

# 1st PERSON



## Passport to Care

by Peg Pamiawski, MSN, RN



In 2007 the Norma F. Pfriem Cancer Institute at Bridgeport Hospital initiated a patient navigation program led by oncology-trained nurses. One challenge identified by our program's patient navigators was that patients did not have tools to empower themselves on key aspects of their oncology care. Patients undergoing cancer treatment are often lost in an absolute maze—regardless of the care setting—as they travel to multiple tests and treatments, points of care, second opinions, and doctor visits. Coupled with the psychosocial and emotional burden of cancer diagnosis and treatment, this maze can be overwhelming to both patients and their caregivers. Our charge is to:

- Guide and support patients and families through the healthcare system.
- Educate patients and families about the patient's cancer

diagnosis and treatment plan.

- Assist patients with resources to overcome barriers to care, such as transportation; prescription assistance; financial, language and cultural barriers; psychosocial support; and caregiver coping.
- Develop a communication bridge between patients and their healthcare team.
- Help patients to coordinate and prepare for their appointments.

Over the past three years, we have developed a unique tool to help realize these goals: a portable, streamlined, patient-friendly document we simply call our *Passport*.

Working under the assumption that *more is better*, our initial Passport was a three-ring binder titled, *The Patient Passport, "Compass for Continuity of Care."* We piloted use of this binder through our patient navigation program. In the process

our team found that most of the information included was actually not required by the patient or caregiver, but was information that provided a guide for navigation. We also recognized that as our patients' treatment continues, they are often in a weakened state. Carrying around big binders is not an activity they can easily manage. Based on patient feedback and staff observations, the navigators were concerned that the binder was a daily reminder of the patients' cancer diagnosis. We respect our patients' privacy and understand that most do not feel comfortable advertising their diagnosis. In response, we adopted a *less is more* approach, and began work to streamline our tool.

We decided to re-design the Passport to resemble a "travel" passport to accompany the patient along their cancer journey. The team recognized the value of the tool and garnered

input from key staff at our Cancer Institute in downsizing the Passport. The Norma F. Pfriem Cancer Institute team is multidisciplinary and includes patient navigators, advance practice nurses, physicians, dietitians, pastoral care, and social workers. This team is focused on supporting our patients during their cancer journey but also allows as much autonomy as possible. It is important for patients and their caregivers to maintain their independence and not become

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Oncology nurse navigator Donna Gonsalves, RN, OCN, (on left) and medical oncologist Robert Folman, MD, (on right) review the Passport with a patient (in center).

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dependent on their support team at the Cancer Institute.

In revising the Passport we researched exactly what our patients need to assist them with coordination and communication of care. We reviewed other documents that were available and found that most were very detailed, therefore not meeting our needs. Working with our marketing department, we designed an affordable, concise notebook that could be easily revised if needed in the future. The project team included collaboration with our physician leaders, our marketing department, our patients, and our nurses. The “revised” Passport was created using a card-stock notebook that is very portable and can easily fit into purses. Our Passport captures the following information:

- My Doctors (a place to list all physicians and their office phone numbers)
- Phone Numbers to our Cancer Resource Center (Communication Hub)
- Other Members of my Healthcare Team (includes community referral agencies along with phone numbers)
- Family History of Cancer (the next revision will include a Genetic Risk Assessment)
- Cancer Treatment Summary
- Chemotherapy
- Radiation Therapy
- Surgery
- Clinical Trials
- Access Device Information
- Survivorship and Post Treatment Plan
- Healthy Behavior Recommendations
- Doctor Visit Schedule (which physicians to see and how often)
- Recommended Cancer Screenings
- Appointment Planner. Because preparation for physician appointments is essential, we included several templates for appointments in the back of the passport. Our patient navigators encourage patients and their families to log questions between appointments

The Passport is designed to travel with patients along their cancer journey.



so they do not forget to ask when they are in the office. The template includes a space for note taking during the appointment, so that the patient or family member can document any key information during the visit.

- Other tools, including a pocket calendar and a pocket medication card, which includes medications, vaccines, allergies and OTC medications, vitamins, and herbal supplements.
- Our patient navigators typically staple or clip their business card to the document for the patient. We are currently looking to add a plastic cover to hold the Passport and other documents.

Our patient navigators introduce the Passport to the patient and support persons at an early visit and assist the patient with filling in the initial information. The navigator reviews the components of the Passport with the patient and caregiver and shows how to use the tool to document and update cancer care information. For example, where to note side effects, questions about next steps, resources, complementary therapies, and nutritional consults. If the navigator knows of an upcoming scheduled office visit, he or she will assist the patient and/or support person to document questions for the physician prior to that appointment.

The Passport also helps by requesting information. For example, the Passport asks for information

on the patient’s personal healthcare representative and power of attorney if applicable. If the patient has not already developed an Advance Directive, we encourage the patient to do so, and provide assistance if needed. In addition to providing a summary of the treatment plan, the navigator helps our patients to obtain any additional information they need or want before their treatment begins.

Our patients have readily adapted to the new format and are putting their Passports to use. Recently, a patient who was admitted to our ICU and then transferred to a tertiary hospital for specialized services called her navigator to tell her how well received her passport was by the other hospital’s treatment team. We believe sharing and networking with our healthcare partners is one way our team can make a difference in patient safety and compliance for people with cancer. Even one of our most non-compliant patients arrives for her treatment with her Passport neatly stowed in a plastic zip-lock bag with her calendar and medications card.

We are so proud of the work done through collaboration among our team members. We have built a program that provides our patients with cost-effective comprehensive care and support systems. ☐

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