

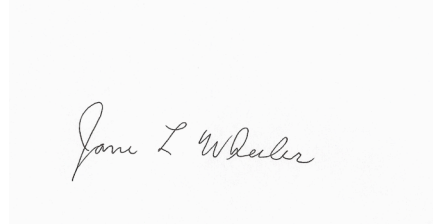
## The Power of Team

Dear Readers,

In this issue of *Breast Cancer Wellness*, focused on Team Power, we would like to talk about one of the most powerful forces in healing – that of family and community, which can be defined in many ways – and to tell you how we envision harnessing this power to benefit women in active treatment and across the journey of survivorship. We are, truly, all in this together and we can help each other in more ways than we usually recognize. The power of the Team will, undoubtedly, be a fertile area of research in the future; at this point in time, the medical community is entering new territory in acknowledging, studying, and incorporating the healing power of others.



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We have all heard the phrase, “It takes a village to raise a child.” Parents, grandparents, friends, neighbors, teachers, coaches, doctors, librarians –when we try to name all of the people who contribute to supporting our children’s growth and well-being, the list stretches on and on. But is a constellation of important players really unique to raising a child? If any of us honestly considers the number of people on whom we depend for our well-being, on a daily basis, we will arrive at an equally impressive list. It seems, therefore, that it takes a village to sustain each one of us. Cancer patients and survivors are no exception.

In fact, a recent research study involving 2,835 women with Stages 1-4 breast cancer found that the presence of close relatives, friends, or living children in these women’s lives was significantly associated with better survival outcomes.<sup>1</sup> Moreover, the health and wellness of the patient herself has important implications for the numerous others to whom she has connections, including relatives, friends, neighbors, and co-workers. These “collateral” health effects, ranging from emotional to social to financial impacts, remind us that the power of the team touches all involved.<sup>2</sup>

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<sup>1</sup>Kroenke CH, Kubzansky LD, Schernhammer ES, Holmes MD, Kawachi I. Social Networks, Social Support, and Survival After Breast Cancer Diagnosis. *Journal of Clinical Oncology* 2008;24(7):1105-11.

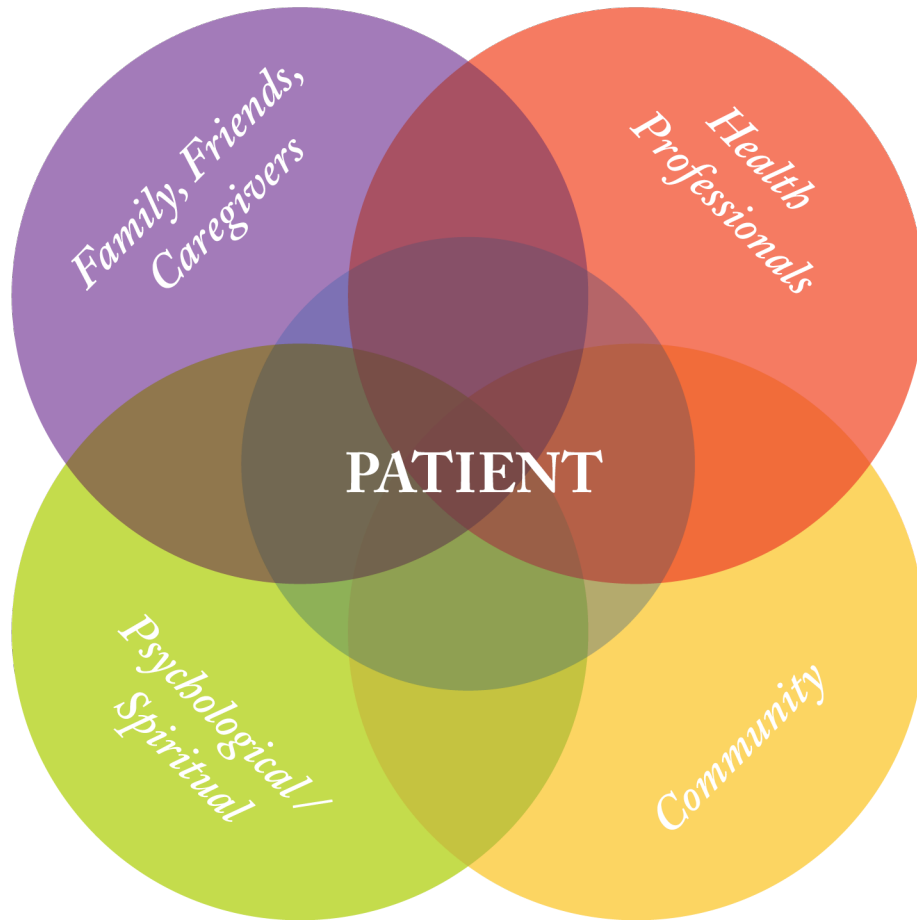
<sup>2</sup>Christakis NA. Social networks and collateral health effects. *British Medical Journal* 2004;329:184-5.

The term “team” conjures up a variety of images: a sports team, with its camaraderie and sense of purpose; a business unit, with its clear goals, determination, and focus; a group of healthcare providers, in which skilled professionals coordinate their diverse roles around vital purposes. In essence, when we boil these different examples down to their common elements, we find that teams have: (1) a sense of shared purpose, and (2) multiple players whose various roles fit together to help achieve that purpose.

In our vision for optimal cancer care, the patient occupies the center of a caring circle. Within that circle, a host of committed individuals with different functions provide a broad range of supports, which together assist the patient in achieving “whole person recovery,” that is, a sense of wellness in body, mind, and spirit. A person can recover, can be fully well, regardless of her stage of disease, if the tumor returns, or if she remains disease-free. Because personal recovery is an internal state of well-being, it is available to anybody and everybody. In this broad sense, the patient’s personal recovery constitutes a team goal.

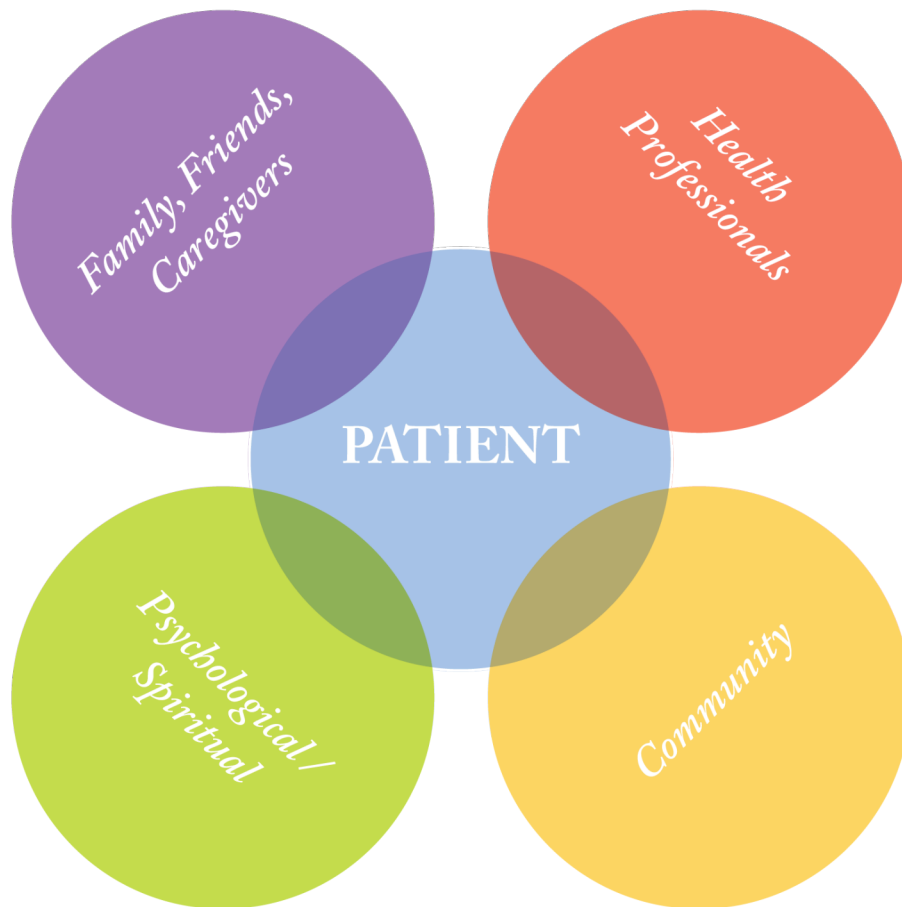
For the individual with cancer, the care team comprises all those who contribute toward the shared purpose of helping her achieve personal recovery in mind, body, and spirit. First, there is the patient’s immediate social network of family, friends, caregivers, and helpful acquaintances. These individuals often provide a substantial amount of social support, as well as logistical assistance. Community-based organizations and support structures, such as community centers or social service agencies (e.g., Meals on Wheels), can help in this realm as well. Then, healthcare professionals are integral members of her team; these include doctors in primary care as well as oncology, nurses, social workers, patient navigators, acupuncturists, massage therapists, and anyone else who helps the patient interface with the health system, and with health-restoring aspects of her recovery. Other members of the team provide psychological and spiritual care; these can include therapists, counselors, support groups, chaplains, priests, ministers, or rabbis.

**Figure 1:** Spheres overlap in a strong patient-centered care team.



In much of cancer care today – and this is especially true of survivorship care – these different categories of team player do not interact together on a regular or well-coordinated basis. It is as if they don't know they belong to the same team, or they each consider their own functions separate from those of other team members. This lack of coordination seriously dilutes the power of the team.

**Figure 2:** Lack of coordination between spheres weakens the care team.



We are very heartened to see that the field of Oncology is beginning to take Team Power seriously and to develop models for cultivating it – to better aid in the patient’s healing and personal recovery, and to support wellness over the long term. We’d like to tell you about three ways in which Oncology is going about this; these strategies are at different stages of development, but will give you an idea of the opportunities underway, and of the level of support for cancer patients and survivors promised by Team Power initiatives.

#### Patient navigators and Pathfinders

In recent years, many cancer centers have added a new member to the healthcare team – the patient navigator. The patient navigation program was originally developed in the 1990s with the goal of ensuring the quality and timeliness of healthcare provided to patients regardless of their education level, socioeconomic status, or race/ethnicity. Working within the health system, the navigator helps the individual negotiate all of the logistics and challenges of being a cancer patient, from scheduling appointments to finding where to go for a lab test to meeting the various providers involved in her care. A navigator serves as the guide for the patient as she works her way through the cancer treatment journey, helps to make sense of often-confusing healthcare systems, and sometimes coordinates the care team. Most navigator programs, however, align their

boundaries with those of the healthcare system and do not extend services throughout survivorship or into the home and community settings.

Pathfinders is an integrative, “whole person,” psychosocial program for cancer patients at all stages of disease, including survivorship. The program combines several strategies for assisting cancer patients, including patient navigation, counseling, nutrition and exercise advice, referral to complementary care such as massage or acupuncture, and liaisons with medical care providers.

Pathfinders implements a carefully developed approach that guides the patient through a process of inner discovery and that teaches specific strategies for improved coping. Each patient works one-on-one with a Pathfinder, a specially trained social worker. Rather than focus on the patient’s needs and deficits, Pathfinders helps the patient to identify her innate strengths, and to awaken those resources to achieve personal recovery. A grounding framework for the program is the Pathfinders Seven Pillars of Personal Recovery; the pillars – hope, inner strength, spirit, balance, self care, support, and life review – serve not only to evaluate how well the patient is doing on these dimensions, but also to organize her inner work as she progresses toward personal recovery. The Pathfinder works closely with medical staff to better coordinate care around the goals of personal recovery, and also helps the patient become more aware of family and community members who could join the team pulling for her healing, support, and recovery.

Pathfinders, started in Aspen, Colorado, has partnered with Duke University Medical Center in Durham, North Carolina. The purpose of this partnership is to conduct a series of research studies designed to determine the program’s feasibility in a busy academic clinic, its helpfulness to patients, and its impact on multiple measures such as quality of life, fatigue, distress and despair, self-efficacy, and various symptoms. Our first study, among patients with metastatic breast cancer, has shown very promising results in terms of the program’s impact on psychosocial measures such as distress, despair, hope, and ability to cope.

Duke does not yet provide a Pathfinder to help care for every cancer patient who needs or desires this input, but we are fast moving toward a day when we can provide this resource more broadly. Simultaneously, we are working to develop strategies for transferring the program to other cancer centers, and to create materials and methods that allow survivors to follow the program from home, over the long-term, so that they can live their lives to the fullest.

#### Specialized primary care provider model

Management of breast cancer at any stage, whether newly diagnosed, in active treatment, or throughout long-term survivorship, has become increasingly complex. In the cancer clinic, the patient requires comprehensive assessment and input from multiple specialties on an ongoing basis. Historically, the breast surgeon has served as the primary provider in the breast cancer clinic for both initial diagnostic evaluation, as well as the coordinator of care and provider of long-term follow-up care. Surgeons, however, are notoriously

busy individuals who have only limited time to devote to each appointment, and whose focus tends to be specialized rather than generalized to include diverse areas such as symptom management, psychosocial care, logistics of being a patient, and spiritual support.

At the Mayo Clinic in Rochester, New York, multidisciplinary care for breast cancer patients is delivered by a reconfigured team in which the surgeon is not the primary provider.\*\* For the last 10 years, primary care physicians trained as specialists in breast disease have staffed the breast clinic. In this unique scheme, the primary care-based breast clinic physician conducts the patient's initial visit and consults with physicians in other specialties as needed. This individual holds primary responsibility for the diagnostic evaluation of breast problems and the management of nonsurgical issues. He or she directs an efficient and thorough diagnostic workup for each patient, resulting in more appropriate surgical referrals.

For cancer patients at Mayo Clinic, the breast clinic physician is the team leader who coordinates the multiple healthcare professionals comprising the patient's care team, and who serves as the patient's central access point for communications and expertise. As the team leader, the breast clinic physician educates the patient about the disease and treatment options and serves as a liaison for the various physicians who may be involved in their evaluation and treatment (e.g., the radiologist, surgeon, pathologist, medical oncologist, and radiation oncologist), in turn allowing these doctors more time to focus on their specific roles in each patient's care. This collaborative practice ensures that the patient receives the best possible multidisciplinary treatment, by coordinating care of specialists who can have more in-depth discussions with patients regarding specific therapies. The breast clinic physicians also provide continuity and stability, and act as resource personnel whom the patient can access during all phases of treatment, as well as after treatment in the survivorship phase.

### Survivorship clinic

With increasing national attention focused on the needs of cancer survivors, many cancer centers are creating survivorship clinics – a new structure within the medical center. The emergence of the survivorship clinic recognizes the existence of unique needs among cancer survivors, the importance of ongoing monitoring and support for these individuals, and the power of a team-based approach to improving care for survivors.\*

Naturally, different sorts of survivorship clinics have cropped up, as different health systems develop programs that best match their resources and structures to the needs of their patients. Current models include: community-based shared care models, in which care providers in two or more specialties, such as oncology and primary care, share

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\*\* We would like to thank Dr. Kanisha Bryant and Dr. Amy Degnim of Mayo Clinic for their assistance with this article.

\* NOTE: The current definition of a cancer “survivor,” as articulated by the National Cancer Institute, refers to any individual who has had cancer, beginning from first diagnosis and continuing throughout the duration of his or her life. It thus includes all those touched by cancer: patients in active treatment, those who have completed treatment and are disease-free, and those who have recurrent or advanced disease.

responsibility for the patient's follow-up care; pediatric long-term follow-up programs for survivors of childhood cancers; disease-specific cancer survivor programs, such as a breast cancer survivor clinic; nurse practitioner-led survivor clinics; and specialized multidisciplinary survivor programs which provide comprehensive care within the medical center.

One example, the Perini Family Survivors' Center at Dana-Farber Cancer Institute established in 2003, addresses the long-term physical and emotional needs of cancer survivors and families and offers them tools to live as fully as possible. An umbrella organization that functions like the hub of a multi-spoked wheel, it coordinates follow-up clinical care, education, and support, and serves as a link to a host of programs designed to meet the needs of cancer survivors and their families. These programs include a back-to-school program, creative arts program, boutique, peer support/mentor program, pain and palliative care service, pastoral care, school liaison program, support groups, patient seminars, and integrative medicine center.

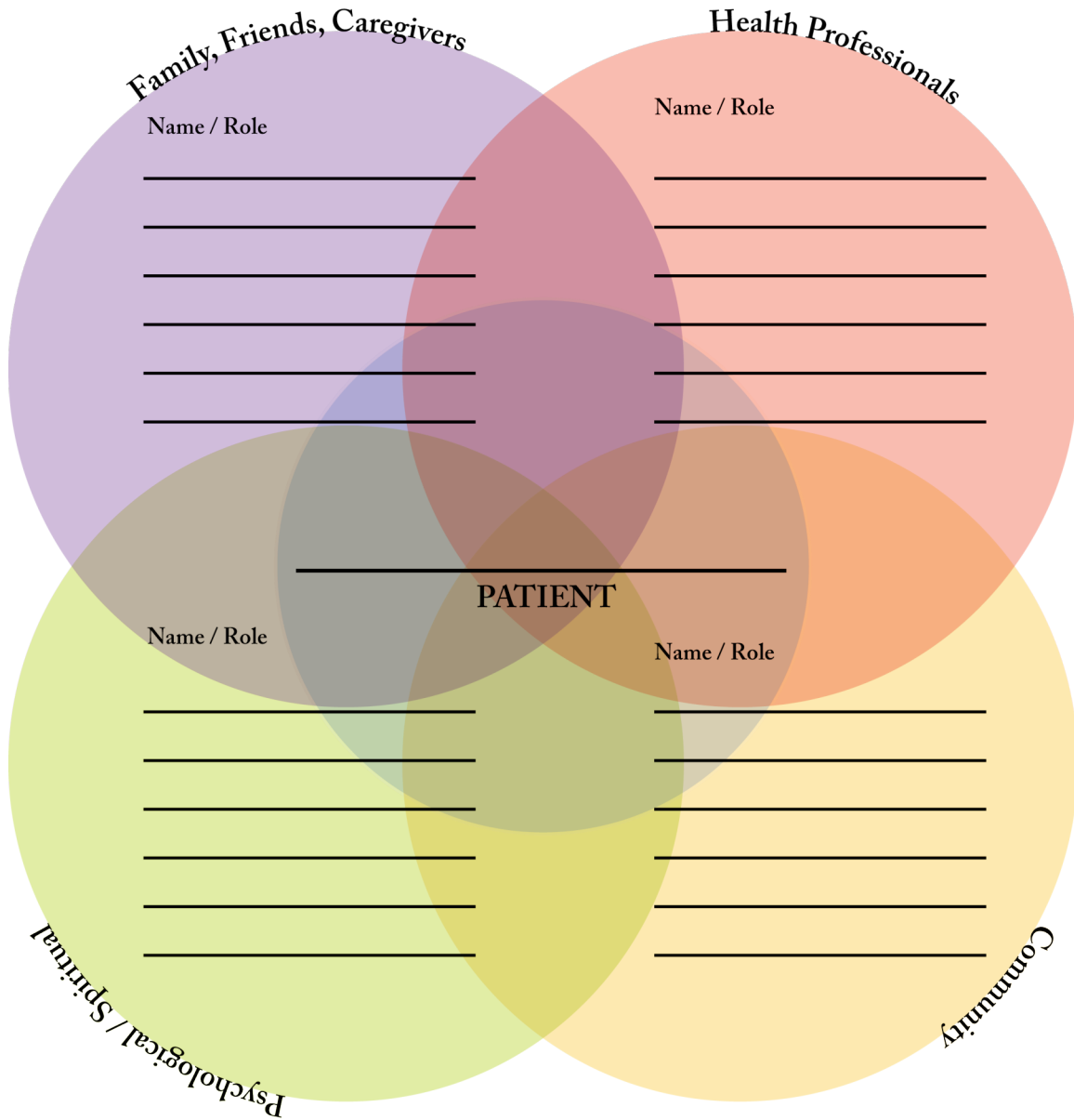
The Perini Center operates like a giant team in itself, bringing together all of the players who can assist in supporting the survivors' optimal well-being. It also provides education and support to help individuals develop and sustain their own personal teams.

At Duke, we offer cancer survivors the opportunity to participate in the Duke Center for Survivorship, which encompasses the services of Duke's Cancer Patient Support Program, Oncology Recreation Therapy, and Cancer Education Program. Within this Center, professionally trained counselors and hundreds of volunteers provide therapy, support, and education resources to survivors at any stage along the cancer journey. The Center provides support groups, individual counseling, and image enhancement services to cancer patients and their families. Music, games, crafts, and laughter enhance quality of life, and opportunities to engage in hobbies such as genealogy research, painting, woodworking, tiling, and flower arranging provide both an emotional outlet and a recreation activity. The Center provides multimedia information – such as books, audiotapes, videotapes, and online computer resources – to help survivors and their families understand their treatment options, make decisions, manage the effects of cancer and treatments, and find meaning in the experience.

#### Build-A-Team: A do-it-yourself model for harnessing Team Power

While some *Breast Cancer Wellness* readers may be fortunate enough to have access to programs such as Pathfinders, the Mayo Clinic PCP model, or the Perini Center, others of you may not. This does not mean that Team Power is out of reach. Quite to the contrary! With a vision and a willingness to enlist others, you can harness Team Power from virtually any location. We would like to present you with a framework for building your own team, one that is effective and supportive in just the way you want it.

**Figure 3:** Build-A-Team worksheet



**Step 1:** Who/what are my resources?

Enumerating your resources can restore a sense of being fortunate, no matter how bleak your circumstances may seem at the time. Write down all of the potential sources of support in your life – family members, friends, acquaintances, fellow community members, and even things like books, pets, hobbies, and other things that give you pleasure.

Step 2: What do I need to get done?

Often the sense of inadequacy, of inability to accomplish what needs to get done, can become overwhelming in the face of cancer. Setting the essentials down on paper helps to externalize them, and to identify what truly does need to get done versus what looms large but is actually not important.

Step 3: What are my current challenges?

Identify those things that you are finding difficult, and therefore that are weighing on you or causing distress. These can be symptoms such as fatigue and pain, tasks such as laundry and cooking, logistical challenges such as getting to your clinic appointments and also picking your child up from school at the same time, or cancer fall-out such as insomnia or depression.

Step 4: What will make me feel better?

“Boosts” are those supports which will alleviate emotional distress, overcome physical challenges, help you conserve energy, or just generally make your life easier. They can be as small as a weekly phone date with an old friend or as large as cooking meals for the family. Identify and prioritize those boosts that will yield the greatest “bang for the buck,” in other words, that will lift your spirits and help you the most.

Step 5: Who can help?

Look back at the list you generated in Step 1. Use the figure below to help you match your resources (primarily people) to your boosts. Knowing the personalities, circumstances, and interests of these people, you are the expert who can connect these dots to get things done.

Step 6: Build a Team!

You offer someone a gift when you ask him or her to do you a favor. Nearly everyone likes to give, to be helpful, to be of service. By inviting others onto your team, and by asking them to take on a particular boost, you are allowing them this opportunity. There is absolutely no need to be bashful, but rather, your resource people will most likely be grateful for the chance to join your team. If you feel too tired, ill, or depressed to convene your own team, consider appointing a team leader to do this for you.

Naturally, as you travel through life, your situation, resources, and needs will change. You can repeat this process as often as you wish, to ensure that you have a plan for supporting your wellness and that you are leveraging Team Power to live your best life.