Jewish women and families facing breast cancer and ovarian cancer at every stage—before, during, and after diagnosis.

Our name, Sharsheret, means "chain" in Hebrew and represents the strong, nurturing connections we build to support Jewish women and their families at every stage of breast cancer and ovarian cancer. We help women and families connect to our community in the way that feels most comfortable, taking into consideration their stage of life, diagnosis, or treatment, as well as their connection to Judaism. We also provide educational resources and create programs for women and families to improve their quality of life. We understand that young Jewish women have unique concerns when it comes to breast cancer and ovarian cancer, and we are the only organization that specializes in serving them. Our programs are easy to access. From Boston to Burbank, Milwaukee to Miami, Sharsheret is wherever you are.

Sharsheret is a growing community of women and families. Together, we are creating a chain of strong links that reaches across the country so that no woman or family of Jewish descent needs to face the challenges of breast cancer or ovarian cancer alone.

Visit **www.sharsheret.org** or call us at **866.474.2774** to participate in our programs and to become a link in the Sharsheret chain. All inquiries are confidential and answered by qualified staff who can help.

OUR PROGRAMS

The Link Program®

- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer or ovarian caner one-on-one with others who share similar diagnoses and experiences
- The Margot Rosenberg Pulitzer and Sheri Rosenberg Kanter Embrace[™] Program, supporting women living with advanced breast cancer or recurrent ovarian cancer
- Genetics for Life[®], addressing hereditary breast cancer and ovarian caner
- Busy Box[®], for parents facing breast cancer or ovarian cancer while raising children or teens
- The Bella Chachky Diamond and Sylvia Diamond Geller Best Face Forward[®] Program, addressing the cosmetic side effects of treatment

- Best Face Forward 2.0, providing services and financial subsidies to enhance women's quality of life
- The Florence and Laurence Spungen Family Foundation Family Focus[®]
 Program, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer
- Sharsheret Supports[™], developing local support groups and programs
- Thriving Again[®], providing individualized support, education, and survivorship navigation for young breast and ovarian cancer survivors

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women and Jewish women facing breast cancer and ovarian cancer
- Sharsheret on Campus[™], outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally relevant publications for Jewish women, their families, and health care professionals

YOU ARE NOT ALONE

A diagnosis of ovarian cancer can be overwhelming for any woman. For women of Jewish heritage, its grip may extend to family, community, dating, fertility, marriage, parenting, and religious or cultural life. Though you may confront many of the same issues as other women facing ovarian cancer, it can feel like a lonely journey.

You are not alone. Thousands of young Jewish women are living with ovarian cancer today — juggling medical appointments as they struggle with concerns about ovarian cancer genetics, cope with the impact of an ovarian cancer diagnosis on their careers and family planning options, or prepare spiritually and physically for the holidays. Their experiences are reflected in these pages.

This booklet raises awareness about issues many Jewish women may face in light of an ovarian cancer diagnosis and the resources available to help address those concerns. These pages highlight some of the difficulties shared by women who have called Sharsheret for information and support, whether they are at risk or have been diagnosed with hereditary or sporadic ovarian cancer. You may identify with some of the issues addressed in this guide, while others may not be relevant to you. Whatever they may be, your questions and concerns are likely shared by others in Sharsheret's community.

Sometimes we need information and support beyond what family and friends can provide. The Resource Directory in this booklet will help you identify many Jewish organizations and cancer organizations that are available to you as well as to your family and friends. This booklet is not intended to provide comprehensive medical information, but many of the ovarian cancer organizations listed in the Resource Directory can help you locate information you may need over time. The Resource Directory is organized by subject so that you can easily access the organizations that will be most useful in addressing your particular needs.

Your own questions and concerns are likely shared by others in Sharsheret's community.

Be assured that regardless of where you are in your journey through ovarian cancer, Sharsheret is here to support you, your family, and friends.

OVARIAN CANCER GENETICS

"When I was diagnosed with ovarian cancer, I also tested positive for a BRCA mutation. I wondered about its impact on my treatment plan and if my teenage daughters were also at risk. I wondered when and how I should discuss genetics with them. With the information I gathered from a genetic counselor, I began to make important decisions with my family." — Ruth

Like Ruth, many women of Jewish descent contact Sharsheret with concerns about a history of ovarian cancer or breast cancer in their family. No study to date has shown that ovarian cancer is more common in women of Jewish descent than in the population at large. However, more Jewish women carry genetic alterations that may increase their likelihood of developing ovarian cancer or breast cancer.

Specifically, 1 in 40 individuals of Ashkenazi (Central and Eastern European) Jewish descent, compared to 1 in 345 individuals in the general population, carries an alteration in the BRCA1 or BRCA2 genes. These alterations can be passed on through either parent to the next generation. Scientists are also studying the hereditary nature of ovarian cancer and breast cancer in families of Sephardic (Spanish, Portuguese, and North African) Jewish descent. While not all women who carry an altered gene will develop ovarian cancer or breast cancer, recent studies suggest that the risk that someone who carries an altered gene will develop ovarian caner over her lifetime may be as high as 46% and for developing breast cancer as high as 85%.

In addition, women who have ovarian cancer that is

related to a BRCA1 or BRCA2 gene mutation may experience improved survival and responsiveness to platinum chemotherapy and novel therapeutics. In addition to the BRCA gene there are a variety of additional mutations such as CHEK2, PALB2, CDH1, ATM, PTEN, TP53, and genes associated with Lynch Syndrome (hereditary colon, endometrial, and ovarian cancer) that predispose an individual to breast, colon ovarian, pancreatic, prostate cancer, and melanoma. Individuals of Ashkenzai descent with breast and ovarian cancer, and individuals with a family history of these cancer, may want to consider genetic counseling and testing.

A certified genetic counselor and your health care professional can help you understand your family history and its impact, if any, on your surgery and treatment decisions. Knowing your genetic status can make a difference in you and your family's lives, both by prevention and through therapy of associated cancers. Sharsheret's certified genetic counselor is available to answer your general questions about hereditary ovarian cancer so you can determine if in-depth genetic counseling or testing is right for you.

PRIVACY AND CONFIDENTIALITY

"I come from a background where illness is kept quiet. The moment I learned I had ovarian cancer, I found myself watching for 'knowing glances' and other signs that people knew that I was going through treatment. Being able to connect with other people about my diagnosis without being public was extremely important for my morale." — Debbie

Living in a close-knit community can be a wonderful source of support for those facing illness. For some women though, ovarian cancer is an experience they would prefer to approach privately. Others are concerned about the impact of a cancer diagnosis on their place in the community – their own marriage prospects or those of their children. For you, privacy and confidentiality may be a critical component of support. At the same time, you may recognize the benefits of connecting with family members, friends, and others who have shared a similar experience.

There are ovarian cancer organizations and Jewish organizations that offer resources and support with the degree of confidentiality you require, including Sharsheret. If you, like Debbie, are concerned about confidentiality, consider asking the organizations you contact to specify the ways in which they can accommodate your privacy needs. Some organizations will offer to mail materials to you in plain white envelopes. Others will allow you to use your first name only or a name of your choice, and will not identify your phone number through caller ID. You can also request that staff calling from organizations use discretion when leaving a message with another person or on voicemail.

Privacy and confidentiality may be a critical component of support for you.

At Sharsheret, we are sensitive to the concerns of those who contact us to receive or offer their support, and we are committed to accommodating your requests for confidentiality. If you prefer not to receive Sharsheret labeled envelopes in the mail, we will arrange to ship materials to you in plain white envelopes. If you prefer not to share your name or to speak with other women who live in your own neighborhood, we will respect these requests as well. We can also help you find a balance in your life between the need for confidentiality and the need for community support. We want you to feel free to share with us any other privacy concerns that you might have.

COMMUNITY SUPPORT

"An integral part of being Jewish is being part of a community. I have never before seen the importance of this aspect of Judaism as much as I have throughout my cancer journey. Knowing that I am a part of a community that cares and being able to share my triumphs and challenges with others around me has been incredibly healing and comforting throughout my experience." — Rebecca

As women, many of us experience difficulty asking for assistance and support when we need it. We tend to think of ourselves as the ones who take care of others. As part of a community that values making the world a better place (*tikun olam*) and giving to others (*tzedakah*), asking for help or accepting assistance can often be difficult for a Jewish woman facing ovarian cancer. Some of the women in Sharsheret's community describe how uncomfortable it can feel to be on the receiving end of another person's good deeds. Others take comfort in being part of a close-knit community that will offer to prepare meals, tend to children, and help with shopping and housekeeping. Understanding that friends and family members feel empowered when they are useful to you can often make their offers of assistance easier to accept.

Continued on page 8



COMMUNITY SUPPORT (continued)

Serving the broad spectrum of the Jewish community, Bikur Cholim organizations and Jewish Family and Children's Agencies offer assistance to those facing illness. Visiting the sick (*bikur cholim*) is a term encompassing a wide range of activities performed by an individual or a group to comfort and support people who are in need.

If you are in need of community support during ovarian cancer treatment, you can contact Bikur Cholim organizations in your area. Many of these organizations offer assistance with meals, transportation, hospital visits, child care, counseling, and home care. For a state-by-state listing of Bikur Cholim organizations, visit the Partners in Health/Bikur Cholim website listed in the Resource Directory on page 21 of this booklet. Another resource you may find helpful is the Jewish Family and Children's Agency which provides social services to children, adults, and the elderly in the Jewish and general community. Links to your local Jewish Family and Children's Agency can be found on the Association of Jewish Family and Children's Agencies website listed in the Resource Directory on page 21 of this booklet. Some Jewish Family and Children's Agencies have partnered with Sharsheret to provide ovarian cancer and breast cancer support groups and programs in local communities.

Sharsheret also offers assistance to your support system through our **Spungen Family Focus Program**[®]. Available to family and friends, staff can provide encouragement and additional resources to the people who are there for you.

Balancing delegation and independence ensures that your needs are met in the way that is most comfortable for you.

8

BEING SINGLE

"When I first learned I had cancer, I immediately started asking questions: Who will marry me? How will I discuss my ovarian cancer history and its effects on my fertility with a prospective partner? Will my treatment compromise my ability to have biological children? I felt overwhelmed by having to manage my treatment without a partner, and at the same time, facing the reality that my diagnosis may one day affect my future relationships. It was very empowering knowing that there were other single women living with ovarian cancer with whom I could speak and who could share their experiences with me." — Rachel

Ovarian cancer can feel overwhelming for a woman at any stage of life. Facing cancer as a single Jewish woman like Rachel can raise a series of unique challenges. Single women who have called Sharsheret have done so to discuss a host of issues, including:

- Establishing a consistent support system of friends and family members
- The difficulty of possibly moving back home to be cared for by loved ones
- How to begin dating again
- When and how to tell a prospective partner that you have or have had cancer
- Concerns about the impact of ovarian cancer treatment on fertility and the ability to conceive a child
- Support groups that are sensitive to the unique needs of single women

 Outreach programs that focus on the needs of single women of Jewish heritage

For the single Orthodox woman, covering her head for the first time due to cancer treatment side effects rather than religious ritual after marriage can also be emotionally difficult.

If you would like to talk to other single women in your Sharsheret community to learn how they handled some of these issues, we can connect you with a member of our **Peer Support Network**. Often, being able to share your concerns with someone else who has faced similar challenges can be very helpful.

(9)

RELATIONSHIPS AND MARRIAGE

"Surgery and treatment had a major impact on my body image and selfesteem. I was worried about how my husband would perceive me. We were both worried about the future of my health. It took some time and sensitive discussion for us both to adjust to the considerable changes in our relationship." — Miriam

A diagnosis of ovarian cancer can impact a committed relationship. Busy with medical appointments and often fatigued as a result of treatment, many women find that they do not have the time or energy that they are accustomed to spending in their relationships. Partners may need to assume additional household or child care responsibilities. Some women express concerns that their partners require support but do not have others with whom they feel comfortable discussing ovarian cancer. Changes in one's physical appearance as a result of surgery or chemotherapy, as well as the side effects of surgical menopause, may affect body image and selfesteem. These feelings can be difficult to discuss with a partner and may affect intimacy both emotionally and sexually, as they did for Miriam.

There are ovarian cancer organizations and Jewish organizations that can address your concerns about the impact of ovarian cancer on life with your partner. Many organizations can provide direct support to your partner, or provide you with resources that may be helpful to share. Others can provide household help or child care assistance. You can find a list of these organizations in the Resource Directory on page 21 of this booklet.

Your Sharsheret community includes many other women who have dealt with the issues surrounding intimate relationships and marriage. Perhaps their experiences can help you put yours in perspective. Contact us to get connected to someone in our **Peer Support Network** who has shared your concerns. Our **Spungen Family Focus Program*** program is also available to provide support and additional resources to your partner.



FERTILITY AND PREGNANCY

"After my ovarian cancer diagnosis, I began to worry about how my treatment options and decisions would affect my future fertility and pregnancy opportunities. Would I still be able to conceive naturally? If not, should I pursue fertility treatment, surrogacy, or adoption? Before beginning treatment, I discussed my options both with my doctors and with my spiritual leader. These conversations helped me to make decisions and to move forward." — Jessica

The emphasis in Jewish tradition and culture on the importance of family makes the impact of ovarian cancer on fertility a particularly important concern for many Jewish women, both single and married. Prior to beginning treatment, you may have questions about your ability to have children after cancer surgery and treatment. Like Jessica, you may find it helpful to explore these questions with your doctor prior to making health care decisions. Many women have surgery that may induce premature menopause and limit their ability to conceive a child naturally. Other women choose fertility-sparing surgery, but are concerned about the effects of chemotherapy on premature menopause and subsequent pregnancies. Regardless of their surgery and treatment choices, women with ovarian cancer face difficult decisions in planning for the future of their family.

In addition to speaking with your doctor, there are cancer organizations, Jewish organizations, and fertility organizations that can help you understand the impact of ovarian cancer surgery and treatment on fertility and your family planning options beyond ovarian cancer. You can find a list of these organizations in the Resource Directory on pages 21-29 of this booklet.

The importance of family in Jewish tradition and culture makes the impact of ovarian cancer on fertility a particularly important concern.

At Sharsheret, we are sensitive to concerns about fertility and pregnancy and can connect you with other women in our **Peer Support Network** with ovarian cancer who have faced these issues. Their experiences can help you better understand your own.

PARENTING

"One of the biggest challenges I felt when I was first diagnosed was how to negotiate being a Mom with being in treatment. My greatest concern was how to talk with my daughters and son about my diagnosis. I also worried about being too weak from surgery and treatment to take care of my children. I didn't want my illness to take over their lives. With a lot of effort and love, I was able to keep their lives as normal as possible." — Abigail

For many of the women in the Sharsheret community like Abigail, questions about how to best parent through ovarian cancer are of significant concern. Some women seek guidance about discussing ovarian cancer with young children and teenagers or how to keep up with an active family life while not feeling well. Other women who are eager to keep their diagnosis private look for help in addressing the needs of their children through cancer treatment and beyond. Still others have concerns about what their hereditary ovarian cancer diagnosis might mean for their children or how and when to discuss this issue with them.

There are cancer organizations that can help you determine the best ways to approach cancer with your family, and Jewish organizations that can provide family counseling and guidance at little or no cost to you. You can find a list of these organizations in the Resource Directory on page 23 of this booklet. Sharsheret offers the **Busy Box**[®], which provides children and teens with materials and activities and helps support parents facing ovarian cancer or breast cancer. You can also talk to other members of the Sharsheret Peer Support Network who have dealt with similar concerns, can share their experiences with you, and will provide you with support as you work through these important parenting concerns. You may also find How Do We Care for Our Children?, a Sharsheret symposium transcript available on our website, to be helpful. If you do not have access to the internet, you can call our office to request а сору.

You will set the tone for how your children will respond to your cancer diagnosis.



SPIRITUALITY AND WELL-BEING

"At many points throughout my treatment and recovery, I grappled with questions that could only be answered by spiritual reflection. How will I find the strength to meet this challenge? When will I be through with this journey and able to embark on one of survivorship? I realized that it was my belief and my commitment to my spiritual life that inspired me and led me through this difficult time." — Naomi

Spirituality can be the way we find meaning, hope, comfort, and inner peace in our lives. Many people find spirituality through religion. Some find it through music, art, or a connection with nature. Others find it in their values and principles.

Positive feelings, comfort, and strength gained from spirituality can contribute to a sense of well-being. It may help you feel better and help you cope with the stress of treatment.

Whatever your path, an ovarian cancer diagnosis may prompt you to ask life's ultimate questions and to begin a quest for meaning. The nature of this emotional and spiritual journey is fluid. Finding meaning in this journey can mean embracing the range of emotions you experience, and accepting that there will be times when you feel less connected spiritually, and other times, more connected. Whether or not you've previously had a spiritual connection to Jewish tradition for meaning and guidance, you may find that the idea of this connection now has increased meaning.

Like Naomi, some women have found support in speaking to Rabbis or other Jewish communal leaders about incorporating spirituality, Jewish tradition, and ritual into their lives as they cope with the emotional and physical impact of ovarian cancer.

It's important for your doctor to know how your spirituality might affect your feelings and your health care decisions.

There are also Jewish organizations, both observant and secular, that can help you find meaningful ways to integrate spirituality and tradition into your cancer journey, in a way that is comfortable for you. See page 24 in the Resource Directory of this booklet for a list of these organizations. Additionally, through Sharsheret's **Peer Support Network** we can connect you with another woman with similar views who is happy to share her experiences.

(13)

PRAYER AND MEDITATION

"Prayer has been integral on my road to survivorship. Through different prayers, I have found value in the everyday and the inspiration I need to fight this illness. The meanings of the different prayers and Psalms have transformed the way I think about my battle with ovarian cancer." — Sarah

Like Sarah, many women of Jewish heritage living through ovarian cancer turn to prayer or meditation for a sense of spirituality and healing during treatment and beyond. Through these practices, women often describe feeling more hopeful about the future, more centered in their life circumstance, and more connected to their community. Prayer and meditation may also provide a quiet and reflective time to momentarily put aside concerns during ovarian cancer treatment.

Some women turn to a Rabbi or spiritual leader for assistance in selecting meaningful prayers. Other women have selected meditations or prayers they find particularly comforting or that hold personal significance for them. Family members and friends may feel empowered by organizing a prayer group and many community groups gather to recite psalms (*tehillim*) for those facing ovarian cancer. Hosting a celebration of thanks (*seudat hoda'ah*) can mark a closure to treatment and a beginning to healing. Whether you are observant or secular, including meditation or prayer in your life may help you feel more balanced.

Prayer and meditation may provide a quiet and reflective time to center yourself and find your balance.

A list of organizations offering spiritual support during illness can be found in the Resource Directory on page 24 of this booklet. Jewish spiritual leaders in your community may also provide meaningful guidance. Through Sharsheret's **Peer Support Network** you can speak with other women who share views similar to yours and have found prayer or meditation meaningful during their journey through ovarian cancer.

CELEBRATING HOLIDAYS

"Rosh Hashanah took on a new meaning for me this year. Just a few days prior, I received my cancer diagnosis. While I looked forward to welcoming family and friends to my home for the holiday, I felt physically exhausted and overwhelmed. I experienced a whole range of emotions, including excited, scared, anxious, and worried. While this was a very difficult time for me, being able to spend it with my family and friends and at the same time being enmeshed in the normal routine of Jewish life was amazingly uplifting and reinvigorating." — Eve

As they did for Eve, Jewish holidays can provide meaningful opportunities for family and friends to celebrate together, bringing us closer to loved ones. The holidays can also be an important time of deepening spirituality and self-reflection, and a reminder of the cycle of life and the year.

Preparing for and celebrating Jewish holidays or other rituals with family and friends can create feelings of warmth and security during a time of life that may feel unstable. But whether secular or religious, for Jewish women facing ovarian cancer, navigating the physical and emotional demands of the holidays may also make these trying times. Some women find general holiday preparations — shopping, cooking, and cleaning — physically taxing.

Others do not feel emotionally ready to celebrate. The High Holy Days (*Rosh Hashanah* and *Yom Kippur*), in particular, can bring with them added anxiety about the uncertain future as the New Year approaches.

The holidays can be an important time of deepening spirituality and self-reflection.



Your Sharsheret community understands the joys and demands of holiday celebrations — both Jewish and secular — while facing ovarian cancer. Call us to get connected to a member of our **Peer Support Network** who can tell you how she handled the joys and challenges of her holiday experiences.

WORKING DURING TREATMENT

"An additional challenge that I confronted in facing ovarian cancer was balancing my work life with my treatment. Although continuing to work while in treatment kept me grounded, managing job obligations, treatment, and personal responsibilities proved to be quite a complicated task. I often felt like I was juggling too many things and not giving anything the full attention it deserved." — Sharon

Working during ovarian cancer treatment can be both normalizing and challenging. Like Sharon, many women find that continuing to work gives them a sense of purpose and a routine in an otherwise chaotic schedule of medical appointments. For some women, it is a financial necessity. Working through treatment can also pose challenges, including sharing one's diagnosis with employers and co-workers, juggling work responsibilities and appointments, and the impact of treatment side effects - including fatigue – on work performance. Some women in Sharsheret's community have also noted the added pressure of balancing work schedules with the responsibilities of preparing for the Jewish holidays and the Sabbath during the time of treatment.

There are organizations that can help you, your employer, and your co-workers address some of the challenges that may arise at work during your ovarian cancer treatment. They offer guidance on sharing the news, managing side effects, and your rights in the workplace. You can find a list of these organizations in the Resource Directory on page 26 of this booklet.

Sharsheret's The Bella Chachky Diamond and Sylvia Diamond Geller Best Face Forward® Program can help ease your transition back to work by addressing some of the cosmetic side effecrts of cancer treatment. Additionally, our Peer Support Network can connect you with other women who have faced the challenges of juggling work, treatment, and the other demands of life

Juggling work, treatment schedules, and the impact of treatment side effects can present challenges.

16

USING THE RITUAL BATH

"Using the ritual bath (*mikvah*) has always played a central role in my life as a Jewish woman. After my surgery, I was no longer required to visit the *mikvah*. However, I still immerse in the *mikvah* from time to time, and find it to be an incredibly healing and reinvigorating spiritual experience." — Leah

Whether or not you have used a *mikvah* previously, some women find immersion in one can be a meaningful way to prepare for treatment after a diagnosis of cancer, or to mark the beginning of healing after the end of treatment. Whether returning to the *mikvah*, like Leah, or using one for the first time, you can experience a range of emotions. Some women may view their time in the water as one of heightened spirituality or as an opportunity for reflection. At the same time, the prospect of using the ritual bath after surgery or during chemotherapy treatment can be accompanied by anxiety and vulnerability about exposure of surgical scars or hair loss. Many women find it helpful to call the *mikvah* in advance to speak with the attendant, or to make arrangements for a private appointment. It can also be comforting to recognize that *mikvah* attendants are generally sensitive to the needs of all women living with illness.

Undergoing surgery for treatment of ovarian cancer can be difficult and painful. For many younger women who visit the ritual bath monthly, treatment means that they will no longer be required to do so. For these women, the loss of a customary and powerful spiritual experience can be strong and painful, especially at a time when they are feeling most vulnerable and anxious. While this change can be a difficult new reality to encounter, like Leah, many women continue to view their time in the water as an opportunity for reflection. The healing power of the ritual bath continues to play a role in the spiritual lives of many Jewish women even following treatment for ovarian cancer.

Some women find immersion in the ritual bath to be a meaningful way to prepare for treatment or to mark the completion of treatment.

Several communities across the country offer "Healing Waters", spiritual support groups at their local *mikvah*. For more information, please contact the organizations addressing spirituality in the Resource Directory on page 23 of this booklet. In addition, Sharsheret's **Peer Support Network** can connect you with other women who have shared similar *mikvah* experiences and can talk with you about your thoughts, concerns, and questions.

HOLISTIC, COMPLEMENTARY, AND INTEGRATIVE MEDICINE

"Sometimes I lie awake at night and think about additional ways that I can move toward healing that will complement the treatment that I am already undergoing. It seems like there is so much out there. The responsibility to choose correctly and act on everything can feel overwhelming." — Hannah

Judaism addresses the importance of collectively caring for our minds, bodies, and souls. Proper nutrition, exercise, and good sleeping habits are also strongly valued and contribute to a sound mind and body. Mindful meditation, yoga, and prayer are other activities that women undertake in order to help heal physically, emotionally, and spiritually.

For some women, changing lifestyle habits such as nutrition, exercise, and engaging in mindful meditation are easy next steps in the pursuit of holistic health. But there may be others who feel similarly to Hannah; you know that there are complementary interventions, but feel overwhelmed with the responsibility of making the right choices or any choices at all.

For many Jews, this is particularly true when food choices are the issue. Food is so much a part of our culture that giving up those "comfort foods" that may not be the healthiest choices can be a challenge. First and foremost, it is critical to consult your medical team when making any lifestyle changes or opting for complementary and holistic interventions. Some natural remedies or nutritional choices may interact with your medical treatments. Consult an expert when deciding on an exercise regimen. Speak with your Rabbi or spiritual leader about prayers or meditations that will fill your soul. And finally, it's important to pace yourself as you make lifestyle changes. Healthy living means finding the right balance in these three realms of mind, body, and soul.

Be sure to consult your medical team when making lifestyle changes or opting for holistic interventions.

You can find a list of resources providing more information on holistic, complementary, and integrative medicine in the Resource Directory on page 23 of this booklet.

18

SURVIVORSHIP

"From the moment I was diagnosed with ovarian cancer, I asked myself when I would be a 'survivor'. One year? Five years? Ten years? Over time, I began to realize that it was not a certain number of years that defines me. Living as a survivor is a choice. As a woman living with ovarian cancer, I choose to live as a survivor." — Judith

Survivorship is a many-faceted framework that includes physical, psychological, functional, social, sexual, and spiritual well-being. The term "survivor" itself raises a number of questions: When exactly are you considered an ovarian cancer survivor? How often do you need to see the doctor once you have survived cancer? How do you reconcile the term "survivor" with that persistent voice in your head asking, "Is it going to come back? Is it just a matter of time?" For some Jewish women, even claiming the title of survivor may be uncomfortable as it is a term often associated with the Holocaust.

For women like Judith, who are contemplating their rights to the title "survivor," on-going issues affecting family, friends, community, fertility, marriage, parenting, and spiritual or religious life remain a challenge.

Many women feel internal pressure or pressure from others to return to being the person they were prior to their diagnosis. Often, great effort is put into maintaining normalcy during this time of life-altering changes. It's not uncommon for women to feel emotionally intact during diagnosis and treatment, but experience strong emotional reactions after active treatment is completed.

Survivorship can include physical, emotional, and spiritual growth and changes.

There are cancer organizations and Jewish organizations that can offer resources, guidance, and support as you work to create a "new normal" beyond treatment. You can find a list of these organizations in the Resource Directory on page 22 of this booklet.

Other women in Sharsheret's **Peer Support Network** can help you find your "new normal" by sharing their post-treatment experiences with you. Contact us to get connected with someone who understands your concerns and can address your questions, and for free, tailored survivorship resources.

HOW CAN SHARSHERET HELP ME?

If you are at risk or have been diagnosed with ovarian cancer or breast cancer, we can help.

Connect with others who share your experience in our national Peer Support Network.

Discuss genetic concerns related to your family history and cancer risk with our support staff.

Let us help you help your children through your cancer journey with parenting resources.

Join our program for women living with recurrent ovarian cancer or advanced breast cancer.

Learn how to address the cosmetic side effects of cancer treatment and access financial subsidies.

Call us for resources and with questions from family members, caregivers, and friends.

Keep informed by experts in the cancer community on our national teleconferences and webinars.

We offer the transcripts of Sharsheret's helpful symposia online at **www.sharsheret.org**, covering topics such as *Taking Charge: Cancer Screening Updates Every Woman Needs to Know, Prophylactic Surgery for Breast and Ovarian Cancer: How Will It Affect Me?,* and *Breast Cancer and Ovarian Cancer: Exploring the Connection.* Check our website for the continually updated list of relevant transcript topics. If you do not have access to the internet, you can call our office to learn about other relevant transcripts available to you.

For more information about Sharsheret's programs, please contact us toll-free at **866.474.2774** or at **info@sharsheret.org**. Sharsheret's programs are free and are open to all women and men. All inquiries are confidential.

Remember, wherever you are, Sharsheret is, and we will be there for as long as you need us.



RESOURCE DIRECTORY

Cancer Organizations

American Cancer Society 800.ACS.2345 www.cancer.org

American Psychosocial Oncology Society Helpline 866.276.7443 www.apos-society.org

BFOR BRCA Founder Outreach Study www.bforstudy.com

Cancer 101 646.638.2202 www.cancer101.org

CancerCare 800.813.HOPE www.cancercare.org

Cancer Hope Network 877.HOPE.NET 800.552.4366 (Helpline) www.cancerhopenetwork.org

Cancer Information Center of the National Cancer Institute 800.4.CANCER www.nci.nih.gov

Cancer.net 888.651.3038 www.camcer.net

Cancer Support Community 202.659.9709 www.cancersupportcommunity.org

Imerman Angels 866.IMERMAN www.imermanangels.org

Livestrong Foundation 877.236.8820 www.livestrong.org

National Cancer Institute 800.4.CANCER www.cancer.gov

Patient Resource www.patientresource.com

Ovarian Cancer Organizations

Camp Mak-A-Dream-Adult Retreats 406.549.5987 www.campdream.org

Familial Ovarian Cancer Registry 800.682.7426 www.ovariancancer.com

FORCE (Facing our Risk of Cancer Empowerment) 866.288.RISK www.facingourrisk.org

Foundation for Women's Cancer 312.578.1439 800.444.4441 (Hotline) www.foundationforwomenscancer.org

Gilda Radner Familial Ovarian Cancer Registry 800.0VARIAN www.ovariancancer.com

HERA Ovarian Cancer Foundation 970.948.7360 www.herafoundation.org

Inspire 800.945.0381 www.inspire.com

My OC Journey www.myocjourney.com

National Ovarian Cancer Coalition 888.OVARIAN www.ovarian.org

Ovarian Cancer Research Alliance 202.331.1332 866.399.6262 www.ocrahope.org

Sandy Rollman Ovarian Cancer Foundation 610.446.2272 www.sandyovarian.org

(21)

SHARE: Self Help for Women with Breast or Ovarian Cancer

866.ASK.SHARE www.sharecancersupport.org

Young Women Facing Breast Cancer

Stupid Cancer 877.735.4673 www.stupidcancer.org

Ulman Foundation 888.393.FUND Ulmanfoundation.org

Young Survival Coalition 877.YSC.1011 www.youngsurvival.org

Cancer Genetics

American College of Medical Genetics and Genomics 301.718.9603 www.acmg.net

American Society of Human Genetics 866.HUM.GENE www.ashg.org

Basser Center for BRCA-Education and Outreach 215.662.2748 www.basser.org

BFOR BRCA Founder Outreach Study www.bforstudy.com

Bright Pink 312.787.4412 www.brightpink.org

Center for Disease Control and Prevention www.cdc.gov/genomics/disease/breast_ ovarian_cancer/index/htm

FORCE: Facing Our risk of Cancer Empowerment 866.288. RISK www.facingourrisk.org Genetic Alliance 202.966.5557 www.geneticalliance.org

Genetics For Life (A Sharsheret Program) 866.474.2774 www.sharsheret.org

National Society of Genetic Counselors 312.321.6834 www.nsgc.org

NCI Cancer Genetics Services Directory 800.4.CANCER www.cancer.gov/cancertopics/genetics/ directory

Norton and Elaine Sarnoff Center for Jewish Genetics 312.357.4718 www.jewishgenetics.org

Program for Jewish Genetic Health 718.430.2000 yu.edu/jill/genetichealth/coreefforts/ awareness-education

Right Action for Women www.rightactionforwomen.org/assistance

Survivorship

American Cancer Society Survivors Network www.csn.cancer.org

LIVESTRONG Foundation 855.220.7777 www.livestrong.org

National Coalition for Cancer Survivorship 877.NCCS.YES www.canceradvocacy.org

Survivornet.com www.survivornet.com

Thriving Again (A Sharsheret Program) 866.474.2774 www.sharsheret.org

Jewish Organizations Addressing Cancer and Health-Related Issues

Chai Lifeline 877.CHAI.LIFE www.chailifeline.org



Chai4ever 646.519.2190 www.chai4ever.org

Hadassah, Women's Health and Wellness 888.303.3640 www.hadassah.org

National Center for Jewish Healing 212.399.2320x209 www.jbfcs.org

Network of Jewish Human Service Agencies 201.977.2400 www.networkjhsa.org

Nishmat: Women's Halachic Hotline Online Information Center 877.963.8938 www.yoatzot.org

Partners in Health-Bikur Cholim 845.425.7877 www.bikurcholim.org

Ritualwell- A Program of Ma'ayan: The Jewish Women's Project of the JCC in Manhattan 646.545.4440 www.ritualwell.org

Sarnoff Center for Jewish Genetics 312.357.4718 www.jewishgenetics.org

The Jewish Board 844.ONE.CALL www.jewishboard.org

Breast Cancer Organizations in Israel

Beit Natan 011.972.2.644.6052 www.beitnatan.com

Bracha 011.972.72.233.2974 www.bracha.org.il Israel Breast Cancer Emergency Relief Fund www.esra.org.il/index.php/projects/

breast-cancer.html

Israel Cancer Association 011.972.3.572.1616 www.cancer.org.il

Lemonade Fund: Emergency Financial Relief for Israeli Women Recently Diagnosed with Breast Cancer www.lemonadefund.org

One in Nine 011.972.3.602.1717 www.onein9.org.il

Tishkofet-Ma'agan 011.972.2.631.0803 www.lifesdoor.org

Spirituality

Ritualwell 215.576.0800 www.ritualwell.org

Shira Ruskay Center 212.632.4608 www.jewishboard.org

Holistic, Complementary, and Integrative Medicine

American Academy of Medical Acupuncture 301.379.8261 www.medicalacupuncture.org

American Association of Acupuncture and Oriental Medicine www.aaaomonline.org

American Holistic Medical Association (Foundation for Alternative and Integrative Medicine) www.faim.org Holistic Primary Care: News for Health and Healing www.holisticprimarycare.net

National Acupuncture Foundation www.nationalacupuncturefoundation.org

National Center for Complementary and Integrative Medicine www.nccih.nih.gov

National Center for Homeopathy www.homeopathycenter.org

Office of Cancer Complementary and Alternative Medicine www.cancer.gov/cam

Oncology Nutrition www.oncologynutrition.org

The Annie Appleseed Project www.annieappleseedproject.org

Family, Friends and Caregivers

American Cancer Society: Road to Recovery 800.227.2345 www.cancer.org/treatment/supportprograms-and-services/road-torecovery.html

Breathing Butterfly Meditation App for Children www.elfenworks.org/butterfly/

Busy Box (A Sharsheret Program) 866.474.2774 www.sharsheret.org

Camp Kesem www.campkesem.org

Cancer Support Community 202.659.9709

Fighting Pretty www.fightingpretty.org

Gilda's Club 212.647.9700 www.gildasclubnyc.org Imerman Angels 866.IMERMAN www.imermanangels.org

Kids Konnected 949.484.9092 www.kidskonnected.org

Lotsa Helping Hands www.lotsahelpinghands.org

Men Against Breast Cancer 866.547.MABC www.menagainstbreastcancer.org

Mommy has Breast Cancer 877.386.7322 www.mommyhasbreastcancer.org

Mothers Supporting Daughters with Breast Cancer 410.778.1982

www.mothersdaughters.org Network of Jewish Human Service Agencies

201.977.2400 www.networkjhsa.org

SHARE Caregiver Circle for Family and Friends 844.ASK.SHARE www.sharecancersupport.org

Sister to Sister 718.338.2943 www.sistertosisternetwork.org

Spungen Family Focus Program (A Sharsheret Program) 866.474.2774 www.sharsheret.org

Take Them a Meal 800.951.7715 www.takethemameal.com

Telling Kids About Cancer www.tellingkidsaboutcancer.com

Wonders & Worries: A Family's Illness. A Child's Journey 512.329.5757 www.wondersandworries.org

Young Cancer Spouses www.youngcancerspouses.org



Fertility, Pregnancy, and Nursing

Alliance for Fertility Preservation www.allianceforfertilitypreservation.org

A T.I.M.E (Torah Infertility Medium of Exchange) 718.437.7110 www.atime.org

Bonei Olam 718.252.1212 www.boneiolam.org

Fertile Hope 855.220.7777 www.fertilehope.org

Hasidah 415.323.3226 www.hasidah.org

Hope for Two- The Pregnant with Cancer Network 800.743.4471 www.hopefortwo.org

Livestrong Fertility 855.220.7779 www.livestrong.org/we-can-help/ livestrong-fertility

Oncofertility Consortium-Northwestern University 312.503.2504 www.savemyfertility.org

Path2Parenthood 888.917.3777 www.path2parenthood.org

Puah 708.336.0603 www.puahonline.org

Reprotech www.reprotech.com/financial-assistance. html

Resolve 703.556.7172 www.resolve.org Will2Love www.will2love.com

Yesh Tikva www.yeshtikva.org

Managing Cosmetic Side Effects

The Bella Chachky Diamond and Sylvia Diamond Geller Best Face Forward ™ (A Sharsheret Program) 866.474.2774 www.sharsheret.org

Chemocessories www.chemocessories.org

Chemotherapy 800.813.HOPE www.cancercare.org/publications/24understanding_and_managing_ chemotherapy_side_effects

Facing the Mirror with Cancer 312.420.5610 www.facingthemirror.org

Girl on the Go-Private in home wig consultations 800.355.6076 www.girlonthego.biz

Impact One 623.738.6794 www.impactone.pink

Knitted Knockers www.knittedknockers.org

Lolly's Locks 240.428.1985 www.lollyslocks.org

Look Good Feel Better 800.395.LOOK www.lookgoodfeelbetter.org

Hair to Stay www.hairtostay.org

Radiation Therapy-breastcancer.org

610.642.6550 www.breastcancer.org/treatment/ radiation/side_effects

Shop Well with You 800.799.6790 www.shopwellwithyou.org

"TLC" (American cancer Society Catalog) 800.850.9445 www.tlccatalog.org

Clinical Trials

About Clinical Trials www.learnaboutclinicaltrials.org

American Cancer Society www.cancer.org

Breast Cancer Trials www.breatscancertrials.org

Basser Center for BRCA www.basser.org

CancerCare www.cancercare.org

Central Watch Clinical Trials Listing Service www.centerwatch.com

Clinical Trials and Me www.clinicaltrialsandme.com

Dr. Susan Love Research Foundation www.drsusanloveresearch.org

eCancerTrials www.ecancertrials.com

Emerging Med 877.601.8601 www.emerginingmed.com

FORCE www.facingourrisk.org

Massive Bio 844.627.7246 www.massivebio.com/find-a-clinical-trial/ free-clinical-trial-matching Metastatic Trial Search www.mbcalliance.org/fins-a-clinical-trialthats-right-for-you

National Cancer Institute 800.4.CANCER www.cancer.gov/clinicaltrials

National Institute of Health www.clinicaltrials.gov

Search Clinical trials 877.MED.HERO www.searchclinicaltrials.org

Susan G. Komen Breast Cancer Foundation 800.IM.AWARE ww5.komen.org

LGBTQ Community

LGBT Healthlink-Centerlink 954.765.6024 www.lgbtcenters.org

National LGBT Cancer Network 212.675.2633 www.cancer-network.org

Cancer and Careers

Cancer and Careers: Living and Working with Cancer www.cancerandcareers.org

Physician Referral Service

ECHO National Jewish Institute for Health 845.425.9750 718.859.9800

Ezra L'Marpeh 718.435.9788 www.ezra-lemarpe.org/en/

Medstar Health 718.787.1800 www.sbhonline.org

Relief 718.431.9501 www.reliefhelp.org



Financial Assistance

A Silver Lining Foundation 312.345.1322 www.asilverliningfoundation.org

All4One Alliance 508.630.2242 www.all4onealliance.org

CancerCare 800.813.HOPE www.cancercare.org

Cancer Family Relief Fund www.cancerfamilyrelieffund.org

Cancer Financial Assistance Coalition www.cancerfac.org

Cancer Resource Foundation Inc. 508.630.2242 www.cancerlsource.org

Financial Wellness Tool Kit (A Sharsheret Resource) 866.474.2774 www.sharsheret.org

Genevieve's Helping Hands, Inc. 516.500.3702 www.genshelpinghands.org

HealthWell Foundation 800.675.8416 www.healthwellfoundation.org

Hill-Burton Free and Reduced-Cost Health Care 800.638.0742 www.hrsa.gov/gethealthcare/affordable/

Impact One 623.738.6794 www.impactone.pink

hillburton

Joe's House 877.563.7468 www.joeshouse.org

My Hope Chest www.myhopechest.org Myriad

800.469.7423 www.myriad.com/myriad-cares-2/ finanical-assistance-program/

National Association of Free Charitable Clinics 703.647.7427 www.nafcclinics.org

National Cancer Institute: Financial Information www.cancer.gov

Patient Advocate Foundation 800.532.5274 www.patientadvocate.org/exploreour-resources/breast-cancer-resourcedirectory/

Patient Resource LLC 913.725.1600 www.patientresource.com/financial_ resources.aspx

Patient Services, Inc. 800.366.7741 www.patientservicesinc.org

Pan Foundation 866.316.7263 www.panfoundation.org

Rofeh Cholim Cancer Society 708.722.2002 www.rofehcholim.org

The Assistance Fund 855.845.3663 www.theassistancefund.org

The Breast Cancer Charities of America 936.231.8460 www.thebreastcancercharities.org/helpnow-fund The Chain Fund www.thechainfund.com

The Pink Fund 877.234.7465 www.thepinkfund.org

The SAMFund 617.938.3484 www.thesamfund.org

United Breast Cancer Foundation 877.UBC.4CURE www.ubcf.org

Zichron Shlome Refuah Fund 718.GET.WELL www.zsrf.org

Health Insurance

Benefits.gov 800.333.4636 www.benefits.gov

Breast Cancer: Covered or Not

800.215.7494 www.pabreastcancer.org/fin-help/patientresources/commonwealth-programs/ insurance-guidebook.html

Cancer for All www.coverageforall.org

Cancer Insurance Checklist www.cancerinsurancechecklist.org

Center for Patients Partnerships 608.890.0321 www.patientpartnerships.org

Coverage for All www.coverageforall.org

Financial Wellness Tool Kit (A Sharsheret Resource) 866.474.2774 www.sharhseret.org HealthCare.gov www.healthcare.gov

Rofeh Cholim Cancer Society 718.722.2002 www.rofehcholim.org

Triage Cancer-How to Pick a Health Insurance Plan Video www.triagecancer.org/animatedvideos

Legal Assistance

Cancer Legal Resource Center 866.THE.CLRC 213.736.1455 www.disabilityrightslegalcenter.org/ cancer-legal-resource-center

Disability Rights Legal Center: Cancer Legal Resource Center 866.THE.CLRC www.disabilityrightscenter.org

Law Help www.lawhelp.org

Lawyer Referral Service www.apps.americanbar.org/ legalservices/lris/directory

National Cancer Legal Services Network www.NCLSN.org

Patient Advocate Foundation 800.532.5274 www.patientadvocate.org

Lymphedema

American Physical Therapy Association, Oncology Section 800.999.APTA www.oncologypt.org



National Lymphedema Network 800.541.3259 www.lymphnet.org

Prescription Assistance

NeedyMeds www.needymeds.org

Patient Advocate Foundation Co-Pay Relief Program 866.512.3861 www.copays.org

Prescription Assistance Program 888.477.2669 www.pparx.org

RxAssist www.rxassist.org

Rx Outreach 888.796.1234 www.rxoutreach.org

Technology Based Resources

Care Pages 888.852.5521 www.carepages.com

Caring Bridge 651.789.2300 www.caringbridge.org

Meal Train www.mealtrain.com

MyLifeLine.org 888.793.9355 www.mylifeline.org

Navigating Cancer 800.925.4456 www.navigatingcancer.com

The Jewish Board-Bikur Cholim www.jewishboard.org/resources/helpfulbikur-cholim-links/ Think About Your Life 818.695.4334 www.thinkaboutyourlife.org

Personal Health Journals

CaringBridge www.caringbridge.org

MyLifeLine www.mylifeline.org

Creating Living Legacies

Memories Live 646.245.1698 www.memorieslive.org

Safe Beyond 800.844.0515 www.safebeyond.com

Thru My Eyes 914.725.1836 www.thrumyeyes.org



BOOKLETS AVAILABLE IN THIS SERIES

Your Jewish Genes: Hereditary Breast Cancer and Ovarian Cancer

Facing Breast Cancer as a Jewish Woman

Facing Cancer as a Frum Woman

Facing Ovarian Cancer as

a Jewish woman

Breast Cancer and the Ritual Bath: A Guide for Mikvah Attendants

Thriving Again®: For Young Jewish Breast Cancer Survivors

Our Voices: Inspiring Words from the Women of Sharsheret

From the Practical to the Spiritual: Caring for Loved Ones Living with Advanced Cancer

ACKNOWLEDGMENTS

We are grateful to all of the women and men of the Sharsheret community who contributed their thoughts and experiences to the development of this booklet. Additionally, we are thankful for the guidance of the organizations and health care professionals who provided invaluable input.

For information about this booklet and other Sharsheret publications, E-mail: info@sharsheret.org Call Toll-Free: 866.474.2774

P 866.474.2774 E info@sharsheret.org www.sharsheret.org

