

# CANCER SURVIVORS

---

## SYMPOSIA SERIES

*Issues & Solutions for Life After Cancer*

### ***New Approaches to Survivor Health Care***

**May 14, 2007**

#### **Survivorship Care Models**

##### ***Mary S. McCabe, RN***

*Ms. McCabe is the Director of the Cancer Survivorship Program at Memorial Sloan-Kettering Cancer Center. She previously served in leadership roles at the National Cancer Institute, including Assistant Director of Division of Cancer Treatment Diagnosis. She participates on several national committees with NIH and NCI and serves on the Scientific Advisory Committee of the Lance Armstrong Foundation.*

Thank you, very much, for this invitation. Thank you, also, for the wonderful weather that you have provided for us this evening. Coming from Manhattan, I have to say that I especially have liked your rush-hour traffic.

I think all of you probably know who this individual is. He's probably the most famous cancer survivor, not only in the United States but perhaps even in the world. He can probably also bring to bear any and all follow-up care that he would need. But that leaves us still with the question about how the other over 10 million cancer survivors in this country can and should be accessing their follow-up care. Dr. Hart gave us an overview about cancer survivors and who they are, what some of their issues and problems are. Dr. Earle talked about the cancer care plan. What I'd like to do in the time that I have is to pull those things together and talk about what we're doing around the country to really think about formalizing a set of services to provide to cancer survivors and their families, that are being tried out and hopefully will, over time, be evaluated as models of care. As Dr. Earle said, there won't be one size that fits all. What will work in a small rural community may be very different than what will work in a large metropolitan cancer center. But there are some core things that are important to include and also that all of you and your family members should really begin to think about as being important to your follow-up care.

As Dr. Hart mentioned, there is fortunately quite a large and growing emphasis on survivors and survivorship care in this country. Perhaps one of the main reasons is that it is beginning to be hard to ignore over 10 million people and their needs. Also accompanying this is an important addition, in that there has been a greater emphasis over the last five to ten years on patient-centered issues in health care by the medical

community and others, looking at not just the quantity of life, how long does a person live, but what the quality of the that life is and what it's like. I think a lot of the patient advocate organizations in this country have certainly brought to our minds, as health care providers, the expectation that patients have for good quality of life.

How are we going to go forward with the young adults that we have who were treated as children? We know that the earlier that an individual is diagnosed with cancer, the potential for late effects is greater and problems that they may have as they grow older. Also, how are we going to take care of the survivors who are older adults diagnosed in middle and later in life, who also may have what we call comorbid conditions? They may also have cardiovascular disease. They may have diabetes. How does that relate and impact their cancer and their cancer care? The other question is, Dr. Earle showed us some of the domains that effect and may be of concern to cancer survivors and their families, and how are we going to make sure that the follow-up care that we develop and the models that we implement and evaluate really do focus on all of the issues that are of importance to our survivorship community – not just the medical issues such as lymphedema, such as fatigue, as were mentioned by the other speakers, but also the psychosocial concerns? Fear of recurrence, as Dr. Earle mentioned, is really a universal for all individuals that have been diagnosed and treated for cancer. Sometimes it can be just very transitory around the time of the exam, of the scan, of the surveillance that is done. But for some individuals we know that it can be problematic and we want to be able to intervene and address the problem. Anxiety and depression, although not common in cancer survivors fortunately, can be very serious for those individuals that it effects. These are people that we don't want to have fall through the cracks and we can actually help them alleviate these problems. The social issues Dr. Earle also mentioned, and I would say that we, as health care providers, need to do a much better job in referring people to community resources and information, accurate web-based information about economic issues and resources, and places that individuals can go if they are facing discrimination in the workplace. Or, how do young people find peers around their community who also have return-to-school problems? How do you get your first job? How do you write a resume when you've spent a good deal of your college life getting chemotherapy? Informational needs are tremendous. I think that is something that goes hand-in-hand with any kind of survivorship care plan and follow-up clinic that we set up. People are in need of ongoing information because things change for the better. We get new medical information that actually impacts what people can and should be doing to assure quality of life for them after their diagnosis and treatment. But we need to have trusted resources. All of us know there is a lot of junk out there on the web. What we really want to do is to be able to refer and have people use accurate information in making decisions.

This diagram turns the negative consequences of cancer diagnosis and treatment into positives, in looking at how to maintain quality of life. One of the things we really want to look at is overall well being – physical, social, psychological and spiritual. When thinking about how we develop a program with a set of services that really maximizes all of these domains which are important to people, we really can take this as a guide in moving forward.

There is a rationale that we can state for why we need long-term follow-up programs, rather than having things done the way they are now. As I have said, and the other speakers also, we have this large number of individuals who need and should have organized care. We are developing a greater understanding of the consequences of cancer and its treatment and, therefore, we really are able to better set up a formal system of care. There is a greater focus on applying interventions to eliminate and reduce sequelae now that we understand the sequelae better. Rather than just describing them, we really need to be much more focused on doing something about them. That leads to using these forums of care to conduct research. We have a tremendous amount of research that still needs to be done about the post-treatment period and what happens to individuals once they've completed their treatment. Over the next number of years we also need to begin focusing on survivorship education and training of health professionals. There aren't really fellowships in this thing. Again, it's a new area. Survivorship care is new in terms of even having clinics and focusing on the post-treatment period. So much of our emphasis as health care providers up until now has been on diagnosis and treatment. A number of our cancer centers are thinking about how we begin to do training of physicians, nurses, and social workers focused on this period of care.

What we have now is a usual practice. Dr. Earle mentioned a number of different scenarios that can occur and I'm sure all of you have your own story to tell about how follow-up care is delivered in your own communities. But oncologists routinely do follow their patients and often will say that they follow them for life. But the duration of this follow-up is variable. It can be variable because people move. People in Manhattan get tired of paying \$25 a day to park. So there are all kinds of things. Your employer may change your health care and the doctor you were seeing is no longer in-plan and you would have to pay a large amount of money out-of-pocket. By and large the follow-up care has been focused on surveillance for recurrence only. As Dr. Earle said, there are varying amounts of evidence as to whether this is both useful and has any impact on long-term survival. We've also discussed that there is a limited transfer of knowledge to primary care providers. Most of us all have an internist, a family practitioner, who we see in addition to the oncologist, but the gap is in communication.

So, in thinking about how to develop a program, how to develop services, whether they are in the community or in an academic medical center such as the Massey Cancer Center, there are some components that can be applied no matter if the place is big or little and no matter if you have large resources or a limited number of resources. I think we will continue to see and hopefully more and more will limit it to where there is the evidence of surveillance for recurrence and also for new second cancers. Encouraging, and then really getting people to be screened for other malignancies. One would hate to have a woman who was successfully treated for breast cancer not get a colonoscopy and be diagnosed with colon cancer at a late stage rather than early when it can be taken care of. Also, one of the most important areas is really to intervene for the consequences of cancer and its treatment where we can, and then to develop and use the care plan, the treatment summary, to be a communication tool not just for the patient to use with providers, but also between cancer specialists and the primary care physician.

In trying to figure out how to go forward and how to set up clinics, how to set up models that we then can evaluate and refine, we fortunately have had a very nice model. The physicians that have been way ahead of the adult community are the pediatric physicians and nurse practitioners who have for many years had long-term follow-up clinics. They are usually freestanding, meaning that the care is provided in a place different than where the treating physicians see patients. They are multidisciplinary so they include physicians, nurse practitioners, and very often a nutritionist or psychologist. Because, fortunately, these diseases are rare, they are not disease-specific clinics so that children, teenagers and perhaps young adults of many different diagnoses are seen by the same team. Very often they approach things on what they called risk-based care. The more likely an individual is to have problems or most likely to have a recurrence, the follow-up care is really thought about in that way. Whether the individual needs to come back long-term for many, many years depends on those risks.

In the adult community, I'll just tell you a little bit about some of the pilots that are being done at many of our institutions and practices. In the adult area, as I said, we're really learning from pediatrics. Some institutions have begun what is called a consultative model. It's a very fine start in term of really providing, in a one-time visit, a treatment care plan with also an ongoing systematic plan for surveillance (how often should someone come back and what kinds of tests will be done). This can be shared with other physician groups. In our own institution we've chosen to really pilot an ongoing care model where the nurse practitioner is the individual who sees the patient at a pre-determined period (either six months, one year, or two years post-treatment). What we are intending to do is really extend the care continuum past diagnosis and treatment and then, now, into follow-up. The nurse practitioner actually sees the patient, and I hate to use the word imbedded, but really is working right alongside the treating physicians. The patients come back to a familiar place. When we did focus groups with our own patients we found that our physicians and nurses didn't like to see the patients that they had treated and were doing well leave them. When we did focus groups with our patients, our patients said they really liked to be close, near and around the care providers who they feel had saved their lives. That's the rationale for why we set up our clinics the way they are. The nurse practitioner sees the patient, but the treating physicians are nearby if there are questions or problems that come up. It's a space intensive effort to do this, but it's one model that we're evaluating among many of our cancer centers around the United States.

The other model is a very important one. It is also very resource intensive because of the very large number of adult cancer survivors. It is a multidisciplinary long-term follow-up model where, very much like pediatrics, a whole team is available to see the patient on an ongoing basis.

One of the most important things in any of these models is the idea of sharing care. We've talking a lot tonight about the oncologist's role and the primary care physician's role. Going forward, I think that we will begin to see more and more of this kind of relationship, not only because of the workforce limitations that Dr. Earle described to you, but also because more and more the long-term consequences of treatment are related and impacted by the consequences of aging. So somebody who is following the individual for their internal medicine problems also needs to know about the cancer treatment and the

problems that can be caused by the treatment itself. So the shared care basically is pretty simple by definition. It's two or more clinicians of different specialties, as we talked about. As Dr. Earle mentioned, part of our problem is that there hasn't been a common understanding of who does what. That is one of the things that the care plan really can do. In our institution we really do set out who does the cancer screening, who is responsible for overseeing that and recommending it, and who does what. This can only happen with improved communication. And the patient clearly has such an important role in helping that communication be really developed and carried out.

This slide shows you a summary from the Institute of Medicine's report *Lost in Transition* that has been discussed. What I wanted to do was to demonstrate to you that a lot of shared care already goes on. This was a survey done of primary care physicians, asking them about cancer-related visits. Of the 20,000 visits that they identified, almost half of them involved shared care about a cancer-specific problem.

This schema is just intended to show you what we're really trying to do nationally through these pilots, not only with the care plan but follow-up clinics, to extend this continuum, to make it more seamless so there isn't a sudden drop-off after treatment. I think some of you may be cancer survivors who were treated in the past where, at the end of treatment, it was a celebratory time on the part of the health professionals, but for you it was very often a very scary time because you always knew what was going to happen during treatment. You knew about the radiation schedule. You knew the chemotherapy schedule. You knew how often you came in for your counts, for your treatment. But then, once the treatments stopped, it was all of a sudden a very scary indefinite period without a plan. That's why we really want and need this focus, so that we can not only extend the continuum in an organized productive way, but make sure that people have a game plan, in particular the individuals who are responsible for your care and follow-up.

This slide is just to show you that we are beginning to learn about the ability of the community physician, the family practitioner, to provide quality care to cancer survivors. It is a study that was published by Dr. Eva Grunfeld in the *Journal of Clinical Oncology* in 2006. She reported on a study that was done of over 900 women with early-stage breast cancer who participated at the end of their treatment and were randomized to either be followed by a family practitioner or by a cancer specialist. What this shows is that the family practitioner provided just as good care as the cancer specialist did in terms of being able to detect recurrence and also serious clinical events.

On a very personal level, and specifically to those of you who have been treated for cancer, rather than just talking about programs and large institutions, what can you do so that individuals are no longer lost in transition and how do you get things started?

First of all, one can begin to expect good communication between your oncologist and the primary care providers that you also see. You can begin to talk about how that communication system might work and recommend that a survivorship care plan be developed for you.

Another way you can take charge is to look around at what is available in the community. What kinds of things could enhance your quality of life, not just medically, but psychosocially? Nutritional counseling. Smoking cessation, if you or members of your family still smoke. Physical rehabilitation. We know that sometimes the chemotherapy treatment, particular surgery, and radiation sometimes actually have impact on one's ability to function. There is a lot that can be done especially by physical rehabilitation specialists who understand the oncology patient. There are support groups, I'm sure, that are being provided around your community by many good groups such as Gilda's Club and others.

Also think about new services that you want for yourself that you could recommend to your oncologist that they should begin to incorporate or refer people to. In my own institution, when we talked to patients about what they would have liked to have had when they were going through and finishing treatment, there were two very important things that they mentioned. One was reproductive medicine and fertility preservation. Our younger patients wanted to have families and wanted to know how they could go about this both pre-treatment and even after treatment, what could be done. They really wanted access to quality individuals who they could be referred to. Legal and financial issues come up. We've been asked repeatedly to have experts come who could help cancer survivors with their post-treatment problems in the workplace and also with respect to how to get back on their feet financially. Even the parents who have a child that is being treated for cancer, the co-pays over the period of x-number of years can be financially devastating for a family. These are the kinds of things that we need to think about in addition to treating the disease.

In closing, I'd like to leave you with these two quotes. One is from a very famous cancer survivor and one is from one of our young Hodgkin's cancer survivors who is anonymous. Each of these quotes really makes the point that survivorship is a distinct phase of care and what we really need to do is make it about maximizing quality of life for people and their families. Thank you.