

## Rumana Dowla Gulshan, Bangladesh



### My Journey So Far...

#### The formative years...

I call myself a product of the subcontinent. I was born in Pakistan and lived there for the first few years of my life. After independence, we became Bangladeshi, yet my formative years were spent in India as I received my medical education in New Delhi.

So truly I am connected with all three countries.

My parents placed great importance on education and virtuous living; we were always encouraged to excel in whatever we did. My father was a Brigadier in the army who encouraged my mother to complete her Bachelor's and Master's degrees in Philosophy. Subsequently, she went on to do two additional Master's degrees in Education and English -- all this while raising three children.

My younger brother is based in Singapore where he heads up the South East Asian sales operation of an international company. His talent also spreads across sports and music. My sister is a renowned marketing expert who won many accolades home and abroad, and is a telecom leader in Bangladesh.

As I pursue my journey as a pioneer in Palliative Medicine, I feel there was enough inspiration from within my family circle to make an impact in guiding me. It is clear to me that Palliative Medicine is something I was destined to do.

#### Family stories

My ancestors came from the Middle East and settled in various parts of South East Asia. They spoke and taught Arabic, Persian, Urdu and Bengali. My paternal grandfather was a lawyer who

practiced in high court in Dhaka. My maternal grandfather used to do Arabic calligraphy on mosque walls and entrances in Kolkata. He was one of the founders of Anjumane Mofidul Islam, a charitable organization. After partition in 1945, the three most recent generations are now well settled in Bangladesh.

We always included educational and cultural events and activities in our family gatherings. Sometimes it was songs in praise of Allah, often poetry recitation or singing Tagore and Bengali songs. We were asked to memorize tables and English grammar as well. As a result, we gradually became used to public speaking.

These family experiences in my early years helped shape my values and my way of thinking.

Leadership was encouraged in our family. Two aunts were Members of Parliament. My second-eldest aunt was the first Member of Parliament in our family from BNP government. Then my eldest aunt became the second Member of Parliament with another political party, the Awami League.

They were both social workers and worked for the welfare of disadvantaged women. They were also involved with various important political movements in the country. They inspired me by their boldness and forthright attitude.

My third aunt dedicated her life to vocal music. A renowned national artiste, she has received various accolades and awards in Bangladesh, India, Pakistan and Australia among others. Her life taught me the meaning of love, devotion and dedication to personal beliefs – qualities which are quite rare these days.

My father was the eldest of three brothers. He regularly told us inspirational stories, such as those about “The Eagles” during the time of Churchill and Casablanca, and recited poems from Shakespeare and Tagore. He also sang many motivational songs with us. He would inspire, encourage and motivate us before we began any task or exam. If we did well he was happy, but he never reprimanded us afterwards if we did not so do well.

My father made me believe that trying my best is what I should strive to do. The result may not be always in my favour – but that's okay. He never differentiated between his son and daughters; we were always given equal opportunity.

My second uncle is now Chairman of a diversified conglomerate which he founded. I saw him demonstrate the kind of true leadership that is so rare in our part of the world. He was always driven by core values, such as integrity, honesty, transparency, fairness in his professional and personal life.

My youngest uncle was a highly respected civil servant who retired as cabinet secretary. He is one of the finest orators I have come across. I spent hours listening to him speak on philosophy

and religion and it has always been a great learning experience for me. His command of many subjects has always been inspirational.

He explained many different aspects of life's spiritual journey to my cousins and me. He put religion into context, too, and those conversations still influence my thinking regarding spiritual care in medicine and Palliative Care.

My maternal uncle designed the Bangladesh Flag; he was a National artiste and a renowned painter. He used Bengali letters on sari to highlight the language movement in 1952.

To my family members each one that I have mentioned above have influenced me and shaped my life I shall always remain grateful for providing me with such an inspirational platform to embark on ....

## Stepping Into the World of Palliation

My paternal grandmother was a very loving and brave lady. Unfortunately, when I was 16 years old in the early eighties, she was diagnosed with stomach cancer. Since my father was the eldest son, my grandmother was brought to live with us. My mother took care of her, and my aunts and uncles were often there to assist with her care.

I vividly remember that this strong lady -- who could kill a snake with a stick, or fire a gun after a thief -- was becoming increasingly frail. Eventually, she was skin-and-bones and was in tremendous pain.

One day, I heard that two senior physicians who saw her and gave her pain medication. They also warned my family that she might soon breathe her last. She passed away, but her pain and suffering remained with us. These memories stayed with me as I was drawn to study the field of medicine.

My grandfather had a stroke when he was in his 80's and was bed-bound. He was a proud man who worked till the day he fell ill, when he was suddenly dependent on others to carry out his activities of daily life (ADL). This was devastating for us to watch.

When I was a child my grandfather had expressed his desire to see me study medicine and become a physician. I adopted his wish as my goal, especially when I saw both of them suffer at the end of life and both in need of home care. Their suffering inspired me to study medicine. By coincidence, I knew someone who studied at Lady Hardinge Medical College in New Delhi, India, so I decided to apply to study there, too.

In 1989, I passed my Bachelor of Medicine and Bachelor of Surgery (MBBS) from Lady Hardinge Medical College. I completed my internship in 1990 and returned to Bangladesh.

Initially, my post graduate training was in paediatrics from Bangabandhu Sheikh Mujib Medical University. I liked the idea of treating children. So when I was offered the post of junior resident

equivalent at the Bangladesh Institute of Research and Rehabilitation in Diabetes, Endocrine and Metabolic Disorders Hospital, I accepted it.

We saw general paediatrics, endocrinology and neurology patients. Soon, the first Special Care Baby Unit (SCABU) in Bangladesh was started there, focusing on complications of children born to mothers with poorly-controlled diabetes. We did alternate 24-hour duties to ensure it ran smoothly, receiving patients from all over Dhaka and outside Bangladesh. Some patients would arrive with ischaemic encephalopathy, cerebral palsy, or congenital anomaly. Parents of children with conditions needed counseling and family therapy

I didn't know it at the time but I was quite stressed out because I was not trained in how to break bad news. Neither had I been trained in communication skills. I knew nothing about palliation.

I wish I had been better equipped to handle those fragile situations. Later, I wanted to work with policy and a wider range of care, so I moved to Public Health where I became familiar with a more holistic approach to medicine. I did my Masters in Public Health and did core modules in Research and International Child and Maternal Health at the Centre for International Child Health (CICH) in University College, London, UK.

But my real break came when I was introduced to Palliative Care by Brig. Gen. Suraiya Rahman, who is an Obstetrician and Gynaecologist -- and a family friend. Her husband suffered from cancer and was treated in Singapore. That's where Brig. Rahman came across Hospice Care palliation and was introduced to Dr. Rosalie Shaw. Dr. Shaw told her about the new upcoming Palliative Care course for physicians from developing countries.

Brig. Suraiya came back to Bangladesh and told me that she had me on her mind during that conversation. She felt I was the right person to learn this field of medicine, which was new to us in Bangladesh.

That single conversation changed my life. I found my niche in Palliative Medicine.

I applied for an APHN-Lien Foundation Fellowship Scholarship and was successful. We were the first group to go through this training! The teaching faculty came from Flinders University, Adelaide, Australia. We had residential teaching at the National Cancer Centre in Singapore. There I met my first coach in Palliative Medicine, Dr. Rosalie Shaw. At that time, she was the Executive Director of Asia Pacific Hospice Network (APHN).

When I learned about Palliative Care, I appreciated its stress on the holistic concept of care. The PC approach to patients and their families addressed physical, mental, psychological, social and even spiritual issues. Its philosophy involves patient and his/her family in setting up goals of care. Palliative Care strives to strike an ethical balance between the four principles of

autonomy, beneficence, non-maleficence, and justice. The focus is on quality-of-life rather than just curative or often-unnecessary treatment.

Speaking of the pioneers who influenced me and my work, first I must mention Dr. Shaw. She has inspired many, but to me she was the sort of teacher one could approach and learn by watching her interact with patients and families. She would walk out of her office to escort her patients back to their rooms. She also taught me to keep striving with my work without expecting immediate results or recognition. She often said, "Your work will speak for itself."

In Singapore, I also met my first mentor, Dr. Cynthia Goh. Her leadership was impeccable. She was inclusive and inspirational; her teaching was clear and uncompromising. Dr. Goh highlighted to me the importance of keeping everything legally sound and risk-free. She also taught me the value of networking.

Now that I have established a Foundation which I Chair and run (Bangladesh Palliative and Supportive Care Foundation), her words echo in my mind.

Professor David Currow also inspired me -- and many of us who did the Flinders course. He once told me, "Rumana, the service that you design, should never expire with your expiry...." He wanted me to keep that in mind while designing a service. Having a good team and delegating responsibility has been of prime importance in designing the service.

I frequently recall his words and realize how significant this advice turned out to be. He inspired me to always implement evidence based care and treatment, to think of research, to read journals, and to keep in mind the importance of referencing everyone's work. He was an amazing teacher of Palliative Medicine, probably the best that I have come across. He inspired me to look at teaching as a form of growth as a palliative physician.

In September 2010, with the support of a few friends and family members, we formed the Bangladesh Palliative and Supportive Care Foundation. It was a stepping stone towards many activities and initiatives. Our core formative team involved a barrister and an HR consultant; later we added a neurologist, a paediatric surgeon, a marketing expert, and a business entrepreneur to the Board.

Initially, we had two physicians and four nurses, and started with two homecare patients in Dhaka. Today we have 189 patients in homecare follow-up, while in-patients number from four to six. We are slowly expanding. We have a few anonymous funders and additionally we did fundraising with the help of the Bangladesh American Women's Association.

The process taught me a lot. I also came to realize the importance of documentation and organizational responsibility.

It will be relevant to mention that even though I was quite motivated and optimistic about implementing Palliative Care in Bangladesh, it was initially very difficult for me to get this idea

across to many people, including donors. But today I am grateful to them for having had the confidence in me -- and eventually supporting me -- in establishing the Foundation. I often wonder that if I had received Leadership Training earlier and learned how to make crucial conversations, perhaps I would have been more successful.

At the Leadership Development Initiative (LDI) at the Institute for Palliative Medicine at San Diego Hospice in California -- and later with OhioHealth in Columbus -- I came across amazing mentors and peers in Palliative Medicine from around the globe. We had leadership courses, books to read and many assignments and tasks; the practical implementation of the theoretical teaching was amazing. My mentor Dr. Eric Krakauer taught me how to focus, and he has given me enormous support in my professional and personal life from the very beginning. He dedicated himself to improving the provision of Palliative Care and pain control in developing countries such as Vietnam, Bangladesh and Africa. He encouraged me to work towards availability of opioids in Bangladesh and is my mentor in the International Pain Policy fellowship program.

Ron Cameron-Lewis influenced my public speaking, public dress sense and media skills, and he has even suggested advice on my writing skills. He would say, "Rumana, follow Hemingway...short compact sentences!"

John Ellershaw has been instrumental in improving my presentation skills by guiding me to include and address other KOLB personality styles. He helped a "diverger" address the "convergers" and "assimilators". Dr. Frank Ferris and Dr. Charles von Gunten lived by example. We saw them face the most difficult time at the Institute for Palliative Medicine at San Diego Hospice and emerge successfully. Their leadership will always remind me that we must be prepared to lose everything and, through perseverance and resilience, rise above to emerge successful.

My suggestion to every physician is to try and join a program such as LDI. Learn about leadership and know the tools, which provide us with the platform to take off or fall back in any given situation.

## **Personal recognition home and abroad:**

2003-2004: Masters in Public Health, Community Medicine.

2005-2006: APHN Lien Foundation Fellowship scholarship.

2006: first honorary palliative care physician and trainee in Medical Oncology at NICRH, Bangladesh.

At the National Institute of Cancer Research and Hospital, Prof. Parveen Sultana and I started the first pain and Palliative Care clinic in a Bangladesh government hospital.

2008: Graduate Certificate in Palliative Care, Flinders University. Australia.

2008: Commonwealth Scholarship for Masters in Palliative Medicine.

2009: Diploma in Palliative Medicine. Cardiff University, UK.

2009-2010: APHN Diploma in Palliative Medicine.

2011-2012: LDI scholarship, Institute of Palliative Medicine, San Diego, California, USA.

2012-2013: International Pain Policy Fellowship Scholarship, Wisconsin, USA.

Early in 2006, I found myself as a pioneer of Palliative Care in Bangladesh. Although I loved the work, adjectives like 'pioneer' and 'leader' made me feel awkward! Being the first certified and trained Palliative Care physician in the country came with great responsibility. Later, with my Diploma in Palliative Medicine from Cardiff University, UK, I became the first physician with additional qualifications in Palliative Medicine. But in a country of 160 million people, that is the very tiniest first step in meeting the needs of Bangladesh!

Since then Palliative Medicine has come a long way in Bangladesh, and I must mention Prof. Nezamuddin Ahmed whose contribution has been enormous. He was the only other physician in Bangladesh with whom I could share the joy and frustrations of my journey in Palliative Care.

We recently worked together -- along with other faculty members at Bangabandhu Sheikh Mujib Medical University (BSMMU) draft the MD Palliative Medicine curriculum. We completed and submitted curricula to Dhaka University Syndicate and conducted three successful workshops. I was delighted to have both my mentors, Dr. Cynthia Goh and Dr. Eric Krakauer, invited to be the international experts at the workshops.

The APHN-Lien Collaborative is also now conducting training programs for doctors and nurses in Bangladesh. I am one of the local mentor faculty, a member of the Management Committee and am designated as its coordinator.

I hope that we can spread Palliative Care to the grass-root level with the new collaboration with BRAC. I have initiated the dialogue and it is now in the initial phase.

## **The way forward**

There is so much left to do and so little time. I hope that we at Bangladesh Palliative and Supportive Care Foundation will be seen as a well-organized, community-based, culturally-appropriate, acceptable and affordable Palliative Care service, integrated with the main health system and available at the grassroots level as a *Choice*.

I would like to illustrate my thoughts for the future of Palliative Care with a song from Rabindranath Tagore "...Aguner Parashmoni Chuao Prane .." (English translation by Anjan Ganguly)

Give a touch of the fiery magical stone to my life, purify me, clarify me, enlighten me  
With all severe pain, purify my soul  
Uphold my mortal body high, Enlightened,  
Allow me to serve your temple as the burning lamp inside –  
Let the lamp radiate through my songs  
With your petite touches into the darkness  
Nascent stars arise glimmering all night  
My eyes will not find a dark spot anywhere,  
It will be light everywhere --  
All my sufferings would burn and soar skyward.

I would end by saying, “Let us have faith and let us live by example.”

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