I like Laura Linney and think she is a good actress, so I was very curious about her new series on Showtime, The Big C. Have you seen or heard about it? It’s described as a comedy about a woman with stage IV melanoma who knows she has a life-limiting illness, which allows her to make drastic adjustments to the way she lives her life. In the first episode, she refuses treatment, chooses not to tell her family and friends about her diagnosis, and starts eating desserts first. The show actually made me sad because I saw many missed opportunities for disclosure and support. I wasn’t sure how a show like this would be received but was impressed by the number of blogs from people with advanced cancer commenting on how refreshing and inspiring it is. And it is providing a forum for people to talk about what has been one of the last taboos in cancer—living with advanced disease.

In reflecting on all the progress we have made in risk reduction, detection, and treatment of cancer, I think we have begun to address the transition from active treatment to the next phase of active surveillance. For those with no evidence of disease at the end of treatment, this is often a time when patients assimilate the cancer experience into their life and world. We develop survivorship care plans and other resources to facilitate life after cancer, but we have yet to tackle the needs of those living with cancer and treatments who hope to control their disease and manage symptoms, but not necessarily cure them. In our current paradigm, you are either cured of your cancer or dying from it. We need to change this outdated paradigm to one that includes people who may be living for years with their disease and may be on and off treatment for the rest of their lives. So what type of survivorship care plans should we be developing for them? P.J. Haylock, PhD, RN, guest editor of the August 2010 issue of Seminars in Oncology Nursing titled “Living With Advanced Cancer,” addresses many of the concerns of this growing population, including coping with disease and treatment, symptom management, information, and communication needs.

So, how do patients live with advanced cancer? Do they go through dramatic changes like Laura Linney’s character? In my career of 30-plus years, I have known only one man diagnosed with advanced cancer who left his job and family and moved to a Native American reservation to make jewelry. More often, I have known those who reevaluated their lives to make changes—whether subtle or not so subtle, abrupt or gradual. Some of those changes have been needed to accommodate the disease and treatment. Others have been the result of facing a life-limiting illness and asking, “Am I living the life I want to lead?” As one survivor told me, “I think a lot of people don’t change much except to slow down and realize what a great life they have and how much love and support there is. A wonderful gift!”

Our current analogies of beating cancer do not apply to those living with a disease that is in check, in remission, or dormant. We have seen this shift as almost 70% of U.S. deaths are now related to chronic illnesses, such as heart disease, cancer, stroke, respiratory diseases, diabetes, and Alzheimer disease (Heron, 2010). What can we learn from the management of other chronic illnesses that may apply to people living with advanced cancer? What can we learn from those who have learned to live with their disease in a resilient manner? How can we share those lessons with others? Haylock’s August 2010 Seminars in Oncology Nursing issue is prescient in thinking about the needs of this overlooked population of cancer survivors. They are not just forgotten, but in many cases, ignored, leaving them with few resources or sources of support. We don’t even know how many survivors are living with advanced disease or what their unique needs are. If you recall, through research and practice, oncology nurses brought fatigue to the consciousness of other providers. As we develop survivorship programs, let us be sensitive to the language we use and to the programs we offer to be inclusive of or specifically target this group. Let us bring awareness to this group of survivors as we did with fatigue. And, every now and then, eat your dessert first!

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