

Partnering with Cancer

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Established in 1991, the Cancer Survivor Network (CSN) at Saint Joseph's Hospital of Atlanta has evolved into a vital partnership among cancer survivors, their families, professionals, and the community and has had an immeasurable impact on cancer care and survivorship at the cancer program.

The Focus of Change

Nearly two decades ago, in 1988-89, the cancer program at Saint Joseph's Hospital of Atlanta began a comprehensive review and multi-year strategic planning process. Patients with cancer and their families formed the cornerstone of this review process. These individuals held the knowledge and experience of receiving care, and, therefore, could inform and critique how care was perceived, received, and integrated, and could suggest ideas and changes for improvement.

At about the same time, patients with cancer were mobilizing and joining together, advocating for quality cancer care and creating a new definition of survivorship. In the late 1980s, the National Coalition for Cancer Survivorship became a vortex of change by celebrating survivorship and letting go of the victim role. The new definition of sur-

ivorship emerged as starting from the moment of diagnosis. This movement was a significant and empowering shift from how survivorship had been defined by the scientific and medical communities, i.e., disease-free after five years post-treatment.

After the strategic planning sessions ended, the oncology leadership found that its survivors wanted to do more about their own survivorship and that of others and to have a more active role in the cancer center's comprehensive approach to care. In other words, survivors were asking the hospital to truly embrace the survivorship component of care and provide a real commitment to their journey from the moment of diagnosis. Here is the story of that journey.

Finding a Model and Founding Principles

The inspiration for developing our Cancer Survivor Network came from the program at M.D. Anderson Cancer Center in Houston, Tex. Its program matched our intent to go beyond support groups and resource gathering to build a working partnership with survivors. The leadership of M.D. Anderson's survivorship program provided us with onsite consultation, direction, and support, as we developed a mission, vision, and principles for our Cancer Survivor

Network. From our program's first year to the present day, survivors and Cancer Survivor Network coordinators have received support to attend M.D. Anderson's annual survivorship symposium to gather ideas and gain insight and inspiration from the energy and enthusiasm of such a national focus on survivorship.

Our Cancer Survivor Network developed the following guiding principles, which reflected the basic values and tenets of the program:

- Survivors are the experts.
- Survivors have experiential integrity.
- Survivors and their loved ones are a whole entity.
- Professionals must be taught about survivorship.
- "They are us" and "we are they."

The last two principles may bear some clarification. Many professionals assume they understand



ILLUSTRATION/GARRY NICHOLS THEBSPOT

Survivors

survivorship by virtue of their role in providing care and managing patients' needs. However, the experience of receiving a cancer diagnosis cannot be fully understood by those who have not received such a diagnosis. At the same time, each person diagnosed with cancer is an individual who will integrate the experience in a unique way. The journey of survivorship has both common and individual themes that must be taught.

Healthcare professionals sometimes cope with the demands of cancer care by distancing themselves from the inherent emotional part of a cancer diagnosis. While this coping mechanism may be important, it can create a barrier that prevents the professional from learning about survivorship and communicating in ways that embrace the true nature of care—listening, partnering, witnessing with an understanding that “we are they” and “they are us,” and allowing respect and integrity to flourish and teach us all.

Building the Case

The proposal for initiating the Cancer Survivor Network focused on three driving forces:

1. Meeting certification criteria set by the American College of Surgeons Commission on Cancer for cancer programs. The criteria regarding follow-up care included providing support to and for survivors, either onsite or by referrals to services in the community. We were already offering support groups but wanted to expand services beyond single disease-oriented groups. Having an active group of survivor volunteers to assist with programmatic issues seemed to be a logical choice.
2. Developing a partnership with survivors was the right next step to take in our comprehensive care trajectory in order to learn and create a better program together.
3. Aligning the survivorship program with the mission of the Sisters of Mercy at Saint Joseph's Hospital was inherently consistent since both share the values of meeting the needs of others with mercy, dignity, and compassion.

The proposal included a lean budget for one full-time equivalency (1.0 FTE) position for a coordinator, office equipment, and supplies. At Saint Joseph's Hospital, one way a new program or service is established is through an internal grant from the Saint Joseph's Mercy Foundation. The grant supports the program for a period of time, during which the new entity is evaluated for its viability and fit prior to being subsumed into the operating budget. Such was the case for the Cancer Survivor Network program. The initial grant submitted in 1991 requested salary support for the full-time coordinator role for two years. Other needs, such as office space, a desk, computer

and the like, were minor costs covered by sharing with other departments within the cancer center or expensed to the center's administrative budget.

The revenue component of the proposal was as a “loss-leader” (or indirect gain). There was no doubt the program would be successful for survivors and the cancer program. The challenge was to interpret that success for decision-makers and the finance team. As stated above, meeting the ACoS, CoC requirements was one indirect gain; others included:

- Being first in the community to create a focused survivor-driven partnership
- Developing a stronger, more integrated cancer program in partnership with those we serve
- Promoting other services within the cancer program through the Cancer Survivor Network
- Creating an opportunity for survivors and their families to become involved and make a difference for themselves, other survivors, and the community
- Building loyalty and trust among patients resulting in increased use of other hospital-based services and referrals to oncologists and other specialists.

Over the years, the Cancer Survivor Network has become a remarkable marketing force that cannot be matched in dollars. Reputation spreads by word of mouth and doing the right thing in the right way while nurturing growth and development is a path of success.

Putting the Structure in Place

From its inception, the structure of the Cancer Survivor Network program included, as it does today, an Advisory Board and a fulltime coordinator. The Advisory Board is the central functioning unit that assesses, develops, evaluates, and sustains many of the survivorship programs and services. The Advisory Board is made up of survivors, caregivers, and others who have an interest in cancer survivorship. Survivor members are the majority board members with other seats allocated to non-survivors, who are often family members or those impacted by cancer. Many of the projects and activities of the cancer program are presented to the Advisory Board for input. Their perspective sheds new light on whatever activity or project is being considered. One example is the editing of a letter to be sent to patients through the cancer registry. The board members suggested language that was clearer and more to the point.

The Cancer Survivor Network coordinator staffs and manages all aspects of the Advisory Board's work in tandem with the board members. Responsibilities include maintaining bylaws, scheduling and participating in meetings, nurturing board growth and development, and advocating

Attending a recent Saint Joseph's Cancer Survivorship Conference are (left to right) David Hong, MD, assistant professor at M.D. Anderson Cancer Center; Judy Kelner, cancer survivor and Cancer Survivor Network Advisory Board member; and Renee Sevy, Cancer Survivor Network coordinator.



for support of the initiatives developed by the board.

In addition, the coordinator manages the office of cancer survivorship, which is the communications hub for the cancer program. The work is multifaceted and includes such activities as answering phone messages; producing the newsletter; staffing support groups; facilitating committees of the CSN and cancer program; and coordinating symposia, Lunch and Learns, and the like.

The coordinator must have certain strengths and talents. The most important of which are being an excellent communicator, facilitator, and organizer. Other important attributes include a passion for advocacy, an ability to engender trust and commitment from others, and the desire and humility to learn from and through others.

Various professionals and non-professionals can fulfill the coordinator role expectations; however, the best fit for our Cancer Survivor Network program has been a community-based social worker. Along with education on human relationships, an MSW with community-based training is focused on developing and managing resources within communities to enhance the outcomes of those they serve. Over the years, four dedicated and talented professionals have served in the role of Cancer Survivor Network coordinator. Each has left a special mark on the program and has helped elevate the Cancer Survivor Network and the cancer program to its next level with spirit, determination, and deep commitment.

Creating and Sustaining Momentum

From the first days of the Cancer Survivor Network program, every detail of work was gathered and reported in as many forums as possible to promote awareness and secure viability. Data collected included the following:

- Numbers and content of contacts (phone, emails, drop-ins) made to the CSN office; numbers of cancer survivor volunteers involved and volunteer hours provided; programs developed and communities reached
- Connections and services provided to and with other community cancer services and groups
- Numbers and types of support groups offered with participation data.

Over time, outcomes data changed from a numbers roster to reporting the broad-based programs and services offered, such as the *Survivor Visitation Program*, the *Living Room*, the *Annual Survivor Symposium*, the Resource Library, and the *Network Newsletter*. Cancer survivors created a logo for the Cancer Survivor Network, which appears on all brochures, flyers, and newsletters. Likewise, the logo has been applied to the *Survivor Visitation* volunteer jackets to identify them as CSN members.

Volunteer hours are tallied and reported annually as in-kind donations, authenticating the contribution of the program.

An important sustaining factor of the Cancer Survivor Network is its inclusion of anyone touched by cancer whether patient, family, provider, or concerned community member. It matters not where a patient received care; everyone is welcome to be involved at whatever level they wish—as a board or committee member, volunteer, or recipient of the newsletter. Membership in the Cancer Survivor Network is loosely defined as follows: 1) general membership with no obligations or expectations and 2) directed membership in which a more active level of responsibility, in some capacity, is assumed. These two paths have evolved over time, are equally important to the program, and intersect on a regular basis.

Another sustaining factor is setting boundaries and providing guidance for survivor volunteers. In our experience, the cancer survivor volunteer is both passionate and determined in the desire to serve. These attributes create an energy that must be guided towards purposeful outcomes for the program and a fulfilling experience for the volunteer. Guidance and support are provided by the coordinator and the cancer program leadership so as to honor the integrity of each volunteer and the group as a whole.

For example, throughout the years, some members of the Advisory Board have wanted to fundraise to secure the program's budget. While fundraising may be the focus of some survivor programs, we did not want our volunteers to apply their energies toward direct fundraising. To resolve the issue, the cancer program administrator met with the CSN Board on a regular basis to explain the cancer program and the CSN fit within the hospital's organizational chart and the operations budget development. Empowered with an understanding that funding mechanisms were in place through operations budget, grants, and foundation support, and by learning the structure, function, and mission of the hospital, cancer program, and survivors network, the CSN Board began to shift from concerns about budgets to creating programs and support for survivors. As the CSN has evolved, however, several of the programs have created a revenue stream for the survivorship program, including the Cards for Cancer, Lunch and Learns, and the Annual Symposium.

The most sustaining factor of our survivor-driven program is the level of true ownership experienced by

Cancer Survivor Advisory Board members, Dick McClure (left) and Jerry Smith (right) with Maggie Riley at a past Saint Joseph's Cancer Survivorship Conference.



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the survivor volunteers. Everything is done with the understanding that it is “their program” with staff time of the coordinator devoted to

assisting with their goals. Our survivor volunteers take great pride in their accomplishments and work hard to sustain the CSN. True ownership creates an energy and focus that, in tandem with endorsement and support from cancer program leadership, is an unstoppable force. Likewise, CSN members are recognized for their efforts through annual survivor events, celebrations of life, hospital board presentations, newsletters, and the like. Every opportunity is taken to put a face on survivorship.

Another aspect of guiding and sustaining momentum is ensuring that volunteers know the limits of their energy and are supported to step away, take a break, or curtail involvement if needed. This is especially important for cancer survivor volunteers because they are passionate about their work and may need gentle encouragement to attend to their own health and well-being. Stepping away can be difficult because it may mean losing connections with the survivor group that has become like family—a support group itself. The reasons for stepping away may be difficult, such as a cancer recurrence. On the other hand, stepping away may stem from a need for more personal time. Whatever the journey of each individual, the sense of community developed through the Cancer Survivor Network is a vital, caring, and connected one. Everyone involved supports and reaches out to others through the bond of the cancer experience.

Like any volunteer, cancer survivor volunteers are looking for ways to make a difference in their lives and in those of others. A common thread is the desire to give back, to find a community that understands survivor issues, to share what has been learned, and to be of help and hope to others on the cancer journey.

These Volunteers are Different

Most hospitals engage volunteers to help with the many needs within the hospital on a daily basis. The Saint Joseph's Hospital volunteers fundraise, manage the gift shop, transport goods throughout the hospital, host reception desks, provide assistance with directions, and help in many other ways, including being the “eyes” and “ears” for patient satisfaction. As such, these volunteers are supported and recognized in many ways for their altruism and service.

The role of our cancer survivor volunteers is different in the key aspects of focus and scope. The focus of

their volunteer efforts is on survivors, and the scope of service includes survivors, families, members of the local community, and the cancer program. Cancer survivors volunteer to create hope, quality of life, and connections to resources, services, and support for other survivors and those impacted by cancer.

At times, Cancer Survivor Network volunteers have been asked to provide a function or service within a busy cancer center, such as transporting a patient, in lieu of calling upon the core hospital volunteers. At the same time, Saint Joseph's “hospital volunteers” have been offered benefits, such as free lunch and invitations to events honoring national volunteer recognition week that were not extended to Cancer Survivor Network volunteers. While these are not monumental issues, it is important to oversee such actions and advocate for inclusion (volunteer recognition) and exclusion (from tasks) to sustain programs such as the Cancer Survivor Network. Protecting the roles of our cancer survivor volunteers, as well as championing their efforts, has been critical to sustaining their energy, identity, and enthusiasm.

Lessons Learned Along the Way

Our Cancer Survivor Network partnership has taught cancer program staff several key lessons, the most important of which is that while true partnering is challenging and requires attention, commitment, and diligence; it is also rewarding and fulfilling. Our Cancer Survivor Network makes the mantra of a comprehensive cancer program a reality.

Understanding volunteerism, and, specifically, volunteerism of cancer survivors, is necessary for creating an environment that honors the gifts and talents of each survivor; provides opportunities to participate; supports and recognizes efforts made; and holds the boundaries intact for the good of the whole. Mutual education and learning is a continual process that deepens and matures over time through formal and informal experiences and through shared values of integrity and inclusion. At Saint Joseph's Hospital, partnering with cancer survivors has been a most enriching experience for the staff and for survivors, each benefiting from the good will, gracious presence, and deeply intentional focus of the other. It has lent a joy and depth to our program that is profound. We are walking with each other in a manner that defines comprehensive care and caring. 📍

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