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# Helping Cancer Survivors Be Well at the Ann B. Barshinger Cancer Institute

INTEGRATIVE ONCOLOGY LEADERSHIP  
COLLABORATIVE CASE STUDY

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*The Integrative Oncology Leadership Collaborative (IOLC) sought to make whole person cancer care routine by creating, testing, and refining a set of tools for delivering whole person cancer care. The team from the Ann B. Barshinger Cancer Institute also expanded their survivorship program to include wellness.*



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## Introduction

### COMMUNITY CANCER CENTER SEEKS NEW APPROACH TO SURVIVORSHIP

**T**he Ann B. Barshinger Cancer Institute (Lancaster, Pennsylvania) is a community cancer center that delivers hands-on, personalized care and advanced medicine to the Lancaster community. Established in 2013 as part of Penn Medicine Lancaster General Health, the cancer institute supports the mind, body, and spirit of patients and their families. It is affiliated with Penn's Abramson Cancer Center.

Penn Medicine Lancaster General Health is a not-for-profit health system that includes:

- More than 300 primary-care and specialty physicians.
- Outpatient and urgent care services.
- Four hospitals with 786 licensed beds.

### Support for Cancer Patients and their Families

From the moment a patient is diagnosed with cancer through treatment, recovery, and beyond, the Ann B. Barshinger Cancer Institute offers comprehensive supportive services, including a survivorship program.

Survivorship programs are fairly new in cancer centers. When Randall A. Oyer, MD, FACCC, completed his fellowship in 1986, fewer patients survived cancer. "In the early days, we worked to cure people and get people through treatment," he says. "Thinking about survivorship as a goal was an evolution." Dr. Oyer is the executive medical director of the Ann B. Barshinger Cancer Institute and a clinical professor of medicine at the Perelman School of Medicine at the University of Pennsylvania.

### Life after Cancer

Today, experts estimate that 17 million people living in the United States are cancer survivors, compared to three million in 1971.<sup>1</sup> About two out of every three people diagnosed with cancer will be alive at least five years after diagnosis, and one in seven cancer survivors was diagnosed more than 20 years ago.<sup>1</sup>

The increase in the number of cancer survivors has made planning for life after cancer an essential part of cancer care.

***"Cancer survivorship is most often defined as the process of living with, through and beyond cancer. You are a survivor from the time of your cancer diagnosis through the rest of your life."***

Source: Ann B. Barshinger Cancer Institute website

## Counseling and the Survivorship Summary

After cancer patients complete active treatment at the Ann B. Barshinger Cancer Institute, they receive counseling and a survivorship summary, as recommended by the Commission on Cancer.

“We are very attentive to making sure that when people finish cancer treatment with chemotherapy, we provide a survivorship summary. That document includes a description with the staging of the diagnosis, a clear description of the summary of the treatment they received and a standard follow-up plan with common side effects to be aware of,” says Dr. Oyer.

But this approach wasn’t addressing all the needs of patients or focusing on what mattered most to them.

“The survivorship summary is a very comprehensive, accurate document, but it provided information in a way that wasn’t necessarily accessible and was certainly not customized for patients. We weren’t providing what was most important and actionable for people,” says Dr. Oyer. Also, research showed that this approach did not result in better outcomes for patients.

Dr. Oyer and his team wanted to improve survivorship services to positively impact outcomes and to focus on what mattered most to patients. The team made some changes, such as looking for openings to discuss survivorship with patients as early as the time of diagnosis.

But finding the right approach to survivorship and the right tools to meet patient needs was a challenge. Dr. Oyer knew that learning more about integrative oncology and how other cancer centers were using integrative oncology would help his team.

## An Opportunity to Improve Survivorship Services

The Integrative Oncology Leadership Collaborative (IOLC) gave Dr. Oyer and his team the opportunity to learn about whole person cancer care from other oncology care teams while also helping to create, test, and refine the HOPE for Cancer Care tools to make whole person cancer care routine.

HOPE stands for Healing-Oriented Practices & Environments. The HOPE for Cancer Care tools are based on the HOPE Note Toolkit, a set of integrative health tools developed for use in whole person primary care. The toolkit includes:

- Personal Health Inventory.
- HOPE note.
- Personalized health plan.
- Related supporting tools.

The IOLC created an approach to integrative oncology called whole person cancer care. This approach focuses on what matters most to the patient and integrates each patient’s personal determinants of healing into their cancer care.

## Whole Person Cancer Care

Whole person cancer care focuses on “what matters” to patients and uses conventional treatments, complementary therapies, and behavior, lifestyle, and self-care approaches to combat the side effects of cancer care and help restore the quality of life and length of life for patients.

Through the inclusion of evidence-based therapies such as nutrition, movement, meditation, and others, patients activate their individual ability to heal as they go through cancer treatment and into survivorship.

The Ann B. Barshinger Cancer Institute was one of 15 cancer centers and other organizations that participated in the IOLC. Samueli Foundation sponsored the collaborative from April 2021 to December 2022.

[Learn more about the IOLC.](#)



# Moving Beyond Survivorship to Include Wellness

## A NEW APPROACH FOCUSED ON WHAT MATTERS MOST TO PATIENTS

The Ann B. Barshinger Cancer Institute developed a new integrative approach that moved beyond survivorship to integrate survivorship and wellness. Dr. Oyer and his team:

- Identified the problems to be solved.
- Developed a process for moving toward wellness.
- Began implementing parts of the process.

### Problems to be Solved

After developing the vision for transforming the survivorship program at the Ann B. Barshinger Cancer Institute into an approach focused on survivorship and wellness, Dr. Oyer and his team identified the problems they needed to solve using the new approach:

- Helping patients recover from cancer diagnosis and treatment.
- Involving patients in their own recovery and health maintenance.
- Creating access for new patients and patients in active treatment.
- Matching patient needs to the right care professional.
- Involving the entire cancer care team.

### Helping Patients Recover and Making them Part of the Process

Recovering from cancer treatment and facing life without the active support and care of the cancer care team is difficult and often scary. Patients need to recover physically and emotionally and cope with worries about recurrence and other practical problems.

“We always thought that we as caregivers knew what our patients needed and what their families needed. Now we recognize that we need to have them participate in telling us what they need so we can better meet their needs,” says Dr. Oyer.

The HOPE note is a patient-guided process to identify the person’s values and goals for life and for healing so the provider can assist them in meeting those goals with evidence and other support.

*“I’m not sure people want to be cancer survivors as much as they want to be well.”*

—Randall A. Oyer, MD, FACCC

*“The HOPE note is key for us in learning what patients need.”*

—Randall A. Oyer, MD, FACCC

Patients with cancer who are involved in their treatment have better outcomes and are more satisfied with their choices, says Dr. Oyer. Moving beyond survivorship to survivorship and wellness enabled Dr. Oyer and his team to involve patients in their own recovery and health maintenance.

### Creating Access to Cancer Care

The Ann B. Barshinger Cancer Institute needed to create enough access to cancer care for people who are newly diagnosed while also helping patients who have completed active treatment recover. Dr. Oyer and his team had to determine how to do this despite an increase in the number of patients without an increase in the number of oncologists.

### Matching Patient and Care Professional and Involving the Entire Team

Matching patients with the right care professional for the task increases access to survivorship and wellness services. For example, social workers are often better trained at providing counseling and support than oncologists. Other care professionals, such as chaplains and physical therapists, can also play key roles in survivorship and wellness.

Practicing at the top of their licenses helps the oncology teams at the Ann B. Barshinger Cancer Institute meet patient needs. This also creates meaningful work for the entire cancer care team and helps team members understand their value to patients and the team.

## The Process for the New Integrative Approach

Next, the team at the Ann B. Barshinger Cancer Institute developed a process for moving beyond survivorship to include wellness, involving:

- New thinking.
- Creating an expanded team.
- Consulting others.
- Using and supporting the existing structure.

### New Focus on Wellness Leads to an Integrative Approach

Calling the end of treatment “survivorship” limited how the team thought about what mattered most to patients and what they needed. During the IOLC, Dr. Oyer and his team learned about the importance of having a wellness focus.

“My team knew that we needed a change. And once we dove into wellness, it was an *aha* moment. People knew that wellness is what our patients and we are working toward,” says Dr. Oyer. This new thinking led to an integrative approach to survivorship and wellness at the Ann B. Barshinger Cancer Institute.

***“Wellness reframed what we need to do to connect with, support, and serve our cancer patients as they recover from the effects of the cancer diagnosis and its treatment.”***

—Randall A. Oyer, MD, FACCC

## A New Survivorship and Wellness Team

The expanded survivorship and wellness team includes:

- Physicians (2).
- Advanced practice practitioners (4).
- Nurse navigators (2).
- A physical therapist.
- A manager of wellness.
- A massage therapist.
- An information services professional.
- A marketing and communications professional.
- Abramson Cancer Center partners (2).

Bringing in a Penn marketing and communications professional helps the team communicate with patients and community partners about the new survivorship and wellness approach. For example, the marketing and communications professional helps the team develop web content and other resources for patients about survivorship and wellness services.

Information services (Penn's name for information technology) has created tools in Epic to automate the integrative approach to survivorship and wellness, including a smart form that embeds the HOPE note and a smart report.

## Consulting Others, Using the Existing Structure, and Being Creative

Dr. Oyer and his team also reviewed the literature and worked with Linda A. Jacobs, PhD, CRNP, a pioneer in survivorship and founding director of Penn's Cancer Survivorship Center of Excellence. Also, they worked with Penn Lancaster's Cancer Committee and used the Commission on Cancer survivorship standards. They went well beyond those standards and are working on one standard for all oncology clinics: medical, surgery, and radiation therapy.

## Early Implementation of the New Approach

Members of the survivorship and wellness team now have a shared understanding of the new integrative approach. "They can see the benefit for the patients and they can see themselves in the picture helping," says Dr. Oyer.

While the team has made some progress in implementing the approach with a new workflow, resource lists, and information technology solutions, much remains to be done. "We have had a slow start. This is a big change," says Dr. Oyer.

## Work Toward a Standard Workflow

Five principles are guiding the design of the new workflow:

1. Help patients recover from their cancer diagnosis and treatment.
2. Involve patients in their own recovery and health maintenance.
3. Increase access for new and actively treated patients in the cancer clinic.
4. Match patient need with the care professional best suited for that need.
5. Involve the whole professional care team.



An advanced practice nurse is the primary survivorship and wellness contact for patients and their families. The team is developing a standard for when to provide survivorship and wellness services and a scheduling tool.

### **When to Offer Survivorship and Wellness Services**

New messages will be developed to inform patients that a recovery phase will follow the active treatment phase, and that a member of the survivorship and wellness team will reach out to them.

The team has not determined the best time to offer survivorship and wellness services, although they expect to do this toward or at the end of active treatment.

### **In-House and Community Resources for Patients**

An electronic list of in-house and community services and resources for wellness and recovery is being developed. Resources include the Penn Medicine Lancaster General exercise program in collaboration with two local YMCAs, bike trails and clubs, and walking groups. The Penn marketing and communications professional will help ensure that all members of the survivorship and wellness team know about and have access to the same resources.

### **Information Technology Solutions for Using the HOPE Note**

While the Ann B. Barshinger Cancer Institute has created a smart form in Epic that embeds the HOPE note, Dr. Oyer and his team need to determine how to shorten it for their survivorship and wellness approach. They may ask a single HOPE note question to start the process, such as “What does wellness look like to you?”

“For the HOPE note to do its job, it’s got to be usable in a busy oncology practice,” says Dr. Oyer.

The smart form with the HOPE note “puts the patient in the driver’s seat to say what’s important and what they want to dedicate their time and efforts to,” says Dr. Oyer. Also, the HOPE note helps the survivorship and wellness team stop focusing on the “laundry list of things” that are considered important to survivorship by Penn Medicine or are part of the Commission on Cancer form.

Whatever the team decides to include from the HOPE note, patients will complete the form before their appointments. Their answers will become part of the patients’ charts. If the patient did not complete the form in advance, the medical assistant or the physician will go over it with the patient or ask the patient to complete the form and bring it to the visit or mail it in. A smart report in Epic will enable the team to review and analyze data.

### **Survivorship, Wellness and Primary Care**

The Ann B. Barshinger Cancer Institute has also started to integrate survivorship and wellness with primary care. “Primary care is a key component of wellness and hopefully a long-term plan for our fully recovered patients,” says Dr. Oyer.

## Key Insights for Implementing an Integrative Approach to Survivorship and Wellness

### **Inventory resources and determine priorities.**

The first step in making a major change, such as expanding survivorship to include wellness, should be inventorying available resources and determining the priorities for the new approach. Priorities for the Ann B. Barshinger Cancer Institute were to:

- Help patients recover from cancer diagnosis and treatment.
- Involve patients in their own recovery and health maintenance.
- Create access for new and actively treated patients.
- Match patient needs to the right care professional.
- Involve the entire cancer care team.

### **Create a vision, including the need for implementation.**

Dr. Oyer and his team developed a vision for survivorship and wellness at the Ann B. Barshinger Cancer Institute to focus on what matters most to patients in helping them recover from a cancer diagnosis and treatment.

The team set out to create a vision that was compelling and beneficial to patients and to allow members of the cancer care team to better understand their role in helping them reach their goals. They agreed that they would not be too rigid in planning so that there was some room to modify.

### **Consult others who are doing similar work within or outside of your cancer center.**

Within Penn Medicine, Dr. Oyer and his team consulted Dr. Jacobs, a pioneer in survivorship who worked with the Cancer Committee. Through the IOLC, they were able to learn what cancer care teams at other cancer centers were doing and get feedback on their own work.

### **Develop a team and a plan.**

Dr. Oyer started with the current survivorship team and expanded the team to include professionals such as social workers, advanced practice professionals, and physical therapists. He ensured that all team members had meaningful work and understood their value to patients.

As part of participating in the Integrative Oncology Learning Collaborative, Dr. Oyer and his team developed an implementation plan. Along with identifying team members, the plan included identifying the problems to be solved and starting to implement the process for the new survivorship and wellness approach.

### **Dream big and think big.**

“When you’re doing something that’s different, it allows you to focus on what you really want to accomplish,” says Dr. Oyer. “Rise above the day-to-day of what you’re already doing. Dream big, think big.”

Dr. Oyer and his team set out to be creative in designing and achieving change. He worked with team members to improve ideas and build small pieces into a new approach or program.

## Challenges and Lessons Learned

Dr. Oyer and his team faced the following challenges in moving to an integrative approach to survivorship and wellness and learned the following lessons.

### **Communicating the new survivorship and wellness approach and obtaining buy-in was difficult.**

“The concept was really too nebulous for people to be able to see it or see what we could accomplish with such a change,” says Dr. Oyer. “For change to be possible, we need to explain what needs to be done, why it needs to be done, how it will benefit our patients—that is always everyone’s primary concern—and how we are going to get it done. We need to have the right people at the table.”

Dr. Oyer began with verbal communication with the people who were already doing work related to survivorship. He described the problem he was trying to solve, why it needed to be solved, who needed to be part of the solution, and what team members could do. After communicating the overarching ideas, he then let the team communicate among themselves.

### **Shortening the HOPE note for routine use in a survivorship and wellness approach.**

“The initial analysis from our front-line care team is that the HOPE note is terrific, but it is long, in depth, and could be difficult or off-putting for some patients and for some providers. We are going to shorten it,” says Dr. Oyer.

### **Change takes time.**

Big changes like this often take more time than expected. Starting slowly let team members learn the new process and get comfortable with doing things differently.

## An Energized Team

Despite these challenges, by the end of the IOLC, the survivorship and wellness team:

- Was excited and energized about the new survivorship and wellness approach.
- Had the outline for a format for the approach.
- Had a draft list of resources.
- Was able to envision the next steps to move the approach forward.

## Making Whole Person Cancer Care Routine Through Collaboration

Along with developing an integrative approach to survivorship and wellness, the team from the Ann B. Barshinger Cancer Institute worked with teams at other cancer centers to review and discuss the current state of the science and gaps and future opportunities in whole person cancer care. They also helped create, test and refine the HOPE for Cancer Care tools.



## Benefits of the Integrative Oncology Leadership Collaborative

### A NEW ATTITUDE TOWARD WELLNESS AND A NEW APPROACH TO HELPING CANCER SURVIVORS

**D**r. Oyer credits the shift from survivorship to survivorship *and* wellness at the Ann B. Barshinger Cancer Institute to his team's participation in the IOLC. "It's a totally different approach," he says. "We probably wouldn't have been able to do this if the Integrative Oncology Leadership Collaborative hadn't changed our thinking."

#### Learning from Other Cancer Care Teams

The survivorship and wellness team met and learned from 13 other oncology care teams. "The Integrative Oncology Leadership Collaborative created a forum for my team to talk about their work, get feedback, and feel good about what they've accomplished and what they can teach others," says Dr. Oyer.

#### A New Respect for Wellness and Integrative Cancer Care

Before joining the IOLC, Dr. Oyer considered wellness a "new age concept for other people, not for people in the business of cancer care." Leaders in the collaborative helped him understand the importance of wellness, the patient's perspective, and the benefits of whole person cancer care. Dr. Oyer also expanded his view of integrative therapy to include exercise, lifestyle modification, mind-body practices, and natural products.

*"I have a whole new respect for integrative care. I met some new professionals, patients and advocates whom I admire very much."*

—Randall A. Oyer, MD, FACCC

Focusing on what matters most to the patient was the most important lesson Dr. Oyer learned by participating in the IOLC. He considers this a refinement of shared decision-making that focuses on what matters most and lets each patient know that the provider cares and is listening.



## Next Steps

### REFINING AND ADDING PROCESSES FOR SURVIVORSHIP AND WELLNESS CARE

**D**r. Oyer and his team continue to work on the Ann B. Barshinger Cancer Institute's survivorship and wellness approach. They are completing the work they started and putting more processes in place to standardize survivorship and wellness care within the institute.

#### Moving Implementation Forward

The survivorship and wellness team will decide how to shorten the HOPE note for use in cancer care and put this into the workflow. The team will complete the electronic resources list and link this to Epic and wellness-survivorship care visits.

Information Services is working with the team to identify patients who are ready to schedule wellness-survivorship care visits and automate the process by:

- Developing a provider smart form for wellness-survivorship care visits.
- Creating a workflow for referral from wellness-survivorship visits to support services.
- Developing scheduling templates that make wellness-survivorship appointments available in medical, surgery, and radiation oncology.

Also, the team is:

- Working with patients and providers to determine the best time for a wellness-survivorship visit.
- Developing a consensus among providers and teams on which department will lead survivorship for specific diagnoses, stages, and treatment paradigms.
- Seeking provider agreement on the scope of care for the wellness-survivorship appointments.



## Endnotes

- 1 OncoLink. Did You Know... The Facts About Cancer Survivorship? [www.oncolink.org/support/survivorship/cancer-survivorship](http://www.oncolink.org/support/survivorship/cancer-survivorship) (June 2022). Accessed 11/22/22.



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**On Social: @DrWayneJonas**

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