

# Ali Xhixha Tirane, Albania



"Let he who would move the world first move himself"
Socrates

I believe my life experience is also my leadership story. My character, every curve and turn in my personal parcel, every element of my style has been formed by my life experiences. Trying truly to understand my past and present has helped me decide who I want to be in the future.

My lovely country of Albania has its history. I am especially interested in the period1990, because this is the year that divides my life in two.

Communist Albania (1944-1992) was one of the worst dictatorships in Europe. Communist dogma and ideology were the regime priorities, not freedom and human rights. Unfortunately, my family suffered many hard consequences. My grandfather was killed by the Communists because of his orientation toward freedom and democratic principles. He was only 28 years old and he left two sons and a daughter who were raised by my grandmother under difficult conditions -- but with affection and love.

My brothers and I were not allowed to proceed with higher education. Despite the restrictions imposed on us in our situation, with many barriers and difficulties, I grew up in a very well-educated family. Qualities like honesty, integrity, trust and aspiration for freedom remained untouchable, even while we were isolated and discriminated against. For my brothers and me, there was only one solution: to be the best, to try, to learn hard and to respect our family code, values and principles. I always remembered and heeded my grandmother and father's advice, "No one, nor

the regime, can destroy your values and principles. You all must go on with your aspirations."

But then with the 1990s, major changes in the social, cultural, politic and economic structures began to take place in Albania. This process was a transition to a new and modern civilization. Finally we were free to live, learn and progress forward, just as many other people had been able to do in this troubled world.

My father was elected Governor of Kruja District for more than ten years. He administered and led major transformations there with courage, trust and honesty. I graduated from the Mother Theresa Faculty of Medicine in Tirana, as did my older brother. Our younger brother graduated in mathematics, and I remember how deeply satisfied my father was with our achievements.

Major change of orientation and values in a short time period -- such as we experienced in Albania -- affects people's conceptions and morale. This was an 'identity search' situation that can often lead to social chaos. The acceptance of some western values -- like equality, success, liberty and democracy -- in a short period of time brought new confusion. I lived these intense days with great optimism and enthusiasm, working hard, focusing but rarely having fun. My parents had extremely high expectations for my brothers and me. My parents and their expectations played a huge role in sculpting my style: taking care and always seeking excellence in whatever goals I set out to accomplish in my life.

## When did I first decide to become a physician? Why?

I was always interested in science and philosophy and I decided I liked medicine. I wanted to help others and, in addition, I knew this career choice would help me realize my father's expectations. He really wanted me to study medicine. In college, I could always master my classes if I worked hard -- and I did work very hard in college. However, in medical school, there was a great deal of information given in such a short period of time. For me, it was impossible to feel like I could learn absolutely everything. It was a bit of an adjustment to be in classes with so many really, really smart people -- who also had a multitude of other talents and accomplishments.

In 1997, I graduated from the Faculty of Medicine in Tirana, accomplishing one of the greatest goals of my life. The education of a doctor which goes on after acquiring his degree is, after all, the most important part of his education. For three years I worked in the Pediatric Department of the primary health center at Kruja, my hometown -- near my family, my relatives, my friends and my people. Although I was taking my first steps in my profession, that whole experience was fascinating.

The practice of medicine will be very much as you make it. To one person, it can be a worry, a care, a perpetual annoyance. To another, it can be a daily job and yet become a life of as much happiness and usefulness as can befall the lot of man. It is a life of self-sacrifice and of countless opportunities to comfort and help the weakhearted, and to raise up those that fall.

### Why did I decide to focus on Palliative Care?

I was very influenced by Dr. Agim's lectures at school and my father's memories he wrote during his brother's illness. My uncle died from a brain tumor at the age of 24 in terrible conditions. I should explain something about Albanian tradition. My uncle's name was Ali and it is our tradition that the younger generation inherits the names of earlier generations.

My father understood what a huge difference it would have made if they had been able to get any support during these days when his brother suffered in many ways. They could only care for my uncle by themselves, offering just affection and love -- and nothing else.

All these memories affected me so much that I decided to focus on Palliative Care. I also found Palliative Care to be very interesting and I knew it would be a field that would continually be moving forward. Lastly, I found that the relationship with cancer patients can be very special. The personal connection is not superficial, and really important things matter since patients may be facing a life-threatening illness. The relationships with my patients remain one of the best aspects of my job.

In 2001, I was recruited to work with the Ryder Albania Association in Tirana, the capital city of Albania. Ryder Albania was founded in 1993, pioneering and leading the new field of Palliative Care in the country. Dr. Agim Sallaku and Dr. Fatmir Prifti were the founders and the leaders of this organization, and I want to thank them for making me part of this initiative and team.

At Ryder Albania, I met the "team". This was very challenging for me because I had no experience of a team approach to work. It was a new concept for many Albanians, including me. But I began a wonderful and intensive journey of relationships, collaboration and communication. Here I met leaders, doctors and nurses who have influenced me, who took a chance on me -- an outsider -- and provided an opportunity for me to demonstrate my leadership ability. We all worked hard to make a difference in our patients' lives, to support them and their families during illness and bereavement.

I clearly remember one relative's question in the early days of our journey. It was, "Why have we not heard about you before?" Actually, I no longer hear this kind of

question anymore. We are well-known everywhere and we are leading all Palliative Care development in Albania.

#### Is it depressing to work in Palliative Care?

We face many barriers and difficulties in our country -- economic, cultural and social problems, too much bureaucracy and an outdated approach throughout our systems, including the health system. We live in a culture that worships the latest in medical technology, whether it has been proven to be medically useful or not. Within the medical profession, a higher status is typically attached to being an "expert" in a narrow field -- rather than being a Palliative Care physician with a wide body of knowledge and skills as palliative medicine requires.

Likewise, most of the public, in its worship of the latest in medical technologies, assume specialists in narrow fields are likely to be more competent in those areas. This assumption is even stronger if the specialists are the providers of newer diagnostic and therapeutic procedures. (Actually, the public often fails to recognize the downside of advice given by specialists concerning questions outside their areas of expertise.)

But the body of clinical knowledge and skills held by a well-trained Palliative Care specialist is much broader than any other kind of specialist. The problem of this misperception of Palliative Care can be overcome -- in time -- when a larger part of the public recognizes the process and outcomes of comprehensive care. Continuity over years will demonstrate the superior approach of Palliative Care physicians. It is not fragmented care, and definitely not a case of "no one cares."

One obvious example that happens daily is that some oncologists prescribe continuous chemotherapy for terminal cancer patients -- without addressing quality-of-life in the patients' last months of life. Patients often receive a service from a specialist that is inappropriate, ineffective or even harmful to the patient's continued functioning in his-or-her particular context.

One of the reasons behind that problem is our profession's over-emphasis on a *cure* paradigm when we should have been shifting to a *care* paradigm. We in Palliative Care strongly believe in this new paradigm, and we will move forward with our accomplishments in a low-resource country with limited access to Palliative Care.

I am proud to share the many advancements we have made in Albania in recent years -- acknowledging the support we have had from several donors, international experts like Stephen Connor, and our public structures.

With reference to the WHO strategy of developing Palliative Care, we have actually increased access for Palliative Care in Albania. We have a strategy and action plan for

developing Palliative Care which has been accepted by the Ministry of Health, as well as standards for Palliative Care accepted by the Ministry. We have made a lot of advancements in education, integrating modules into the curricula of the faculties of Nursing, Medicine and Social sciences, and with a one-year Diploma in process. We have started other initiatives with the Ministry. Among other things, progress has been made addressing the availability of opioids and other essential medication for Palliative Care.

Lastly, we were involved in a project assessing the capacities of 11 regional hospitals in the country. I was part of the working group, offering my expertise in a challenging and wonderful process. These 11 regional hospitals will provide Palliative Care for patients. While working on this project, I had the opportunity to see my entire little country. Don't be surprised! I had not done so before. It was amazing and we had a lot of fun with colleagues and people everywhere.

Looking at my present situation, I strongly believe the key characters that have shaped my leadership story have helped me strengthen my beliefs and values. Through my experiences, I have tried to be of service and show others what was possible in the face of challenges. So, if one wants to serve, to make a difference, and to become close to patients, family and community, there is no better field than Palliative Care. I hope one day Palliative Care will simply coalesce into the foundation of all healthcare systems in all countries around the world.

#### What was the experience like being part of the LDI community?

Dr. Stephen suggested I should apply for the Leadership Development Initiative (LDI) program at the Institute of Palliative Medicine at San Diego Hospice. I did so fairly quickly, and applying for it was an intense process.

Then one day I received the news that I had been selected to participate in this amazing program. I remember the day when I had to leave to travel to the United States. I was excited -- but some strange fear took hold of me when I was preparing to leave. Sometimes I regret my past situations: I feared, "Somebody is going to arrest me now." This is the scenario that would have played out if I had been offered this LDI opportunity prior to 1990. Moments later, these fears dissipated and my soul was full of happiness -- and still continues to be --- because of this wonderful opportunity I had to be part of LDI community.

At LDI, I met wonderful people. I learned so much through mentoring and coaching from experts and leaders' experiences and practices. We gained vast information there, as well as structure, a lot of resources, and overall great appreciation, respect and love.

I can't find the words to thank all the people of LDI at OHIO HEALTH: Dr. Frank Ferris, Dr. Shannon Moore, Debra Pledger-Fonte and all the others who made this beautiful journey possible. A big thank-you goes to my mentor, Dr. Lukas Radbruch, one of the greatest global leaders. Every day I am mindful of his words, "Ali, you are doing well. With so few staff, you are doing good things."

The most important thing that LDI has made me understand is that I actually am a leader, and I will keep growing and advancing. Tools and support from the LDI team have facilitated this growth. LDI has empowered me. It equipped me with techniques and skills which help me lead and coordinate our team and organization, as we try to provide care for increasingly more patients in need.

I am proud and deeply grateful to be part of the Second Cohort of the Leadership Development Initiative. This opportunity was one of the greatest things that ever happened to me.

#### Do we need leaders like never before?

By seeking to live the leadership principles I learned, I have achieved better balance, satisfaction and joy in my life, I feel very blessed for the work I do -- for the joy of learning and the joy of leadership, and what it brings to individuals and organizations. Leaders don't have to be Presidents or Prime Ministers. We can all lead in our own way, standing for our values, showing respect and support for each other, by helping and encouraging other people, and by doing it from the beginning with dignity and integrity.

We are the leaders, it is time to lead, and the time is now.

The world is ready.

"We ourselves feel that what we are doing is just a drop in the ocean. But the ocean would be less because of that missing drop."

Mother Teresa

Ali Xhixha, MD,

Ryder Albania Association Tirane, Albania