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## The value of being elderly

**Ms Knox:** Hello everyone, my name is Susan Knox and I'm the former CEO and Executive Director of EUROPA DONNA, the European Breast Cancer Coalition in Milan. It's a pleasure to be with you today. But when I was asked to give this speech, I had to ponder it. And I decided I don't really think of myself as being elderly, so I changed the name of the presentation and decided to call it Getting Older, Better and Wiser. I'm not going to talk so much about my advocacy work today, but rather the fact that I was diagnosed with breast cancer twice, once in my early 40s and again at 65. So, I think it's important to underline the differences between being diagnosed at an early age and being diagnosed at a later age. "Two roads diverged in a yellow wood, and sorry, I could not travel both and be one traveler, long I stood and looked down one as far as I could, to where it bent in the undergrowth." From "The Road Not Taken" by Robert Frost. "The Road Not Taken" is definitely a theme for my life. Recognizing the individual and not their age is exceedingly important. Some lives follow a linear pattern or some form of it, proceeding in a fairly straight line through school, to career, to family and retirement. Others like mine are more of a zigzag going up and down with changes throughout in career and lifestyle because of what life gives us and what we want from life. In my twenties, I went from being a concert pianist to doing music therapy, to hospital administration. And then when I was 30, my husband died of cancer, and I took a break and went to Siena to study music. And then I came back to New York City, and I completely changed my career and went into banking, which I did for the next 10 years. But that's what led me to Milan. When I was 35, both of my parents passed away and I realized that I could now take off on whatever road I wanted to follow. So I asked the bank to transfer me to Milan, where I've lived now for more than half my life. So the next part of my life was really becoming a mother. And that was extremely important to me. It was really my life's dream and the happiest moment of my life, only to be shattered two and a half years later when I got breast cancer at the age of 44. This was a moment of huge fear and anxiety. There was less time to recover because I certainly had family and financial responsibilities and concerns. There was a lot of uncertainty at that time and there was no information available. There was really no internet available in 1991. But I got surgery and radiation at the Istituto dei Tumori in Milan. And finally, I started to look all right, and in time I felt all right. But I had a huge fear of leaving my child to grow up without a mother, so I left my career at the bank, did independent consulting and spent time with Marco for a number of years, because I really did not know what the impact of the disease and the treatment was going to be on me. And in time, I recognized that I would be fine. And I was, so in my early 50s, my marriage having ended, I went out to seek a new career and answered an ad in an English newspaper for Europa Donna, the European Breast Cancer Coalition. And here I thought to myself, "Well, I can make a difference because my experience having had breast cancer could be an important thing in helping women and helping to improve breast services in Europe." The European School of Oncology gave us an office and a computer. We had no funds of our own at that time, we were certainly not independent. We had a small board and a small number of members. So, I worked for the next five years to develop the organization, to raise funds from

sponsors, to work with the commission and the parliament on breast cancer directives, and to set up advocacy training, and to hire a staff. So that finally we were independent, had our own office, had many members, and we were establishing ourselves as Europe's Breast Cancer Advocacy Organization. But then again at 65, I was diagnosed with breast cancer once more. At that time of course, I had much more knowledge about the disease, and I had much more time to look into treatments. But also, I had people in the field who could help me navigate my treatment. So, Alberto Costa and Aaron Goldhirsh were instrumental in helping me at that time to determine what treatment I should take and what kind of rehabilitation I would need afterwards. So, I went to the European Institute of Oncology for surgery, and my first goal was to attend my son's graduation from university in the United States. And everyone told me I would be fine in three months and could do that. And indeed, I was, but I was taking aromatase inhibitors and I had significant side effects for a number of years because of these. So, I started an exercise program, walking five kilometers a day, something that I still do. I did Tai Chi. I did Pilates. I did laser treatment because I had trigger finger and tendonitis and I really didn't want to have an operation on these. But I think the important thing about being older was that I had the time to do all of this, to talk to people, to do research, to go online and see what kinds of problems other women were having. And there was time for recovery because I really didn't have the responsibilities for my family anymore. My son was already grown. So, there was much less anxiety about being diagnosed at 65. There was freedom and flexibility. There was time to enjoy my family. And indeed, there was time for advocacy. There was time for my advocacy career, to travel, to work with members of the European parliament on resolutions, to set up advocacy training, to visit our country members, to work on the European Breast Cancer Conferences, to work with our wonderful board, many of whom are made up of women who are over 65. And indeed, in February 2020, to be present at the launch of the Beating Cancer Plan with our dear friend, Stella Kyriakidou, who's now the EU health commissioner, but was many years ago the president of Europa Donna and herself, a breast cancer survivor. So, it's been an exciting time and we've been able to establish many things. These are the balloons that we presented at the 2019 Pan-European Conference in Vienna, but it does just give you an idea of the very many projects and activities that Europa Donna has conducted over the last 25 years, 23 of which I have been present for. And so, it has never been dull. It has never been boring. It is constantly an inspiring experience to work with the incredible advocates and people that we work with at Europa Donna. So, what's important, I think, for everyone to recognize is that one size does not fit all when it comes to treatment for breast cancer and chronological age should not be the basis for treatment decisions. It is essential that we do individual assessments of the health status of each patient. And that patient doctor communication is key to making the right decisions for each patient. Decisions on treatment really must take into consideration the patient's quality of life, expectations, and lifestyle. And decisions on treatment have to take into consideration her decision to live longer, or to have a better quality of life sometimes. Background, beliefs, education, culture, all play an important role, possibly more important than age. Patients really know what the impact of treatment will be on their quality of life. They need to understand what survivorship looks like, not just at three months, but at six months, at one year, at two years, even at five years, because there's a major amount of followup and rehabilitation that may be necessary at different times after treatment for this disease. And it's important for them to have a description of likely side effects. It's far more important to know what to expect than to not be aware of it and then to be shocked when something happens to you. And if treatment risks are different as age advances, then women should know about that. It's quite important. Above all shared decision-making between doctors and patients is really essential. While doctors have to base their diagnosis and their treatment concerns on data and research, they also need to practice medicine with people, and that is a true art. So, they need to invite the patient to participate. They need to present the options because there very often are many options. They need to provide information on benefits and risks to weigh options, to facilitate deliberation, and to assist with implementation. All of this is really essential. You must get to know the human being that you're dealing with. It is not just enough to tell them what sort of treatment they need to take. Patient goals and clinician goals may differ. Patients often want quicker, simpler treatment, to stay home as long as possible, to overcome these troubling side effects I've described, to continue to care for family, which

is so important, particularly in the younger patients, to manage pain and be able to sleep, to stay in a local area and not have to travel far for treatment. I've known many women who have preferred mastectomies because they don't want to travel for radiotherapy. And to receive end of life care at a hospice or receive this care at home if it becomes necessary. So, doctors need to find out quite a bit about each patient. Does she have a social network, a family, a relationship, a job, significant health issues? Is she able to access the various treatments and is she prepared for the side effects? And really what her values are. I may be a less is more kind of person, but there are many patients who really want to have the most aggressive treatment they can to deal with their breast cancer. So, you need to know whether the patient will benefit from standard treatment or do the risks outweigh the benefits. Well, I think we all know that life expectancy is increasing in Europe with screening programs and better lifestyle. Many people are reaching older ages in much better health. Here are some of them, but we all know many people in public life who are still active and working in their 70s and 80s. And I have to say that there are many Europa Donna advocates who are leading our countries at these ages as well. So, if 70's the new 50, 90 might be the new 70. Patients need and deserve treatment based on the person, on the individual, on their values and background, not on their age. So, am I older? Well, yes, I am. I'm 75 this year. Better? Yes, I think so because my health is fine, and life's key concerns are resolved. I am 10 years from my last breast cancer diagnosis. My son is grown, living in Paris with his fidanzata, a management consultant. And I am free to pursue interests, practicing the piano, visits with friends and family, and of course, advocacy work. While the greater part of my life may be over, I'm also relieved and feel liberated and content with what I've done and at peace, but still convinced that new challenges and adventures lie ahead. During COVID lockdown, I experienced a new appreciation of enjoying nature and walking on the beach each day. It was exhilarating and somehow gave me new strength, both physically and spiritually. And I have to say that many of our Europa Donna leaders showed such resilience during this COVID period, perhaps because they had already been through breast cancer. I retired this March as the CEO of Europa Donna but remain involved on a voluntary basis as senior policy advisor and still serving on the Guideline Development Group of the European Commission Initiative on Breast Cancer, and on the steering committees of the MINDACT trial and AURORA. I could not really retire from breast cancer advocacy or Europa Donna, as it's a cause I will always believe in, to improve breast services for women. And I'll continue to interact and be involved with all the incredible advocates and friends I've known over the years. So, I will remain part of this forever and want to dedicate this lecture to two of the finest human beings I've ever known who dedicated their lives to breast cancer. One, a scientist, Aaron Goldhirsch, and the other, a committed advocate and friend, Karen Ben who died of metastatic breast cancer last September. "I shall be telling this with a sigh ages and ages hence. Two roads diverged in a wood and I, I took the one less traveled by, and that has made all the difference." Yes, indeed, it has made the difference. I took the road less traveled, and it has been rough at times, but I have learned many things as a result, so I would not change it. And I would not go back and take another road. It has been and continues to be an exciting adventure and exciting journey. Breast cancer does not need to be the end of that, nor does advancing age. While forevermore is shorter than before, the journey is not over. There are more wonderful times ahead. There's more advocacy work to do. And for sure, there's a lot more music in my future, but I'll repeat it again as I end my presentation, breast cancer does not need to be the end of exciting adventures and the exciting journey that life is, nor does advancing age. Thank you.