

The struggle within!

Stories of battles against Cancer

Published as a part of
3rd Annual Surgical Meeting, AKU

This book is dedicated to the unsung heroes in this
fight against cancer.

Table of Contents

- Foreword	05
- My experience in Pediatric Oncology - <i>Chaman Urooj</i>	07
- Bed 52- Letting go - <i>Bushra Maqsood</i>	10
- Battling brain tumour - <i>Anis ur Rehman</i>	12
- Ammi's story - <i>Soufia Siddiqi</i>	15
- Cure - <i>Ayeesha Kamal</i>	21
- When life throws a curveball - <i>Sara Abedin</i>	23
- Hold tissues as you would hold your mother's hand! - <i>M Shahzad Shamim</i>	27
- Untitled - <i>Saniya R. Sabzwari</i>	30
- 101 years of a peaceful heart - <i>Bushra Maqsood</i>	32
- Reading the skies - <i>Sadaf Khan</i>	34
- He decided his own code - <i>Mahin Janjua</i>	40
- A series of haiku poems about cancer - <i>Kulsoom Ghias</i>	47
- Best birthday gift - <i>Fahmina Buriro</i>	48
- Victory of willpower - <i>Dur-e-Sameen Ilyas</i>	50
- The gas won't pass - <i>Faisal Siddiqi</i>	51

Foreword

Greetings Dear Readers,

Cancer. A single word, not a sentence. Yet enough to instill dread into the hearts of even the hardiest of us mortals. The NIH National Cancer Institute attributes cancer to be among the leading causes of death worldwide with 14 million new cases in the year 2012 and 8.2 million cancer-related deaths worldwide. Even scarier is their estimate of the number of new cases to rise to 22 million within the next two decades. Siddharta Mukherjee in his aptly titled biography of cancer “The Emperor of all Maladies” writes, “Cancer is indeed the load built into our genome, the leaden counterweight to our aspirations for immortality”.

As physicians we encounter the “biological” aspects of cancer. We are transient passengers with the patient in their journey in battling this disease, offering our expertise in diagnosis and management. It is less common for us to be cognizant of the entirety of the journey that the patient and his or her family and friends go through. And this is where the idea of this anthology of stories was born.

The Aga Khan University’s Surgical Annual Meeting 2018 is centered around the theme “Surgical Oncology – Evidence and Practice”. It is in association with this conference that this book is being published. Stories were invited from people from all walks of life with the intent of presenting varied perspectives on the battle with cancer. We have stories written by cancer survivors, the families of patients with cancer and the physicians tasked with caring for them. Throughout we have attempted to preserve the voice of the author, wielding our editorial knife only when absolutely necessary.

We are immensely grateful to all the writers for sharing their stories with us. We realise that most of these stories are based on real life experiences and can quite understand the courage required to share these personal experiences with a large audience. We applaud these writers and hope that their effort will inspire some, and make it easier for others going through similar hardships. We had to turn down several contributions largely because they did not relate to the theme of the book, but nonetheless, the overall response was outstanding. The editors would also like to thank Mr. Shariff Charania, the co-ordinator for this book, who has been instrumental in keeping the editors together, and making sure they behave. Shariff has almost single handedly taken care of the long list of tasks required in the making of this book.

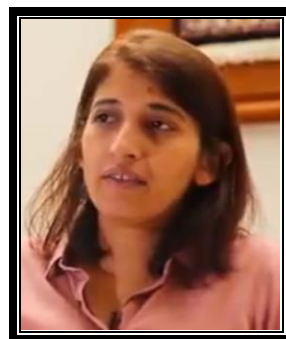
Send us your comments. Tell us how this book made you feel. Write to us, if you would like to connect with the authors, if you would like to improve upon this effort, if you would like to share a story of your own (that can perhaps be a part of the second edition), or if only to criticize. We do hope that this collection will provide the reader another frame of reference when encountering this truly 'transformative' disease.



M Shahzad Shamim



Amir Shariff



Munira Moosajee



Chaman Urooj is FCPS in Paediatric Medicine and completed her training from National Institute of Child Health – Karachi. Later, She joined Indus Children Cancer Hospital for second fellowship in Paediatric Oncology.

"In the line of work, multiple times I came across situations that deeply moved me; but during my training in Paediatric oncology, the resilience of children and their families left me speechless."

My experience in Pediatric Oncology

As a pediatric oncology fellow, I had the opportunity to closely deal with children and their families fighting with chronic diseases and various forms of cancer. On this venture, I explored and experienced a new avenue of human emotions particularly those of children, which was previously unknown to me.

The diagnosis of cancer, of whichever the type it maybe, always comes as the greatest shock of one's life. Most parents brought their child with a two-week history of fever followed by some blood investigations and ending up as a suspicion of malignancy; along with an unspoken request in their eyes, "doctor, please tell me that this is not true". One cannot blame the family if they refuse to accept your diagnosis since a couple of week back they had seen their child playing with other children completely normally. They become so perplexed that they don't know who to blame or how to cope with the long term suffering the whole family was going to face. I have seen many families refusing the treatment in denial, despite that it was completely free in our hospital, and also despite our repeated assurances.

I used to feel guilty when I was not able to convince someone for the treatment but the fact is that overall we do have refusal rate of approximately 20%. There could be many reasons, scarcity of specialized hospitals for cancer treatment, lack of awareness about chemotherapy, denial of family, easy availability of alternative medicine, or lack of patient trust on doctor as compared to alternative medicine practitioners. I have come to realize that we lose a large number of patients to delayed presentation due to being mistreated through alternative medicine. This is especially common in leukemia patients, who get a rapid initial clinical improvement from steroid based medicines but subsequently succumb to widespread, incurable disease. It is also common in retinoblastoma patients, since parents have difficulty believing that their child's eye has been affected by cancer. Such people usually fall prey to any practitioner who tells them that this is not cancer, as that is all that they want to hear.

The strength of the kids undergoing chemotherapy and their families gave me lessons that I will never forget. Every morning we used to have kids lined up in day care to undergo chemotherapy or one of the other procedures. I saw children with eyes filled with gloominess rather than stars, universes and galaxies, looking at their hands, wondering where the doctor will choose to put cannula today and showing that to each other. Others talking about how long they have headache and vomiting following intrathecal injection. Also, their siblings sitting with them, who used to be usually of the same age group, sharing the same sadness in their eyes cause they had also given up their own joys of life just to share the pain of their brother or sister. But, somehow I had very rarely seen children crying pre or post procedure or chemotherapy. Mostly they used to be either quiet or looking like they were wondering, will I ever get rid of this place. One of the adolescents once asked me while I was auscultating his chest, "what did I do to deserve this? I never wanted to disturb my family". I knew no words would console him. I observed that as the treatment continues and their strength weans off, they don't become more irritable rather they stop smiling and stop responding to things, a behavior not meant for children.

Posting in ICU was the toughest part. Although, working in ICU was not something new for me, being a pediatrician already, but seeing a patient deteriorating so quickly despite all the efforts, was heart breaking. Having a patient and his family survive the shock of a diagnosis as dreadful as leukemia, then watch him complete different phases of the treatment day by day, seeing him every other day or weekly passing through several phases of depression and pain and then eventually celebrating with him the news, that he has completed his delayed intensification phase and only maintenance phase is left; but one day receiving him in emergency room in a dehydrated condition due to diarrhea and vomiting which did not respond to treatment and then seeing him landing in ICU, catching a fungal infection and then die helplessly, is one of the many such sad experiences that I had there. I thought I was a strong and realistic person with enough experience in medical field to help me deal with situations but many times I found myself completely broken.

Isolation rooms were mainly for the children undergoing palliative care. We tried to keep them and their families away from the rest of the patients so that they may not get disheartened. The mainstay of treatment here was pain management and to let the family spend the time with their child. Their families were counseled about the nature of their disease and the treatment being provided. I remember a 7 years old child admitted for palliative care with severe respiratory distress but completely conscious, sitting by the side of his mother and in her arms, and was calling me for help almost every ten to fifteen minutes on the last day of his life. I used to go to listen to whatever he could say and just give him some supportive care and re-assurance and at the same time offer some support to the parents in that tough time. Then, the child called me again and asked me to give him water. I couldn't say no to a dying child though I knew he was in so much distress that taking water by mouth could straight away choke him to death. I knew it was a wrong decision but I decided to hold him in my arms and let

him have a sip of water. As expected, on the second sip he got choked, started coughing and turned blue. Immediately I putted his oxygen mask back and provided him with physiotherapy. I thought I was going to lose him there and then but somehow he revived, opened his eyes, looked at me with difficulty and said, "See, that is how it feels".

However, oncology is not only about pain and suffering. There are many happy ending stories as well that provide the oncologist with the strength to fight with the disease along with his patient. Pediatric cancers have better prognosis that is getting even better day-by-day. Treatment failure is on the decline and this is a very promising advancement. In every OPD, we used to have about 10% of follow-up patients who had completed their treatment but were supposed to be in follow up for next few years. They used to come to get their checkup done and also interact with the patients who were undergoing treatment at that time to give them strength and hope. I remember one of the patients, who had become 16 years old then, asked me, "how long you people will keep checking me? I am a grown up now and should not be seen in pediatric specialty anymore".

Pediatric oncology is a difficult but an equally promising and satisfying field. With the new advancement in disease diagnosis and treatment options, we are heading towards a better future where we will have a larger number of success stories and lesser number of patients avoiding treatment because of the non-availability of facilities or more trust on alternative medicine.



Bushra Maqsood is working as a House Officer in Oncology Ward, JPMC.

"My areas of interests have always been Neurosurgery, General Surgery and rare diseases. I believe that you learn more from your life and surroundings than from books. Fifty working days are better than a hundred days of solely reading and not applying."

Bed 52- Letting go

I was told to sample blood of one of the patients in the female ward. With this objective in mind, I entered the female ward with my eyes wandering to trace Bed 52. After going through all bed labels like a flick-book, my eyes rested on a crimson label "Bed 52, HTN, DM, Breast Ca." I converged my gaze on the lady lying on that bed to see a rather large, floppy body, drowsy and helpless.

I uncovered the lady to expose her arm so that I could proceed with sampling her blood, although I could feel a sense of hesitation. I was surprised to see such her swollen hand the likes of which I had never seen before. I felt sorry and placed my hand on hers to check the state of edema more in a sympathetic way than in a clinical way. Her hands were cold and clammy. I looked at my tourniquet to find that it was not long enough to be tied around her limb. I examined her feet to find a vein, but in vain. So the idea of withdrawing blood for sampling slipped off my mind and I sat on a couch beside to converse with her husband instead. I initiated the conversation to know her history. I witnessed some tears roll down her eye, while I listened to the details her husband was telling me:

"It was around 8-9 years back that she noticed a lump in her left breast. It grew slowly and started to bother her, so we took her to a Hakeem." Her daughter added, "He was not a small scale Hakeem but we researched and took Ami to a very renowned Hakeem who is often invited to TV shows." As I nodded, patient's husband continued, "He gave multiple medicines for about 6 months. We were very compliant with those medicines. Gradually, my wife began to feel that the lump reduced in size and was now felt farther from the skin. This made us even more obedient and submissive to the Hakeem. Months passed and the skin around the lump changed pigmentation and texture to become sore. It reached to the point when it spontaneously began oozing out blood and purulent discharge. We were really worried then and hurried to our Hakeem. He examined the lesion and suppressed our anxiety with his smile that signified his

confidence. He looked at our blank worried faces and told us that he has successfully performed surgery of my wife without any admission and surgical instruments and he was really proud of it. He gave some symptomatic treatment including a skin ointment to apply on the lesion and repeatedly told us not to worry about it now."

"Doctor Sahiba," he added, "that's what makes me most regretful in life! This mistake brought my wife into a stage that cannot be cured. She is now a candidate of palliative treatment only."

I have always listened to stories of quacks and Hakeems notorious for worsening potentially treatable conditions into untreatable ones. Many conditions give pain but what gives more pain is losing to something that was once curable. If only the patient was taken to the right place.

During my rounds, whenever I walk past that bed and greet the caretakers, I find them busy in taking care of her every need. She had become difficult to take care of but the family remained steadfast. What was always present at her side table along with her medicines, was a bottle of talcum powder that her attendants used on her. If I ever smell such fragrance again, it would take me back to how I felt about Bed 52.



Anis ur Rehman has recently graduated as a Dental surgeon. The story attached herein is regarding the battle his mother fought with a glioblastoma.

"I was gratified by this platform that AKU has provided for sharing stories especially from the perspective of caretakers. I hope this story contributes to the cause and proves helpful in any manner for those who are going through a similar experience".

Battling brain tumour

I am 23 and I have lost both my parents to a deadly disease, cancer.

I will only share the tragic journey that my family and I went through during my mother's illness, and I have tried incorporating as much as I can remember of those days. I have made an effort to be as precise about the events as possible, and to avoid the emotional side of the story as much as I could.

My mother was a gynecologist and has always been my inspiration to become a doctor. Due to her irrefutable help, I qualified to attain a merit seat in one of the most prestigious government medical college.

On the morning of June 10th, 2013, my mother was in the kitchen preparing breakfast when she complained that her vision had slightly blurred. She was 56 at that time and quite healthy. This was followed by a headache and as she closed her eyes to rest, I could see a sweat dripping on her face. Sensing something wrong, we persuaded her to go to the hospital. She did not respond verbally but only nodded her head. I went into the kitchen get her something to eat, when I heard my brother shout. I quickly ran to him and noticed that my mother had developed rhythmic twitching of left side of her face, although she remained conscious and could walk on her own. Her seizures became severe and to avoid biting her tongue, she rolled the edge of her 'dupatta' herself and inserted in her mouth. I was a naïve 1st year medical student at that time and had no idea what was going on but my elder brothers handled the situation well. The primary care provider at the local hospital assumed it was a stroke and said he could not do anything about it. So we called an ambulance and took her to a tertiary care hospital, all within 20 minutes. When we reached the emergency care of the hospital, they gave her intravenous Valium to control her seizure and got an immediate MRI of her brain. The radiologist was pretty sure from the first look of her MRI that there was a large space occupying lesion. Her seizures settled and she was discharged the next day on an anti-epileptic drug, counseled and asked to return after a week.



After that terrible day, my mother looked better the next morning, as spiritual as she was, she continuously reminded me not to worry for anything as Allah puts his favorite people in pain and only those who can bear it. I have yet to see anyone with such a strong will. A week later, we went for a follow up and she underwent another contrast MRI that actually showed an increase in size of the tumour. The radiologist reported it as Gliomatosis cerebri. Slowly and gradually, her condition worsened. First there was short-term memory loss, followed by abnormality in gait, and gradually her left side became so weak that she started limping. She started ignoring her left side, and also complained of worsening numbness on her left side. As days passed by, we got collective opinions by specialists and her biopsy was scheduled on 20th of August. Three days before her biopsy, she was advised a thallium scan to assess her cardiovascular condition. During the test, she collapsed and had to be moved to the emergency room in a state of coma. We could see that we were losing her. A fresh MRI revealed that she had suffered a massive brain hemorrhage. At this moment we pleaded with the neurosurgeon to save her at all cost and he agreed to perform a craniotomy. As we shed tears in waiting room, lost in despair and pondering about the past, aware that the day was probably going to change everyone's life in our family and beyond. We waited for hours and hours for someone to give us a hint of what was happening in the operation theatre, lost in sorrow. After about 5 hours, the doctor came out and informed that my mother was alive, and the surgery was a success, and now it all depended on how well she recovers. He also explained that he had removed as much tumor as possible but we should not be too hopeful. He also consented us to perform a tracheostomy to assist her in her breathing. After the surgery, her consciousness improved to some extent, and she was shifted to neurosurgery ward, although she was still in a milder form of coma. She was breathing on her own through tracheostomy but was not opening her eyes, and was fed through NG tube.

After six painstaking days, she opened her eyes for the first time. This was obviously very emotional as it gave us hope and endurance for further events to unravel. This also meant that her GCS had improved a lot, she also initiated some random movements but still very restricted. It also became clear that she understood what we said. She could not speak but communicated a little with her eyes and fingers. We were greatly appalled by the nursing care provided to her. We learnt through other doctors, Google and people with similar experiences that how to take care of a bedridden person. When she started developing bedsores in hospital it was clear that nursing care wasn't sufficient. Eventually we decided to take her home and it seemed like a fair decision. My family and I vowed to care for her like professionals. To understand the necessities required for such patients, we researched in depth and sought to provide the best possible care.

We arranged all surgical and medical equipment that was required for her at home. Care for my mother included timely feeding, physiotherapy, tracheostomy care, oral care, bathing, tilting to sides regularly, medications, and the list goes on. We had few doctors who would come and regularly examine her at home and a part-time nurse to

assist us. We did not compromise on anything. She was quadriplegic, but we would somehow manage to get her into a wheelchair. We completely disconnected ourselves from the outside world and focused only on one goal, which was to take care of my mother. We had a strict schedule and divided responsibilities. We were very grateful to our relatives for providing us with an excellent support system.

In October 2013, she underwent radiotherapy that made her a little better. She appeared more conscious than before, movements of wrist, hands and fingers were more coordinated than before. For the first time after two months, she could speak a word. The word she spoke was actually the name of my brother. We were again filled with joy and unprecedented happiness.

By December 2013, she was quite emancipated, improving a little, but worsening thereafter. She remained bedridden and required a jejunostomy tube to replace her NG. The placement of jejunostomy tube was complicated by an infection that was not healing by local or systemic antibiotics. This led to the development of sepsis and other complications that were difficult to tackle. However, she recovered miraculously. We would be overwhelmed with joy every time she won a battle. We were prepared for the worst, yet hoped for the best.

On the night of 6th January 2014, while she was in hospital, her condition took a turn for the worst. She didn't sleep that entire night, drenched in sweats. Obviously we stay awake too. Tests were conducted but nothing wrong could be picked. To our relief, she was better by morning, although we noticed that she was skipping breaths. Later in the day, she had difficulty maintaining her oxygen saturations and the doctors advised that since this is an irreversible condition it would be logical not to resuscitate her. We left the decision to the doctor and focused on providing her with the best end of life care. Upon further worsening, she was moved to the ICU and we were asked to leave her side. I was watching everything from the slit between ICU doors. We all gathered and somehow knew the fate. It was a cold night of 7th January 2014. I never felt more alone even with so many people around me. My mother passed away that night.

I am an introvert. I cannot truly express my feelings and hardships that I went through, but I definitely got stronger beyond my own expectations. I was deeply bereaved. I did not share the tragedy with friends or people I came in contact with, and rather than focusing on social constructs that people usually follow when their loved ones pass away, I focused on my education, the gift my mother left for me. Today I am a House Officer and a position holder of my batch. There were times that I would look after my mother the whole night despite an exam in the morning, and in those nights, I could not have imagined that I would one day stand among the high achievers. I shall continue her legacy.

A year after my mother passed away from brain tumour, my father was diagnosed with adenocarcinoma of lung, a man who never smoked even a single cigarette in his entire life. Soon after, he passed away too. But that is a story that I may share later.



Soufia Siddiqi is a research consultant alternating between Lahore and London. She was Pakistan's 2010 Rhodes Scholar to the University of Oxford, where she read for an MSc, and a DPhil in Education. Between the two degrees, she took time off to act as her mother's primary caregiver following a diagnosis of recurrent pancreatic cancer. Soufia dedicates her spare time to architectural photography, cake art, and creative writing.

Ammi's story

My father spoke about my mother with so many doctors, we lost count. He never seemed to tire of a 'second opinion' for her. Maybe this is a natural response when your wife complains of a backache one day, and the malady is diagnosed as fatal at age 49. Maybe Ammi's pancreatic cancer was just that rare.

As a result, we found ourselves sifting through lots of advice, most of it entirely reasonable: if the cancer is operable, it is best to find a specialised cancer centre that performs at least 15 Whipple's procedures annually under an expert lead surgeon. Ideally - if affordable - go to America or the UK for the surgery. But remember that 4-15% of candidates die on the table, and that even with a successful surgery, less than 8% are expected (at the time, anyway) to live up to 2 years. And if remaining in Pakistan is the only option, Shaukat Khanum in Lahore or Aga Khan in Karachi should be the hospitals to trust.

We couldn't follow most of this advice. It wasn't intentional. It was Muharram. Schedules at Shaukat Khanum were packed before and after the holiday, and the scans indicated Ammi's *in situ* tumour of the ampulla of Vater could rapidly progress to non-resectable Stage III within a couple of weeks without any intervention. The Government Services Hospital on Jail Road presented an irresistible, although risky, deal. It had a surgical team trained to perform a Whipple's procedure, but which hadn't actually performed one yet. And it was willing to skip its 10th of Muharram holiday to perform it, this being the only free day on the roster for the next few weeks.

This was a gamble. In exchange for the earliest possible pancreaticoduodenectomy within the country, Ammi could either become a surgical milestone or fade into the filing cabinet of a public health mortuary in Lahore. The thing with pancreatic cancer is that it leaves you little to no time to think, just enough to do. So on the 6th of February 2006, we saw off Ammi (along with one sly cat) into the Services Operation Theatre. Over the course of 14 hours, a small piece of history was made (after they diligently

escorted out said cat), and only my family, our close friends, and a surgical team of 9 were there to witness it. This was just before the days of Twitter. The only fame her operation ever received was when she was invited to a surgical seminar a few months later as living evidence of a successful Whipple's at a public hospital in Lahore.

* * *

We don't have cancer history in my family. Other than my obsession with the genetics of oncology since childhood, the word 'cancer' only referred to June/July birthdays of cousins, uncles, and aunts. Ammi's diagnosis took everyone's breath away. Not just because she was loved, and celebrated immensely by everybody who knew her, but because she seemed such a young patient for such a massive burden that nobody had ever even heard about. None of my siblings or cousins brought it up with her as we took turns sleeping by her side in Surgical Ward IV, where she stayed for two weeks.

Everyone who knew Ammi admired her willpower, but it was her post-op recovery that disarmed even her consultant surgeon. She silently tolerated chains of doctors and nurses probing, prodding, injecting, measuring, and documenting the elements of her constitution. She smiled when we joked about entering her into Mr Pakistan contests because the nurses diligently pumped her with 3-5 bottles of albumin a day. She would joke back, remarking that the albumin was probably leaking out of the numerous holes multiple canulas had pricked all over her upper body. She was determined to be out of bed by the 23rd of February, her grandson's first birthday. Somehow, she'd convinced her consultant that if she could walk by that day, he would permit her to shuffle out further to see baby Yusuf in the corridor outside the ward.

The post-Whipple's phase of Ammi's health inevitably allowed doubt to creep into everyone's minds. Had this really been cancer? She didn't receive chemotherapy; her follow-up scans indicated no recurrence within the first six months. In fact, 4 months after her operation, Ammi had returned to her original weight, which she maintained for the next several years. She also never developed diabetes – a common consequence of so much compromise of the pancreas. In June 2011, as I stood outside Exam Schools on the High Street in Oxford, my father gave me some happy news by phone – Shaukat Khanum had officially closed Ammi's file. Five and a half years after that fateful day in Services Hospital, Ammi was no longer a 'cancer patient'. Follow-ups were now scheduled only biannually.

* * *

It comes back with vengeance. Maybe it has lurked in an obscure corner of your cytoplasm or hibernated in a nucleotide that escaped the knife. It nudges you as you're celebrating your youngest daughter's completion of a Masters. It snakes back in the middle of the night, rashly rubbing at your skin, pulling at the muscles of your upper right quadrant, biting at your appetite, leaving its discomfortingly familiar metallic taste at the tip of your tongue. It rushes up your oesophagus, retching mossy fluids across your gleaming white toilet bowl. It announces its return through the bewildered, apologetic silence of your oncologist.

When Ammi's cancer recurred in August/September 2011, it wasn't just my father who behaved with what I assume was denial. So did her consultant at Shaukat Khanum. Perhaps he wanted to be absolutely sure of such a significant diagnosis before planning next steps, but the first two weeks of September became an exercise in both patience, and complete confusion. Our days became a blur of Tramadol¹, green vomit, CT² scans, nocturnal restlessness, an aggressive ERCP³, and odd-hour runs to the Shaukat Khanum A&E⁴. We were introduced to Ranson⁵ criteria, and, after he tested her lipase at 10x normal levels, Dr Zafar⁶ showed me how to line a stomach tube with Xylocaine⁷ to pass through the nose. Repeat biopsies returned positive. As doctors pieced the puzzle together, a miserable diagnosis emerged: this was recurrence, and there was no cure this time.

I watched Ammi stare vacantly at the ceiling in a recovery bed after they had inserted a stent into the remains of her bile duct through a PTC⁸ procedure. All this work, all this pain, and she wasn't even going to live. Over the next few days, an uneasy relief accompanied the colour slowly returning to her jaundiced skin. We brought her home bundled in a fog of codeine⁹, metoclopramide¹⁰, variations of omeprazole¹¹, and a sense of despair. Palliative care: this was all this was. It wasn't leading to progress, to a win. It was all meant to slow the inevitable: Death.

After her surgery in 2006, people often asked my father how much Ammi had known about her disease the first time. He would solemnly reply, 'Nothing. She thought she had a stomach ulcer, and we did nothing to change that perception. It kept her fighting spirit alive.' Maybe this was the explanation through which my father coped with her diagnosis. It is equally possible Ammi had not, in fact, known she faced a prognosis of 4 months without surgery, and immediate death in case of an unsuccessful one. Perhaps willpower is a still underestimated component of post-operative treatment, but it was certainly a prominent feature of my mother's post-cancer recovery.

In hindsight, I think my mother suspected she was gravely ill in 2006, and again in 2011 – hard not to think that way when one is unable to painlessly sit, stand, lie, eat, keep food down, or pass coloured stool. My mother is now gone, but sometimes my father and I still argue late into the night about what she knew, and how much. The casual bystander might find this disagreement of ours a terrible waste of time; the patient is

¹ Opioid pain medication

² Computerised tomography, a diagnostic test than produces multiple images of the inside of the body.

³ Endoscopic retrograde cholangiopancreatography

⁴ Accident and Emergency Room

⁵ A measurement for severity and prognosis of acute pancreatitis (inflammation of the pancreas)

⁶ Name has been changed to maintain anonymity

⁷ Local anaesthetic

⁸ Percutaneous transhepatic cholangiography, a procedure that helps manage obstructions of the bile duct

⁹ Opioid pain medication

¹⁰ Antiemetic to manage nausea

¹¹ Proton pump inhibitor to manage stomach acid and movement of food through digestive tract

deceased, after all, so what good is it to reflect on history? We argue still because Ammi's illness raised very big questions about doctor-patient relationships in our minds. We wonder, for instance, how much of Ammi's willpower was shattered in 2011, when a young doctor candidly told her – without consulting her oncologist or family – that she had an incurable recurrence of pancreatic cancer with about 3 months to live.

Because she was a generally quiet person, my mother did not reveal the incident easily. She pandered to our false reassurances of her imminent improvement. We all played Bluff: with each other, with ourselves. But over the months that I spent almost every waking minute with her – as her primary caregiver – she silently withdrew from this game. Instead, she reminded me of the things she had wanted to get done for different people, and asked me to execute them. Normally very reserved about her early years of marriage, she narrated in meticulous detail what I should keep in mind should I have the good fortune of being married myself one day. She would correct me: 'not *should*, Soufia, don't be such a pessimist – *when*.'

We played a new game called Suppose. Suppose your mother is dead, and you like a boy, how do you reveal this to your father? Suppose your mother is dead, and somebody claims she was safeguarding their jewellery, how do you know? Suppose your mother is dead, and somebody speaks ill of her, how do you conduct yourself? The game reached its final stage when she started pausing mid-sentence, and stopped breathing. I would start with a quiet, 'Ammi?' and she wouldn't respond until I would yell 'Ammi!' I understood reluctantly: she needed me – her youngest – to process what she knew: she was dying, she just couldn't say it out loudly. After many rounds of Suppose, she told my father and me about the young doctor who had turned her world upside down in her effort to be 'professional'.

As the cancer invaded her liver, our life lost its elasticity. We could not – did not want to – stray much further than the front door. I wondered about the PhD at Oxford I had deferred. My eldest sister wondered about the children she had left her husband to mind in Chicago whilst she was in Lahore. My brother wondered about the job he had said goodbye to in Silicon Valley to move back for my father. My middle sister remained perpetually angry, my father perpetually silent. Our *khandaan*¹² watched helplessly, sometimes in awe, as we woke up every day to wait for an irreparable hole to assume place in our lives.

As we struggled with our thoughts, people stopped believing she had cancer. My mum was a magician: she had everyone believing she was fine, and was going to be fine. By her bedside, her medicine plate grew into a platter, then a basket, then a box until the painkillers and digestive aids finally occupied her entire bedside drawer, but we never heard her moan or cry in pain – not even at night as we lay by her side or at her feet. Her hair was still on her head, her big smile alive, and although she had thinned out

¹² Extended family

tremendously, still baked my father his last birthday cake of her life. Before the ascites set in, she drove herself one last time to the fruit-and-vegetable grocer she had been a regular customer to since moving back to Lahore in 2004.

People would visit by the hour, almost all day. I ached inside from mixing *Rooh Afzas*¹³ and teas with my artificial smiles, knowing that my siblings and I were halfway to orphanhood. But Ammi greeted everyone warmly, even if slowly; she spoke as much as her now short breath permitted; she asked after their children, parents, troubles, and happy memories. My *mamoos*¹⁴ visited her, and felt unable to leave for home for hours thereafter. My *khalas*¹⁵ wept quietly, sometimes in marvel of her strength, mostly out of sadness that such strength might leave them very soon. Everyone visited, and wept, and Ammi comforted them. People stopped believing she had cancer.

My father still wonders about this. He wonders whether she died of overmedication or whether the Dengue she had developed earlier in the summer of 2011 had been conflated with inflammation of her pancreas or liver. Even though this upsets me, I let him hypothesise because it is only in make-belief that grief has any chance of subsiding. In early April, Dr Kamil¹⁶ told us there were about 2 weeks left. He was in awe of Ammi's determination, and strength: in his routine as an oncologist, he could not think of any other patient yet who had stretched a 3-month pancreatic prognosis to 8 months without any treatment. But the signs were there now, and we should make whatever preparations were required.

I developed a kind of chest strain from holding my breath. How does one prepare for a mother to die? How does one know that she will be rushed, not to Shaukat Khanum, but to the government Jinnah Hospital close to home because it will be 3 in the morning, and her diastolic will be at 55mmHg? How does one not lose their breath on That Last Day when through her oxygen mask, a mother cracks the slowest, but surest smile? How does one not lose balance, watching Ammi lie in a hospital bed surrounded by nurses as she wavers in and out of consciousness, her right hand clumsily trying to reach for something above her face?

We were told to expect a coma. After months of ending up at Shaukat Khanum, I had passed by enough rooms housing patients in a coma to know this was an entirely reasonable suggestion. But we hoped she wouldn't because the Muslim sentiment in our lives wanted earnestly for her to be able to recite her prayers before passing. At about 11 pm on the 23rd of April 2012, I remember Appi¹⁷ holding my conscious mother's hand, reciting the *shahada*¹⁸ to her in a hushed voice. I was escorted away from Jinnah at this point, presumably nearing collapse from exhaustion.

¹³ Traditional rose-based drink in Pakistan

¹⁴ Mother's brothers

¹⁵ Mother's sisters

¹⁶ Name is deliberately changed to protect identity

¹⁷ Elder sister, in Urdu

¹⁸ The Muslim proclamation of faith, typically recited at important occasions including the deathbed

In our front room, I immediately fell asleep in an older cousin's lap, leaving behind the traumatic hospital for the comfort of a surreal dream: my mother as her old self, in a white *gharara*¹⁹ smiling, waving, walking out through the far doors of a classroom from a university in which I had once delivered a speech. I was never sure whether this was my mind playing tricks on me, or Ammi being her inventive, miraculous self, occupying some intangible realm between mother and youngest child. What I am sure of is that a few minutes later, when my middle sister gently interrupted my dream to tell me Ammi had passed away; I finally let out a long breath.

¹⁹ A traditional, formal dress for women that originated in Lucknow, India, but is also frequently worn by women of Urdu-speaking descent in Pakistan.



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Cure

After so many years,
It appears that I stand
Back to where I began
In the wonder of the sand
Sun
The wind
And the ocean

Elemental
To breathe
To swim
Let the waves ride over you
Tide you over
Catch the next one
Breathe – don't forget to breathe
Sun shining
Simple
That's what mattered
In the whole universe
That blue
That Present

Remembering to
Catch the next wave
So many years ago.....
Today
I am reminded of
That child of wonder
I was once
Again
It just matters
To Live
When with all the complicated chemos
And un nameable difficult infections

And cold hard science
The ones you love
Are being erased
From whom they are
Wiped out sepi versions of their life force...
All this rational science of probability and
predictions Is chatter ... pointless
Nothing will bail us out of this dark deep hurting
Except to remember
To live
Elemental
And never forget
To breathe
To catch the next wave.....



Sara Abedin did her MBBS from Ziauddin University. She completed her FCPS Part 2 training in Internal Medicine from Ziauddin Hospital North Campus. She is currently practicing as a General Adult Physician at DHA Clinics and simultaneously runs her father's business "Associated Home Textiles (Pvt) Ltd" which manufactures and exports hospital apparel and readymade textiles.

When life throws a curveball

It was year 2004. Life was good. Or so it seemed. Then suddenly it happened, shattering us all completely.

My father, aged 52 years old, an absolute health buff, woke me up one Sunday morning with severe back pain. For someone like him who would daily play tennis post fajr prayers and vigorously exercise pre- Isha prayers, I thought it was probably a muscle strain or renal colic (he had fasted consecutively 14/15 Shaban 2 days ago). We rushed him to nearby hospital ER where the duty doctors also agreed to my differentials and administered IV fluids and pain killers which subsided the pain. There was only slight hematuria in the baseline labs done. We returned the next day to the hospital for ultrasound kidney which showed normal kidneys only 'right lower pole calcification'. On discussion with the family internist and radiologist, we decided to go for CT Abdomen than conventional IVP to visualize "the calcification" a bit better. What waited before us was beyond our expectation. As I stood in the console room watching the images appear on the screen with the radiologist, I knew this wasn't any calcification!

Lo and Behold. This was Renal Cell Carcinoma (RCC). No prior fever, no history of weight loss, no loin pain, no prior history of hematuria, simply one day history of back pain, which was all it was.

By the time we reached home, hell had broken loose. For any patient who is expected to go through the phases of "breaking the bad news" from a shock, denial, grief to acceptance, we didn't even have time to process that. We were told to rush for surgery as soon as possible, preferably radical nephrectomy within few days. My father not wasting time, decided to opt for England for his surgery. Within next few days he was admitted at St Thomas Hospital London and Right radical nephrectomy was performed by Uro-Oncologist. Biopsy confirmed adenocarcinoma. He returned home 2 weeks later happy that the storm was over. What was waiting ahead was unforeseen.

Four weeks post- op, he started having a gnawing pain in his groin. No chemotherapy had been administered so far. DVT was suspected as RCC are hypercoagulable but Doppler ultrasound of the legs was clear. But MRI pelvis showed a different story. There it was a 2-3 cm metastatic lesion sitting in his right neck of femur. Furthermore, CT Chest showed multiple lung metastatic lesions. So my father from a T2 stage became a stage 4 patient in a matter of one month!

He underwent surgical resection of tumor neck, Austin Moore implant followed by leg radiation and rehabilitation. Meanwhile repeat CT scans showed increased chest lesions. Till now, no chemotherapy had been administered so far. Another dilemma was the chemotherapy availability in Pakistan and when was the appropriate time to start. He was again post-operative recovery phase and chemotherapy administration was being delayed due to its impaired healing effects. It seemed the tumor was just too aggressive and time was running short. There are not many case reports or studies on RCC in Pakistan, let alone availability of affordable treatment. Our only savior at that time was AVASTIN (Bevacimuzab) which was yet to be launched in Pakistan in year 2005 and had just come out of Phase 3 trial in USA. High cost and delivering it to Pakistan while maintaining its cold chain was one issue, but which oncologist would be the first one to dare enough to administer it under his/her care here in Pakistan was another. Last reported case was of Peshawar where the patient survived only one dose of chemotherapy particularly Interleukin IL-2.

As luck would have it, we arranged the chemo drug from USA and started fortnightly infusions of newly approved FDA drug hoping it would serve a miracle. Four weeks into chemotherapy, my father started experiencing un-usual side effects especially palmo-planter erythro-dysthenesia (hand-foot syndrome) which was something even the dermatologist took time diagnosing and treating. But the results looked promising. Chest lesions reduced in number and size, while my father tried to recover both physically and emotionally from surgeries, radiations and chemotherapy side effects.

For once life seemed to settle. He regained his strength his valour. Some days were good some were bad. As time progressed, everyday there was discovery of new chemotherapeutic drugs. Intravenous infusions were changed to newer tyrosine kinase inhibitor chemo- medications requiring once daily dosages with controlled side effects. From Avastin (Bevacimuzab) to Sutent (Sunitinib malatate), Nexavar (Sorafenib) to Torisel (Temsirrolimus), Thalidomide to interferon alpha, the years in terms of life we gained as survival rate were at the interplay of these drugs. Elixirs of life so as you may say, were at the expense of painful side effects sometimes life threatening and innumerable trips to the ER compromising the so called “ quality of life “.

Then in year 2007, persistent SIADH warranted an MRI brain which showed a single 1 cm brain metastatic lesion in frontal lobe. Due to unavailability of Gamma Knife radiation in Pakistan at that time, and multiple consults with neurosurgery decided against whole brain radiation, we opted for India where at Rancan Gamma Knife Centre in New Delhi he underwent Cyber-knife radiation. As the sodium settled, he

started having malignant pleural effusions both lungs. After multiple drainages, it was decided to perform pleurodesis with talc at AKUH hoping to stop the fluid accumulation causing respiratory compromise.

Things took an ugly turn from then. The cancer stopped responding to the chemotherapeutic drugs and there were further organ metastases. Post pleurodesis there was still fluid accumulation causing massive respiratory compromise eventually leading to intubation and ventilation. So after a battle of 3.5 years with this horrendous disease, my father left for heavenly abode on 5th March 2008 aged 55 years.

The reason I wanted to share this story was to highlight that there are times when no matter how much we screen our patients, no matter how many investigations we subject our patients to, many at times life throws you a curveball. At times there are no etiological risk factors present in a patients history to render him/her diseased. Yet they are found to have the most notorious, most difficult and most un-responsive oncological entity known to mankind. And that is when it hits you not just as a physician, but also as a regular human being. That when you break the bad news to the patient and they say “why me doctor?”, you are absolutely clueless in your choice of words to console . You might have done hours and days of trainings on “ how to break the bad news to a patient “ and yet stammer on your robotic lines of sympathy At times the only sentence that comes out is “It’s because you are the chosen one and this is an absolute trial from Thy Lord!”. If by His decree there is health and recovery so it will be. If not, you might have all the money in the world to buy the best possible medications , treatments and resources in the world has to offer , yet it will not be fruitful or respond if it’s not the will of Allah. Some find a bit of faith and solace in these words. Others go into a pensive ponder.

No one loses the battle to cancer. Nobody asks for it in the first place. So to fully embrace it, with head held high and the move forward is a herculean task every person undertakes who is engulfed by this disease. Ask any cancer survivor or the ones sufferings, it’s not a matter of physical pain but rather a deep emotional turmoil as well as a spiritual challenge that one endures and moves on. The people around them try to make every possible effort to provide the very best care and support. So when we say the battle has been lost, it isn’t for the person who was fighting it. But rather it is us, the on-lookers who are standing at the loser’s bench.

Like any other stories I wished this one would have had a happy ending. That is what we all hope for. It is that small ray of hope that makes every cancer-stricken person courageous enough to undergo any chemotherapy despite knowing the probability of success, to its horrible side effects, in hope to get better for their loved ones. In hope to see their children grow up, in hope to support them as long as they have the strength. In hope to walk their kids down the aisle or live up to see them graduate, or see a progeny. It is not easy for any patient to walk down the doctor’s office with pitiful stares of surrounding people of their disfigurement or disability due to cancer or drugs. But it’s the little happiness that makes it all worthwhile. With each decrease in lesion or

pain, to a negative scan or tumor free status warrants a victory lap and celebrations. It's the small little things of joy that make the patient survive the day "hoping "tomorrow will be a better day. Small bucket lists are made to ensure that they experience the very best in life with their loved ones. Some get lucky and are cancer-free in no time. Some unfortunately don't get that chance.

Be it any medical school training program, surely they will teach you how often to screen patients, which tumor markers are prognostically important, to TNM Tumor staging and all, but what they don't teach you is adequate empathy towards patients. We as doctors are morally and ethically bound to be empathic. But what if you are the one suffering or your near and dear one is suffering, how do you cope with that? With so much happening around us, we as doctors have become rather "apathetic" to these patients. The compassion and respect is what every patient expects out of any doctor involved in their health care. And any misbehavior or lack of empathy by medical staff personnel easily shatters the patient's morale, which almost always goes un-noticed by the treating physician and their team. Support groups and rehabilitation services are all indeed important for a patient's recovery, but the best reaction the patient yearns to hear or to see from the doctors and team member is a hearty laugh or a compassionate smile which makes his/her day. The irony is while our politicians and philanthropists are in a race to build many cancer hospitals across Pakistan to eradicate this evil, but will our medical colleges and training programs produce and provide compassionate doctors at the same pace too?

With so much of rapid advancements in medical technology and its treatments each passing day, makes us forget one thing which all patients need to survive.

That is to celebrate life and to live it to its fullest.

Live so beautifully

That if death is the end of all,

God himself may be put to shame

For having ended thy career

Allama Iqbal



M Shahzad Shamim is an Associate Professor and Consultant Neurosurgeon at Aga Khan University, and the Director of AKU Internship; and Surgical Neuro-oncology Fellowship Programs. He is also the Service Line Chief of Mind and Brain. In his free time, he likes to go deep sea diving, play golf and tennis. Those who play these sports with him insist that he should stick to operating on brain tumours.

He wrote this story in 2010 and has not read it since.

Hold tissues as you would hold your mother's hand!

As surgical trainees, during surgical procedures we were constantly reminded to “hold tissues as you would hold your mother's hands”. Very few families will be as familiar with this lesson as ours. We live in Karachi, the trade capital of Pakistan, but perhaps also its healthcare capital. My father is a well-known General Surgery Professor. Both my older brother and my brother in law are also General Surgery Professors. My sister and I on the other hand rebelled against the tradition as she became a Gynecologist (Professor, obviously) and I became a Neurosurgeon (an ordinary Neurosurgeon, not a professor, yet) instead, the apples not falling far from the tree though. My other sister is an artist and a child prodigy, being the only deaf girl from Pakistan to have graduated from a regular American University. My brother the typical egotistical surgeon has a saying that there are two types of people in the world, general surgeons, and patients. Needless to say, we were constantly looked down upon, as inferiors. Coming from such a family, surgical principles and culture was ingrained into me on dining tables and family outings. Everything we talked about had surgical references, whether it was the thick walled overcooked chicken stomach (pota or kaleji if you may) at dinner, the povidine colored bride's dress at a wedding or the plot of a recent American movie, everything revolved around surgery. We talked about surgical cases as other families would discuss politics or weather. Surgery was a way of life for us.

Mommy on the other hand was a general physician, popularly known as a GP, possibly the only sane and socially acceptable family member. She avoided surgical jargon and would be least impressed at our “scientific” discussions and tales of our operating room heroics. Once when I told her of one of my initial surgeries that I did independently, a unilateral decompressive hemicraniectomy for stroke (wherein a part of patients' skull bone is temporarily removed to accommodate the rapidly swelling brain), she ridiculed that our work resembled a low cost horror movie and commented that neurosurgeons are over rated. She kept us in check and was in fact our only connection to the normal

society. Mommy herself did two community clinics every day and easily treated many more patient than any of us “specialists” in our fancy hospitals and expensive operating rooms. As a child when my school was off, I would go with her to these clinics, chatting with her patients and reading storybooks bought from a bookstore across the road, an experience repeated by my son three decades later. Her patients would walk into her clinic with no need for appointments and at times with no need for consultation, merely to take advice regarding their personal rather than medical problems. She would give them a lot of time and I personally know couples whose marriage she saved. All in a day’s work! It took me years to realize that she was doing a far greater service than any of us. She was worshipped by her clientele which comprised mainly of middle and lower class social strata. Even we “the specialists” would look up to her for our medical problems which as “specialists” we had no clue towards. This would include treatments for fever, sore throat, runny nose, etc. Yes that’s right; most surgeons don’t know how to treat these ailments.

As a child, I remember her to be an embodiment of patience, strength and stamina. She single handedly ran our house, taking care of her perfection driven husband, four spoilt children, a huge house, and at the same time running her two clinics and a hospital we owned. As is in our culture, being the eldest in both their respective families, my parents also had certain responsibilities towards their siblings and their children, totaling to around three dozen adults and probably a million children. Despite this, all through my life as a child, I remember hers’ to be the last face I saw before I shut my eyes at night, and first when I woke up for school. I would wear my school dress still warm from her ironing and finish my homework while she fed me my breakfast, spoon by spoon. When I fell ill she would sponge me, gently run her fingers through my hair and sing to me softly all night, and yet be there to continue with her hectic morning schedule. I remember every bit of it as if it was yesterday, every word and tune of the song, and how it felt to have her fingers through my hair. As grownups we all stayed in the same house, a common cultural choice. Every morning we all went to different hospitals at different hours depending upon our seniority at respective institutions. I as a trainee I would get up first and as Professor, my dad would be the last. Mother would wake up each one of us and each of us had our favorite breakfast and clothes ready when we were. We would all leave, saying “Khuda Hafiz” (May God protect you) to her, almost as a rule. She would leave only after seeing everyone off, but not before enjoying her favorite breakfast, a single boiled egg, cut in four pieces and sprinkled with salt and pepper, with a crisp, warm buttered toast and a hot mug of tea. She would be back from work before any of us to prepare lunch. In the meantime, she took care of groceries, household bills, household chores such as faulty pipes or dysfunctional electric sockets, and still have time to keep our wardrobes organized, and maintain her garden where she grew roses, golf ball sized lemon and an array of spices. She even looked after our hospital accounts that included dealing with insurance companies and suppliers. We were a spoilt lot and wouldn’t have it any other way. I don’t ever remember her falling ill or telling us that she needed to rest. I also don’t remember her

angry or loud. It is almost unbelievable how she managed to do it. I wonder if she ever did rest or what did she do to entertain herself. As a physician, a wife, a sister, a daughter, and daughter in law and later as a mother in law and grandmother, she worked round the clock all her life. I would marvel over her unrelenting commitment and her unmatched attention to details. That's not all, during winters she would give us all new sweaters, hand knitted by her throughout the year. She was like an invisible angel that looked after everything, responded to all our calls of help and never reminded us of her presence. At social gatherings she would be the most graceful lady of the evening. Diamonds suited her like they were made to be worn by her. She remembered everyone's name and had something to talk about with everyone she met. Once at my sister's wedding, after a lot of persuasion from her sisters, she sang, and we were spellbound by the melody of her voice. Sounds too good to be true, right? Well, that was my mother, a real life super mom.

As an unsaid rule, worst things tend to happen to the best of us. In 2005 at the age of 60, mommy was diagnosed to have breast cancer. The event changed our lives. We suddenly began to acknowledge the visibility of our angel. It's a pity that we only realize how much we love someone when it becomes apparent that we are about to lose her. She fought her cancer with vigor and humor. Even after receiving the best surgical care, radiation and chemotherapy, her cancer recurred. She underwent another cycle of surgery and radiation with several combinations of chemotherapy that greatly weakened her. Despite all our efforts and prayers, her disease prevailed and mommy was found to have metastases at several levels of her spine and lungs. In her last few days, her body became very weak but her extraordinary willpower remained undeterred. In between chemotherapy sessions, at the slightest improvement in her physical ability she would be found doing her clinics, shopping for groceries, or cooking our favorite "chanay ka halwa". Even though her right arm and hand had become immensely swollen due to clearance of her axillary lymph nodes and radiation but she continued to knit for my second son who we were expecting in a few weeks' time.

She died in 2008 before his birth after fighting her illness for more than 3 years. At her death, hundreds of people came to our house and her funeral, crying as if a child had lost his mother, people we had never met before. Right before her body was being moved to the cemetery, I had an opportunity to hold her left hand for one last time. I don't remember how long I held it for, but I will always remember how it felt. The hand that had fed me, raised me, protected me and prayed for me, the hand of my angel. Those who were present there say that I was crying when I held her hand. I only remember holding it. "Hold tissues as you would hold your mother's hands", whoever said that obviously did not have an ailing mother.



Saniya R. Sabzwari is working as Associate Professor, Family Medicine Department, Aga Khan University.

"I have a large elderly population in my clinical practice. Just as their medical problems are complex their social issues further compound their day to day existence.

This story is one example of many from this generation who forge ahead against insurmountable odds that they face in their golden years of life."

Untitled

She was one of those patients that left an impression; actually she was one of those individuals that left a lasting impression.

A thin and vibrant septuagenarian came to my clinic a few years ago accompanied by her tall husband whose quiet disposition complimented her exuberant personality. She had recently undergone surgery for colon cancer.

Talking to me as if we were long lost friends she described how in less than three months a single episode of bloody excrement turned her life upside down. A whirlwind of tests had ended in the dreaded diagnosis of cancer. She had undergone surgery hoping for a cure only to find out more was needed. She came to see me as she now wanted help with healing.

After a routine ritual of examination, I found a fully functional spry female with mild pallor, clubbed fingers and a healing incision.

Going over her medical records I saw recommendations and referrals for adjuvant therapy. Assuming I was to oversee her care in the next stage of her treatment, I inquired her oncologist's name.

That is when she proceeded to share with me plans for her health restoration.

The last few months that had triggered anxiety and dread had by now been replaced by tranquillity and a clear sense of it all. She had surrendered the last few months to her treatment and now wanted her life back, whatever was left of it.

As someone geared towards medicating and maximizing recovery, her idea sounded absurd. I let it go hoping to have greater influence on her decision in a follow up visit.

For the next couple of encounters I dogmatically hung on to convincing her of the benefits of definitive treatment.

Thoughts of her decision stemming from dementia and depression also surfaced; but were quickly negated by her discerning nature and ever present sense of humour.

During our conversations, she defined her healing as living her life doing what she loved; reading, eating and spending time with her beloved husband with whom she shared a 50 year bond of love that held strong despite illness and frailty. She had therefore chosen not wanting to be a slave to her disease in the remaining time she had with him.

Overtime, my discomfort with her decision abated and even started making absolute sense allowing me to settle back into my role of care provider and advocate rather than a decision maker.

I continued to be her primary care physician for the next three years treating various ailments from anemia to back pain still always wary of her cancer returning. Feeling obligated to share these concerns with her always led to a reiteration of her decision.

Throughout this time I watched her heal and beat her illness psychologically, emotionally and spiritually. She accepted her cancer but never submitted to it, living her life to the fullest till one day a fall in the bathroom ended her life swiftly; just as she had wanted.

No one will ever know whether it was her cancer or a sudden unrelated event that took her but did that really matter at the end?

After all, the journey was so much more important than its end.



Bushra Maqsood is working as a House Officer in Oncology Ward, JPMC.

"My areas of interests have always been Neurosurgery, General Surgery and rare diseases. I believe that you learn more from your life and surroundings than from books. Fifty working days are better than a hundred days of solely reading and not applying."

101 years of a peaceful heart

I stepped into the ward to see a very old man resting on his bed. I kept the syringe and the swab box at the table to look for any veins in his hand. Meanwhile, I introduced myself and also inquired about his health. He didn't say a word in response. I thought he didn't like my presence. I tried again to win his comfort but he said nothing. I proceeded with what I was assigned to do as his silence gave me an affirmative answer instead of a no. But he said nothing.

I gathered all my samples, and opened his file to enter the necessary details to find he was suffering from carcinoma larynx. He was 101 years old. He was unable to speak. I closed the file and looked around to see any attendant who would take his samples to the lab but couldn't find any. I took my pen out to label the sample and make a receipt but my pen gave no signs of life. He smiled. He then took a pen out of the front pocket of the safari shirt he was fond of wearing and presented it to me. I smiled back. It seemed like I had begun to understand the language of smiles. I did my work and asked, "Do you have someone to take this to the lab?" he replied in affirmative. I looked around again to find his attendant but nobody was there. I told him, "That's fine; I will ask another attendant to do this for you, no problem." He closed his eyes and swayed his head in negation. I didn't know what he wanted. He pulled a piece of paper from his pocket and took back his pen from me and started writing something on it. I inclined myself towards it to find something legible inscribed on it.

It said, "I have an attendant."

I asked, "Where is he".

He wrote, "He is everywhere, my child"

This dazzled me. I felt like something divine was happening to me. I looked again at the beautiful handwriting of that man and praised him. He brought his ear near me as if he wanted to listen to it again.

I said, "Uncle, you have got a beautiful handwriting!" he smiled again and blushed.

He took another piece of paper out of his pocket likely to be used for the same purpose.

It said, "My child, give me the tops, I'll take them to the lab."

I was not okay with his idea of going alone to the lab since we have a long walking distance with an intervening large ground with bad terrain that was flooded with rainwater. And we could still hear thunders. He got up from the bed and requested me to take out the drip set for a while so that he could go out. While doing it, I said, "How can you go alone like that." He smiled, wrote something and went away.

It said, "God will accompany."

I was surprised to read "My child" in every message that he wrote. It gave birth to a lot of questions in my mind. I was asking myself why has his sufferings not made him irritable; what has made him so strong; why is he wasting his energy in writing "my child" again and again, never letting any impoliteness take over our conversation. He has got a very valid reason of this disease to excuse himself from any politeness that is needed in conversations yet he is so patient and courteous. Why?

Once I asked him if he could eat like a normal person or should I plan some intervention for that purpose such as nasogastric tubes. He wrote, "Nobody has asked me that before, my child. Let me tell you that I would be more than happy to eat like a healthy person and I can do it." I then gave him a diet plan very happily. He even executed the plan very well without anything to worry about.

Since then, we started to chit chat on paper pieces and he was very happy to find me patient enough to read what he always wanted to say. I loved how he was equally polite throughout his conversation with me despite cancer taking over his life. From the time of his admission till the time of his discharge, he remained a very thankful human being living the best out of his life that could have been so miserable without the attitude he had towards it.

He taught me how to be happy with whatever you have. He taught me how this life is like a changing sight just as you look out of the window of the train but you have to be composed and targeted towards your goal, trying your best not to affect your journey and destination because of what you view outside the window. What you see outside the window is just a glimpse and glimpses are short-lived.



Sadaf Khan is a 40 something, proud mother of three. In her free time, she is a Colon and Rectal surgeon and Medical Educator at the Aga Khan University.

Reading the skies

Everyone's life is a series of stories. The feel good stories with auspicious beginnings, predictable middles, and happy endings make for boring reading, but very few of us would decline the chance to live them. There are the truly harrowing stories, the kind that make you want to quit reading. Or if you brave your way through to the end, they leave you scarred and fearful, because after all, anything can happen to anyone. And then there are the stories that are like a good mystery – tense enough to hold your attention, calm enough to make you stay. On that shelf sits my story.

I won't bore you with the details. We can all agree that cancer is such a disrupter of life. In all fairness, so is injury, or a stroke, or a heart attack, or the godfather of disruptors – death. But cancer has the privilege of bringing with it an insidious fear that if given the chance, can seep into the soul of anyone it touches. There it chisels away at hope and joy, diminishing the intensity of a life that may be struggling but is still very present. The antidote is intuitive but often unappreciated and underrated. When cancer comes to visit, you and your loved ones can choose not to let the fear enter. It's as simple as that.

So let me give you the gist of my story. Allow me to share my thoughts, reflections, and some of the lessons that I hope I will never forget – because I really don't want to do this again.

The storm is forecast:

I feel a lump that shouldn't be there. With intention, I don't pretend it's not there. I see a surgeon. The diagnosis follows the biopsy. The first thought that comes to me when I am told is 'Thank God I am here'. For reasons so complex that they comprise another story, we had recently relocated to Pakistan after many years away. The knowledge that we would battle this beast with the full force of our family and friends with us was akin to holding a secret weapon. It gave me the bravado to face what I knew was coming over the next few days.



The wheels start turning: a bewildering list of tests, waiting rooms, changing rooms, examination rooms, starchy sheets, cold tables. I become familiar with radiology ceilings. Gypsum tiles with their pinpoint perforations, slightly stained edges where the cleaning brushes can't reach. There are concerned eyes, compassionate smiles, gentle hands. Things don't look too bad. It's still cancer, but it's not too bad.

What exists cannot be changed. It just has to be dealt with. In the space of one breath, the entire course of life changes. Not just yours, but those you hold dearest and those who hold you dearest. While the beast is quantified and qualified, the vise of uncertainty overshadows every interaction. The only way to deal with it is one step at a time. Slow deep breaths, consciously calm your thoughts, don't overthink, don't try to predict.

The clouds gather:

I put myself in my surgeon's hands. I don't think I asked many questions. I had my operation. It was easier than coming down with a cold. I am a surgeon. I respect the scalpel. The pain of an operation does not scare me. There's nothing a pill or at most an injection can't fix. It is predictable and finite. Things can go wrong but there is no point in focusing on that possibility. My recovery was smooth. The only apprehension and uncertainty related to the pathology report. That piece of paper would decide the course for at least the next year, if not the years to come. It would even attempt to forecast how many years there might be. The preliminary report raised more questions than answers. More tests needed to be run, more complex interpretations attempted. At this point, we decided to take the vacation that we had planned when life had been sailing along smoothly. Everyone needed to take a breath and not think about cancer.

Some reflections from this period - there is nothing like stepping away from your usual environment to help you take the edge off anxiety and uncertainty. It isn't always possible, but if you can, when faced with situations that are out of your control, take a break. For us as a family, the short break allowed us perspective. It allowed us to laugh and celebrate each other and life without awkwardness, apprehension, or guilt. We returned rejuvenated and ready to take on the next set of challenges. The wild, unpredictable beast appeared more docile.

Also at this point the barrage of advice kicked in. Why so soon? You must get a second opinion. Did you see Dr. so and so? Oh, but you must! Try apricot seeds first. Aab-e-Zam Zam will make it dissolve. Drink Haldi(turmeric), eat it, make a paste and rub it on it the cancer. Wait and see - sometimes its nothing. I can't imagine how the unfamiliar manage to negotiate through this period. The amount of misinformation and misunderstanding is phenomenal, compounded by distrust for the medical profession and the intentions of those who practice it. Too many people get lost in this quagmire, losing precious time and chances of cure. As medical professionals, this is a challenge we need to actively address. I'll save my ideas on that for another time and place.

Sailing into the storm:

From my perspective, all the anxiety and fear related to the cancer boiled down to my apprehension towards the chemotherapy. Everyone knows about the nausea and vomiting. Baldness. Then there is the vast wasteland of symptoms that vary from drug to drug and person to person, hard to describe, harder to understand.

I focused on the obvious – my hair. I scheduled an appointment with a friend of a friend, whom I thought wouldn't know me. I walked in and asked for a short cut. We went through photos. I looked at a certain style and suggested it might work for me. The stylist, very gently and with much empathy replied, 'You will have to go shorter.' And just as I had relinquished control of the tumor to my surgeon, I gave this lady control of my soon to vanish hair. She gently led me through the process, reassuring me as she wielded her instruments. When she was done, my hair was as short as it has ever been since my parents shaved my head after welcoming me into their world. This wasn't the first or the last time that the kindness of a stranger stood firmly between apprehension and me. And it helped that the new look was *tres chic*!

I now put the burden of my wellbeing on my oncologist's shoulders. It was a mean thing to do to a good friend, but these were extenuating circumstances. The intravenous port was in place and ready to go. A date was selected, blood-work done, a regimen chosen. Dry goods stocked up in the larder, an assortment of meat in the freezer. My mother took over the reins of my household. The children's teachers were in the loop. I presented at the infusion center with my husband and sister. We were gradually joined by friends, some physicians, some not. All novices when it came to this particular experience. Always present, the doctors and nurses, with their sunny smiles and gentle hands. One after the other, drugs of various colors, volumes, and effect were infused.

Everything went as expected. The aftermath, intense and unpleasant, lasted for the two-month duration of the regimen. The first few days were not too bad. Not much nausea. Some tiredness; nothing that a nap couldn't fix. Then it started. My mind slowed down. My otherwise constantly thinking, planning, talking mind was suddenly quiet. There was just enough sound in the silence to make me aware that there was something wrong. I had very few thoughts, and those that I had were knots of fear that this would last forever. I saw the worry in my mother eyes but couldn't find the words to explain. I saw the fear in my husband's eyes when he found me staring off in space and asked me what I was thinking, and I answered 'nothing', and we both knew that I meant it. As the medication did what it was sent to do, most times it was easier to give in to the intense fatigue. But whenever I could I tried to crawl out of there and every time I resurfaced, I resolved that there would be no second dose if I didn't return to myself. Mercifully, I did. As the treatments progressed, my family would affectionately proclaim my return with 'She's back!'. There were some casualties. My hair started to leave on day 14, almost as if it had read the book. My husband shaved the rest of it for me on day 16. That didn't change how I looked too much. Over the months, I chose to cover up in public, but within the walls of my home, I rocked my bald head. The other casualty of this storm was my verbal filter. Words would form in my brain and leave my mouth without check. A lifetime's reputation of diplomacy and measured words up in smoke.

Thankfully, when you have cancer, people give you some leeway. Having said that, everyone should try it once in a while. It's liberating.

While I was struggling to find coherent thoughts, I realized that without them it was impossible to control my mind's tone or function. Here is some convoluted logic so bear with me. The mind is a powerful, powerful entity. It can be thrown into uncontrollable chaos, amplifying fear, pain, despair, and hopelessness. But if you can harness its power and assert yourself as the boss, it can get you through anything. It is the secret weapon that the Creator gave each of us. It can control pain, discomfort, anxiety, terror, and despair. As you sleep at night it can reset all your systems so that when you awaken, the day seems brighter, the breeze cooler. Even though your tongue can taste nothing, it can keep the memory of ice-cold lemonade just a thought away. The mind takes its cue from the spirit, your essence. The spirit in turn, a changing, morphing force, is nurtured by your thoughts. A fearful thought, for example 'this cancer is going to kill me', can wreak havoc on your spirit, beating on it till there is no joy left. The mind will follow and create the physical manifestations of despair. Conversely, the calmer, more hopeful, and positive your thoughts, the brighter your spirit will glow, the easier the journey will be. And so, of the many lessons that I hope I learned, this is perhaps the most important. I don't ever want to hold on to a negative thought again. Where there is a storm, I will admire the power of nature. Where there is anger, I will look for reason. Anytime I see a problem, I will be spoiled for solutions. Where there is fear, I will create joy. I refuse to ever have a thought that is without light.

In the eye of the storm:

After the saga of the first chemotherapy regimen, I moved on to the second part. This was going to be very easy. I could go back to work part-time. I would be stronger and healthier. I would lose my eyebrows and eyelashes, which finally does change the way you look, but my hair would venture back. There were some possible complications, but they could be anticipated and circumvented. That's what my doctor, family, friends, and I believed. I set up the 'Thursday morning happy hour' WhatsApp group that kept my chemo support group in the loop about what time and what room to report to with smiles, stories and snacks. And then they started - the nasty, life threatening, life-altering complications. Side effects that were only supposed to happen rarely, showed up like they were old friends dropping in for a cup of tea. Every week a new and exciting challenge presented itself and had to be dealt with so that the treatment could be continued, because you can't ever forget about the beast. There were medications for the side effects that in turn had their own complications. By eight weeks, I was hosting a garden party for unusually occurring sequelae of treatment. I had to stop working again. Commitments made had to be broken, responsibilities reassigned, projects left in limbo. I have kept a count of how many times in my life I have called in sick. Till before this nuisance, it had happened twice over 24 years. Amidst all this, there was an unexpected silver lining. I required a fairly large dose of steroids to deal with some of the side-effects. I have never had more energy in my life. I cooked, cleaned, wrote, read, painted, sorted, redecorated, rearranged, reimagined, slept a few hours, and then

started all over again. That steroid euphoria was a great feeling that I am certain I will miss. Drug-induced high or not, to not be at work if I could stand upright went against my grain, my work ethic, and principles that I felt defined me.

But you can't change what you can't control, and the faster you get at computing that equation, the quicker you can re-deploy for the next skirmish. Lamenting about the why and why me only wastes time and precious energy. How to go about it is simple. It's what we teach toddlers. If you fall, brush it off, stand up, and go. Looking forward with intention keeps your spirit strong, your mind in the game, and your body as fighting fit as it can be with the beating it may be taking.

Saving the ship:

At this point a decision had to be made about whether to continue with the remaining cycles of chemotherapy. My spirit, after consultation with my mind and body, had made an executive decision. The challenge was to make sure that everyone else came to the same decision without suggestion or coercion. My husband, whose only response to every setback was to prop me up a bit more, thought a retreat was in order. My resilient, stalwart children were showing signs of fatigue. Family and friends were asking for statistics of treatment regimens. My surgeon, as we surgeons tend to be, had had enough. But this most crucial decision would come from my beleaguered oncologist. She who had prescribed chemo with generous helpings of emotional and moral support would have to battle all the clamor and opinions. She came to the decision herself. Or maybe I pushed a little. We were going to stop.

Cutting your losses is a tried and tested strategy in life. It should never be taken lightly. Due diligence is essential. It must be done with resolve and meaning. But at the core of any such decision is the understanding that no matter the outcome, regret has no place in the aftermath.

Sailing back to port:

Done with treatment. What a deep, rich sense of relief that was. The six months, that at one point felt like a lifetime, were over. There were still challenges. After all, I had a side effect garden-party going. Every night I fell asleep anticipating a better morning. Such a nice way to end the day. My loved ones didn't have guarded eyes when they looked at me. My taste buds started to peek out of their shells. Or maybe they had to be reborn. I was able to have whole fruit. I had never noticed the perfect balance of flavor between a peach and its peel. I was able to eat out again. Crispy samosas, Afghani kebabs, Pakistani-Chinese food, chicken rolls, greasy, spicy, store-bought Nihari. I was getting stronger physically. I thought I would gain back some of the weight I had lost, except as muscle. It turns out I still hate working out. Even cancer can't change some things.

Taking some time to reconnect with life is required. Falling right back into place where one left off is probably a colossal waste of all that cosmic enlightenment. It requires deliberate thought to reacquaint oneself with the person that came through the storm.

There are new perspectives, reordered priorities, and new goals. Things that used to be of concern now matter not at all, whilst some priorities that may have lived on the fringes take center stage. It is naïve to think that I was in this by myself. My parents, spouse, siblings, and children were all dragged along. They will all have changed, grown, and hopefully found their own truths. I will have to reconnect with them as they make their discoveries.

Through this all, together we will pray and hope that this is the end of this particular story.

Deciphering the storm:

- The only certainty about life is death. Don't waste time stressing about it.
- In the kingdom that is you, you are the strongest. The only way to get reinforcement is from your faith.
- Love and friendship are like salt and pepper in your life. Not the same, not different, each holds its own separately, but they do very well together. Love is probably the stronger force. But when you draw strength from a person who loves you, you most likely cause them pain. Friendship is unique in that the support it can provide is almost limitless, and the strength it generates is shared by all.
- Some things you can't control. Accept it and move on.
- For those who have children, they are your greatest responsibility. They each come with their stories and it falls on us to ensure that as much as possible, their stories begin well.
- If you were given a gift, use it. You have a beautiful voice, sing. You have an eye for color, paint. You weave words, write. You have a soul that can hear, listen to a soul that needs to speak. Imagine the embarrassment of having to explain to the Almighty why you chose not to use a gift he had bestowed.
- Feed the good wolf in you. I suggest a diet of hope, joy, laughter, and love.
- Make it impossible for negative thoughts to find a foothold in your life.
- If something needs to be said, say it. If something needs to be done, do it.

As I write, I hope I am in the concluding days of this story of mine. I leave you with the words of Faiz Ahmed Faiz:

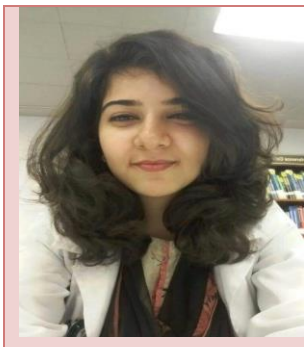
'Your ailment has no cure save the lancet
And this cruel cure is beyond me -
Beyond anything that breathes on earth.
Yet it rests with you
Only you!'

ترے آزار کا چارہ نہیں نشتر کے سوا
اور یہ سفاک مسیحہ مرے قبضے میں نہیں
اس جہاں کے کسی ذی روح کے قبضے میں نہیں
ہاں مگر ترے سوا - - -
ترے سوا ----
ترے سوا ---

My friend, my mate

Faiz Ahmad Faiz translated by Shiv K. Kumar





Mahin Janjua is a medical student at the Aga Khan University. She aspires to enter the field of Surgical Oncology and work to instill hope in the hearts of cancer patients.

She continues to work towards changing the perspective about cancer in the minds of the people.

He decided his own code

Biography:

An ordinary human being who has seen a few extraordinary things happen.

As the rickshaw stops before the house, I spot my mother awaiting me at the gate. Everything has changed. The family of six that once inhabited this house has now been reduced to that of five.

Nostalgia drips from every corner of the house. As I step into what used to be my bedroom, I recall the 13 year old girl lying on that very bed, her face pressed into the pillow as she cries her heart out, minutes after she is told that her father probably has cancer.

The attached bathroom brings back memories of the day when the same girl locked herself up in there to release all the emotions she had bottled up in front of her family. I can almost see her stare back her reflection; the tears rolling down her cheeks, as she tries to digest the news that the cancer had metastasized to the lung. Standing before the same mirror, I now see the reflection of a much older, version of the same girl.

Only this time, she is fatherless.

Life had somehow brought us back to where it all began; back to where the news was broken; to where our childhood was snatched from us.

‘Suffer’ – the word reminds me of the innumerable times *Papa*, in good humor, used to ask whether we meant the English ‘suffer’ or the Urdu ‘*safar*’ (journey). It is interesting how he himself suffered, both in the English sense and the Urdu.

I am not sure exactly when we embarked on this journey. Though formally diagnosed in 2008, *Papa* had been complaining of occasional dull pain in his lower abdomen, groin and back since 2004. A doctor advised him to get a colonoscopy. However, the seriousness of the condition never occurred to *Papa* and he dismissed it, afraid of the

discomfort the procedure might cause. Whether the pain was linked to what was to be diagnosed in the future, we can never say for sure.

‘What did not happen in the past is just as uncertain as the future,’ - *Papa*.

The year 2007 saw *Papa*’s promotion to the Head of the Department at his University. His past few years had passed in immense turmoil involving losing his job, and being made to start over at a different University. This promotion meant that his struggles were finally bearing fruit. Around the same time, however, he developed lower abdominal pain with altered bowel movements. He visited a gastroenterologist who assured him that he was fine, and prescribed some antibiotics and laxatives. He emphasized that *Papa* must not see any other doctor. The medications helped only temporarily and within 6 months, the pain aggravated forcing *Papa* to see another gastroenterologist.

After examining *Papa*’s abdomen, the doctor ordered a barium enema. It revealed a narrow, tortuous lumen of the descending colon with prominent shouldering. Being a doctor, my mother immediately knew that this indicated a malignancy.

A CT scan of the abdomen confirmed the presence of a 6 cm mass obstructing the descending colon. Initially, no metastases were reported, indicating that a simple resection of the tumor would suffice. My mother responded, ‘*Alhumdulillah*’. As we celebrated the good news, however, the radiologist called again to inform that he had spotted a 2 by 2 cm lesion in the liver. Chemotherapy was a must. My mother again responded, ‘*Alhumdulillah!*’ thankful that at least the lesion had been spotted.

When my mother told me about the lesion, she told me to pray that it turns out to be anything but a metastasis. ‘If this tumor has spread to the liver, your father might only have 3 to 6 months to live.’

My parents met with the surgeon to discuss the resection of the mass. He acknowledged the worried look on my parent’s faces and gave them as much time as was needed to address their concerns. He helped them understand that ‘cancer’ was not synonymous with ‘death’. He comforted them, gave them hope, and made them understand that people can still continue to maintain a good quality of life despite surgery and chemotherapy.

Within a week of diagnosis, *Papa* was admitted for a left hemi-colectomy. My younger brother and I went to live with our family friends. Despite *Papa*’s surgery, we continued to attend school. Education being top priority, our parents saw no reason why we should miss school because of this. Fortunately for us, school work distracted us from thinking about *Papa*. However, there were still instances when I would think about *Papa* and my heart would sink with fear of possibly losing *him* in the operation. At such a time, I would quietly recite a prayer before getting on with my work.

Very few people in school knew about *Papa*’s diagnosis and of those, even fewer seemed genuinely concerned. I soon realized that letting my inner state of mind show, especially on my sad days, only distanced me from those around me. So instead, I

started pretending; to be happy and carefree. I would crack jokes and talk about all sorts of things that were of interest to those around me, but never about *Papa's* illness, or the other problems we faced, unless asked directly. I would often smile internally, thinking of myself as a superhero that was fighting battles rest of the world was unaware of. Slowly and steadily, somewhere down the road of pretending, I got lost in the act, and actually felt happy and ultimately hopeful.

At the other end, my mother was handed the consent form to acknowledge the worst possible outcomes of *Papa's* procedure. She wished she had someone more mature to handle these matters. She was left alone and terrified as they wheeled *Papa* into the operating room. It was a long procedure; longer still for the person waiting outside the OR for any news about her husband. When the surgeon finally came out, he looked exhausted. He showed my mother the resected tumor. She felt nauseous looking at it, thinking about the havoc this tissue had caused. There had been a complication in the surgery because of which an ileostomy had to be done; meaning that for the next couple of months, *Papa* would have to live with an ileostomy bag.

After 7 days in the hospital, *Papa* returned home. Seeing him for the first time post-surgery, I felt a lump in my throat. He had lost considerable weight. Forcing a smile on my face, I went to greet him and simultaneously, thanked the Lord for letting him live. The smile helped generate hopeful thoughts, convincing me to believe that with the operation done, *Papa* would soon get better and that the disease had been treated. 'Isn't that why people go to the hospital; to be treated?' a tiny voice inside me reassured. Little did I know that the journey was not yet over.

Visits to the oncologist came next. He also played an important role in changing our perception about cancer. He would listen carefully to everything my parents had to say, often cracking jokes during his consultation to make the atmosphere less intense. Most importantly, he refused to talk about *Papa's* life expectancy.

'I cannot predict my own life expectancy; much less predict something for you. I do not even know whether *I* will be able to live another day, then how can I number the days for anyone else?' he said.

My mother used to say something similar to us. Lots of people die every day; do all of them have cancer? Death is a reality of life that we have to be prepared for and it does not necessarily come in the shape of cancer. It can come to any of us at any point in time. 'Live each day as if it is your last.' This became our chant for years to come, anytime we worried about *Papa*. It was strange how, in the tangle of life, the thought of our own non-existence was more comforting than the thought of living without *Papa*.

The oncologist told my parents that 12 cycles of chemotherapy would be needed. He warned us that it will cost at least Rs 30 lacs. Our bank account by this time was empty. Even though *Papa* had re-joined work soon after his operation, there was still not enough money for even the first cycle of chemo. The decision of whether to go for chemo or not was a difficult one. Our minds were filled with stories about the innumerable side effects of chemo. We were told that we would inevitably have to sell

the house to afford the treatment. The children would need to be sent to a cheaper school. There was so much that could go wrong if *Papa* started chemotherapy. Then a miracle happened. One of *Papa's* friends, living in the US, called and asked if we needed help. When he was told about the financial situation, he formed a bank account on *Papa's* name where old friends and students of *Papa* poured in money anonymously for his treatment. We perceived this as a sign from God to go ahead with chemo. As soon as the money for the first chemo was arranged, *Papa* got ready for his first cycle.

For the next 6 months, *Papa* received chemotherapy fortnightly. It was arranged such that on Fridays, he would return from work in the afternoon, and drive to the hospital for chemotherapy. My mother accompanied him and stayed by his side throughout. *Papa* would receive chemo for the next 2 days and return home on Sunday evenings. My brothers and I were left at home, all by ourselves. The days in between two cycles were consumed in arranging the money for the next chemotherapy, and reviving *Papa's* health to sustain the next cycle. For the latter, my mother ensured that *Papa* was fed frequent, highly nutritious meals. He was given cashews, coconut milk, fresh juices of carrots, oranges and apples each day. Each meal was prepared fresh to minimize any risk of infection. We had been warned that chemotherapy will reduce his immunity such that even common flu could prove to be fatal. I was given the responsibility of making sure that the house was spotless. Every time my parents would be away for chemotherapy, I would scrub the floors and the bathrooms, prepare food for the family, and ensure that everything was clean and in place before *Papa* returned from chemotherapy. Every Monday, regardless of how groggy his condition was post-chemotherapy, he got ready to drive to work the next morning.

Around this time, the histopathology report of the resected tumor came out positive for adenocarcinoma of the colon; the lymph nodes were all negative. 3 months into the chemotherapy, a repeat CT abdomen showed a decrease in the size of the liver lesion. The disease was labeled Stage IV Adenocarcinoma of the Colon.

Here onwards, *Papa* had multiple recurrences of the tumor for which relevant surgeries were performed, followed by chemotherapy. Within a span of five years, he underwent a total of six major surgeries, from the initial colon surgery to surgeries for excision of tumor that had spread to his liver and lungs. He received chemotherapy on five occasions in total.

By 2013, most of the available chemotherapeutic agents had been tried on *Papa*. The PET scan showed a nodular lesion along the para-mediastinal suture and a right anterior mediastinal mass measuring 2.8 by 1.7 cm in size. Being close to the great vessels, the tumor was declared inoperable. Around this time, *Papa* received a job offer to set up an Engineering college in Sialkot. The College was located in the outskirts of the city; surrounded by greenery, allowing for a massive change in atmosphere. *Papa* decided to take the job, with the mindset that he would try to fight the disease by changing the air that he breathed. Fortunately, it worked. The first PET scan, after he had shifted to

Sialkot, showed that one of the lesions had disappeared completely, and the other had reduced in size. During the first 2 years in Sialkot, the tumor remained stable.

On the 1st of January, 2016, as the world celebrated the New Year, I was given the news that *Papa's* cancer in the lung had progressed. The latest PET scan reported multiple nodules in the both lungs. Being a medical student, I no longer needed my mother to explain what this meant. *Papa* was started on chemotherapy again.

The following year and a half saw *Papa's* health slowly deteriorate. He continued to work in the college he had set up. By the end of 2016, his appetite had decreased, and he had begun to lose weight. On my visits home, I noticed he had developed a chronic cough, which often disturbed his sleep. Off and on, he complained of excruciating pain in his right shoulder. In the past years with this disease, I had seen *Papa* bear all pain in silence. But this time, his pain and discomfort often made him cringe and moan scaring us out of our wits as we tried to imagine its intensity. Often, he would be found sitting up in bed in the middle of the night, sighing in agony, unable to fully explain what was happening to him.

On the night of 11th May, 2017, I received a call from my mother, telling me that *Papa* had had a silent myocardial infarction. The diagnosis had been made based on the changes in his ECG which had been ordered to investigate his pedal edema.

'The prognosis is not good. I haven't told your father about it yet, because I do not want to scare him. If you want to come and see him, let me know. These might be his last few days.'

I was speechless and numb. I gradually managed to process that this was probably how it was supposed to end; our journey through cancer.

Friday morning, I flew to Sialkot, reached home and went straight to *Papa*. He sat on his bed, looking weak, breathless and drowsy, wearing an oxygen mask. He took it off when he saw me. I kissed him on his cheek, as I did every time I met him.

'Thank you,' he said.

It made me want to cry, but I knew this was not the time for tears. As I sat with him, I cracked jokes and tried to make him laugh, and talked about him getting better soon.

Later that afternoon, I made him a cup of tea, and read out verses of the Quran that were very close to my heart. They were comforting as they talked about the Hereafter and the rewards for people who remained patient and steadfast against hardships. That night, I felt hopeful. *Papa* was sitting, standing, walking and talking on his own. He was fully oriented, regardless of his drowsiness. I feared if we had possibly given up too soon. We asked *Papa* if he wanted to go the hospital. He refused, saying that the hospital staff will only give him more pain and separate him from his family.

The next morning *Papa* was better although, by night, his condition had deteriorated even more. He could not walk on his own without losing balance. By the third day, *Papa* found it even more difficult to stand up on his own, and by night, he was catheterized.

That night, regardless of his condition, *Papa* sat in bed without support, as our family gathered around him. We all laughed and cracked jokes with *Papa*, and recalled fond memories from the past. He listened to our conversations and responded by smiling, shaking his head or through short sentences he managed to speak. We asked him if he was proud of his children and he nodded in affirmation. We told him innumerable times that we loved him, and every single time, he smiled and nodded his head in reciprocation. It was a happy and a sad night, all in one.

The next morning, *Papa's* condition had worsened. He had become completely mute. We realized there was very little that we could do to manage his condition at home. His oral intake had decreased remarkably. I was scheduled to return to my University that day and *Papa* acknowledged that. I asked him again, if he wanted me to go, and he nodded. He seemed quite oriented with his surroundings. The ambulance arrived to take him to the hospital. As they lay him down on the stretcher, and carried him downstairs to the ambulance, I bid him farewell for the last time.

-As the monitor shows a flat line, it is understood that there is going to be no attempt to pull him back. An hour earlier, my mother kneels before our Lord and prays for mercy. Seconds before the flat line, she stands before the bed he lays on, staring at his body; expecting the end anytime. 10 am on the clock, 16th of May, 2017, his soul leaves his body. My father is no more.

Back in Karachi, I stand in the corridor outside my clinic and stare at my phone. I had missed a call from my mother. I could think of only two possibilities why she may be calling; either *Papa* had made it through the night, or he had not. I don't call back. I defer the call for later, for I am not ready to accept either news at the time. I get back inside the room where my patient waits; I smile and greet them as if nothing is wrong. A few minutes later I am pulled out of the room and taken to another- where my mother's best friend awaits. My face lights up as I see her and she smiles back, painfully. As she stands up to greet me, I know exactly why she is here.

'Beta, *Papa*...' she shakes her head as she struggles to complete her sentence.

'...has left?' I ask.

As she nods, I smile and repeat, 'Alhamdulillah.'

Deep breath.

'Alhamdulillah.'

I had seen his pain and his struggle to breathe. I was not sad that he had left this world- I was relieved that he was now in a better place. It was like the feeling you get when you are done with the toughest exam of your life.

It was a beautiful morning back in Sialkot, and *Papa's* death was followed by light rain that made that day seem even more majestic. He was declared a martyr, for he had

fought like a soldier against the battle against cancer. He had been given 6 months after his initial diagnosis, yet he lived 9 ½ amazing years. His smile never left his face, even in his last days. His ability to joke and laugh in any situation had made it a happy journey, instead of the expected dark one. As a family treading this difficult path, we never cried together. Our tears were only meant to be shed when we turned to God. It was our laughter and happiness that we shared with each other. Since day 1, we did our best to keep *Papa* happy, because we believed that laughter and happiness could cure any illness and we saw a practical demonstration of that on this journey. We focused our energies towards the solution of the problem rather than the problem itself. Despite Stage IV Adenocarcinoma of the Colon, *Papa* maintained quality life till his last days, and did not become bed bound until the last 18 hours of his life. It was his strong will power, and courage, along with patience, positivity, and faith in God that eventually helped him win against cancer.

‘Life is like an album of suffering and misery. But between each photograph there are unspoken moments of joy and happiness.’ - *Papa*



Kulsoom Ghias completed her PhD and post-doctoral training at Northwestern University's Robert H. Lurie Comprehensive Cancer Center in Chicago, Illinois. She is currently an Associate Professor in the Department of Biological and Biomedical Sciences at the Aga Khan University Medical College in Karachi where she is involved in teaching in the undergraduate medical program and the graduate program, and in research on head and neck cancers and colorectal cancers.

A series of haiku poems about cancer

The first sets the stage, the rest tell the story from the perspective of the disease, a cancer researcher, an oncologist, the patient's family and the patient, respectively.

The fig tree needs the fig wasp
Sweet symbiosis
But, cancer is no fig wasp

I have ravaged this body
I need it too though
Am I victorious then?

Beautiful complexity
or vicious disease?
Study beauty of the beast!

Is the news good, bad, ugly?
Counsel, cure, repair
We will *all* survive today

Every day, her pain is our pain
And our grief is hers
Hope then... hope to grieve no more

See? I am not your fig tree
You are not a wasp
I choose to fight, I choose hope



Fahmina Buriro is working as Consultant Plastic and Reconstructive Surgeon in Patel Hospital, Karachi.

"My main interests are microvascular surgery, cleft lip and palate, soft tissue sarcoma, and breast reconstruction. I love my patients and love to write articles, stories and blogs on social media."

Best birthday gift

It was a routine day in clinic when a little girl with a beautiful trendy head scarf came in with her mother. At first glance, the little girl with shiny wide open eyes seemed no different to any other child of her age. However, she had rhabdomyosarcoma of her right forearm and after complete workup and chemotherapy by the dedicated oncology team of a cancer hospital she was sent to us for surgery. I examined her, reviewed her MRI and other tests and planned for surgery. Her tumor was involving the flexor digitorum profundus of all four fingers and flexor pollicis longus muscle and an area over the pronator teres muscle. I discussed the surgical plan with another consultant surgeon and the little girl's mother and promised her that we will attempt tendon transfer for involved muscle if tumor resection will be satisfactory. Unfortunately, during surgery we found the tumor to be involving the pronator teres muscle more than anticipated and periosteum had to be excised from this area for good margins. At that point we had second thoughts about doing a tendon transfer but decided to proceed.

The surgery proceeded unremarkably and her recovery was uneventful. The real challenge was ahead: that of physiotherapy for tendon transfer in a little girl who is weak and post chemotherapy. She started very slow and progress was not that satisfactory. However, the young girl always listened carefully and understood what was instructed to her regarding physiotherapy and other post-operative care. She was rather quiet, but I always felt that she communicated with her eyes.

Histopathology revealed close margins at pronator teres insertion from where periosteum was also excised. Her case was discussed in our multidisciplinary tumor board meeting and she was planned for radiation. Radiation was started while physiotherapy was continuing and I explained to her mother in detail that during radiation more effort will need to be put in. During radiation she came once for follow-up and her progress was lagging, but the little girl was trying hard and was actively

involved in the process. She wrote something for me on a piece of paper too. She did not come for follow up for some time and I was planning to contact the cancer hospital where she was under treatment, but had not yet made the call.

After a few days, it was my birthday. The residents arranged a surprise birthday cake and beautiful candle and I had little celebration with them. After such a great start to the day I was on my way to theatre that I saw the little girl standing outside my office with her mother. She waved her hand at me. When I went close to her she smiled and made a fist in front of me. In my office she showed all the tendon movements and that she could write better now. I have not forgotten the waving of her hand and showing of her fist - this was the best birthday gift I've ever had.

This story is not about the cancer hospitals who work day and night for children suffering from cancer. Nor is this story about tendon transfer surgery which every plastic surgeon can do. Neither is it about the efforts of the physiotherapists who are trained in doing what they do. This story is about the determination of this young child, her understanding of the process she went through, her efforts on her rehabilitation and of course the hard work of her mother.

I have operated on many children suffering from cancer and encountered many determined children who persevered with their efforts more than adults with cancers. A little boy with sarcoma who had undergone a below knee amputation used to show sign of victory with his hand every time we used to meet him during rounds or when he used to come for dressing in theatre. A cute boy with thalassemia whose post infection wound was skin grafted always had a beautiful smile on his face. A teenager with fibromatosis whose hair turned curly after chemotherapy used to say that his hair has now become like Sachin Tendulkar. This little girl with sarcoma is one of these determined children who gave me the best birthday gift of my life and reminded me a quote about children.

A child can teach us three things

- 1) Always be curious
- 2) Be happy for no reason
- 3) Fight tirelessly for what we want



Dur-e-Sameen Ilyas is an A-Level student from Beacon House College Campus P.E.C.H.S.

"I am a poetess, and photography is my passion. My aim is to spread peace and happiness because the hatred has already ruined our lives. And also I love to motivate people because I think life is the name of challenges. If you don't face any ups and downs you will never be able to experience the life. So, with faith and prayer face the reality!"

Victory of willpower

When there is love, there are trials. This is the story of Aqil Ahmed and his wife Almas Bai, who loved each other dearly. After being childless for a decade they were finally blessed with 5 children. However, as fate would have it, those cheerful days were numbered.

Almas Bai felt some cysts around her breast, but considering their finances, she ignored it. As time passed, the pain increased, and she saw a doctor, who told her that she must undergo a surgical procedure in order to get rid of this disease.

After the surgery, the biopsy reports diagnosed Almas Bai with breast cancer. When Aqil Ahmed got to know about his wife's illness, he could not bear the news and fell sick. This sickness swiftly took his life.

Thus began the most challenging period of Almas Bai's life where she had no partner to console her or to wipe her tears. However, she proved to be a very strong woman and raised her children while continuing to fight with this deadly disease.

Almas Bai resolved to stay optimistic at all times. With time her condition worsened. Her arm grew swollen and seemed to her as if it would burst at any minute. Frequently the doctors would tell her that she was left with merely a few days yet she persevered courageously.

All her five children grew up, received their education and were married. With one son left to be married, the doctors warned her that the cancer had progressed significantly and could kill her at any time. Instead of depressing her, this made her even more courageous. And she spent five more years as a warrior.

Almas Bai's story demonstrates the importance of your willpower. With determination you can even move mountains. Just like the brave Almas Bai, who spent 20 years fighting a fatal cancer.

(The names have been changed in order to conceal the identity)

Greetings, everyone!

Love!



Faisal Siddiqi is a sporadic writer, a reader, a tech nerd, a gaming freak, a self-proclaimed thinker, a doctor and a general surgeon.

He is working as a consultant in Liaquat National Hospital since 2011. His interest is largely towards laparoscopic surgery with a special interest in bariatric surgery. He also has a newfound interest in research, medical writing and has recently passed the specialty FRCS in General Surgery.

The gas won't pass

The wind had stopped. It felt uncomfortable. He didn't feel like eating and it had been like this for some time. It had stopped earlier as well, but had resolved after a while. This time it had been two days and even the herbal laxative had failed. He had started to feel his tummy getting bigger, bloating up like a balloon as time passed.

"Hina, I haven't passed gas since the morning", he told his wife later in the evening.

"Saleem, I have been telling you to get yourself checked, something is wrong but you won't listen".

"Stop nagging me and give me something to make it better", he replied in his newly acquired agitated tone.

"Ok, but we'll go and see a doctor in the morning, you agree?"

He nodded assent to that and settled on the big sofa in the lounge and lit a cigarette. Even these had stopped working. He had the weirdly sweet tasting powder which was supposed to do wonders with the bowels. Had it with a glass of water which seemed to weigh his stomach down. He started walking in his lounge massaging his now protuberant rotund belly. It felt different this time, it was not resolving. He could feel his belly getting bigger and tightening up. The strange buzz had started in his head, the one he had whenever he had a bout of an upset tummy. Walking made him breathless. He slumped back into the couch, a sheen of sweat forming on his forehead. "Hina, turn on the AC I'm feeling very warm". Even the turned up air conditioning did not help. In the following hours his discomfort escalated by the minute. He could tap his belly resonantly. He was finding it hard to breath in deeply. His belly had gradually started hurting, it started as a dull ache on his right side which had increased during the past two hours. The buzz in his head transformed into light headedness. He felt cold, not on the outside but on the inside. A deep chilling sensation emanated from his tummy and

spread to his limbs. His eyes were weighing down and the fan on the ceiling looked blurred.

"Hina, can you come here please?" These were the last words he remembered before passing out.

He woke up to noise and beeps and more noise. There were so many lights, it was hard for him to focus. There was something sitting on his face and his nose felt weird. As he moved his hand to his face, he saw a needle sticking into the back of his hand connected to a tube. He followed the tube with his blurry vision to a blurry bottle with water in it. Next to the bottle was the blurry silhouette of his wife talking to someone.

"Let her sort it out, she always does", he thought to himself as he slowly took his hand to his face.

"What's this?" was his question to himself when he touched the oxygen mask covering his face. There were two tubes, one attached to the mask and another one going inside the mask. He felt it attached to his nose as he pulled it testily.

"Oh man, this time it seems bad...it will sort out...it always does...where is she...which hospital is this...I feel like I want to pee".

These were the fleeting thoughts in his mind at that moment as he lay in the emergency room with tubes connecting him to infusion bags, drainage bags and urine bags. He was drifting in and out of sleep.

"Saleem, wake up, they say that you need surgery". He fought his way back to lucidity and tried to comprehend.

"It's only gas, why do they need that, I will be ok", he replied.

"They are saying that the intestine is blocked somewhere and it might burst if an operation is not done", she tried to make him understand.

"Ok ok, do whatever, let me sleep" he drifted off again...

He woke up in a quieter environment but with the periodic beeps ringing in his ears and a new dull pain in his abdomen. The tube in his nose was not there but the mask was still on. As his vision cleared he could make out that he was in a room with his wife sitting on a chair and a nurse writing something on a table near the foot of his bed. He could feel a long bandage down the centre of his abdomen and a bag like thing attached in his right lower abdomen. It felt like a bag filled with gas. The nurse noticed him awake, greeted him and smiled. He drifted off to sleep again. During the next five days as he slowly improved he was allowed to first drink and then have some solid food as well. The pain waxed and waned. He was fascinated by the stool bag which filled up after every few hours. The doctors told him that this would stay for a while. He was ok with that, for the time being at least. The gas was not stuck anymore.

This was my forty years old patient, Saleem. He had married a few years ago and had a small hyperactive son. He had been transported from his routine life to the ER on my on call day. His X-rays showed a dilated colon with no air beyond the sigmoid - a closed

loop obstruction due to an obstructing lesion in his sigmoid. An emergency laparotomy was performed and he ended up undergoing a sub total colectomy with an end ileostomy. It appeared to be a localised lesion in his sigmoid colon. He had a smooth post-operative course and was discharged in a few days.

On the followup I was staring at his histopathology report which showed a poorly differentiated signet cell adenocarcinoma, one of the worst kinds of cancers out there. At that time walking out of my office and going to his cubicle seemed the most difficult thing that I had to do. They were waiting. Accompanied by my resident I walked into the cubicle. He was looking good although he had a tired look on his face. I slowly started unravelling the bad news to him and his wife. I could sense the expressions change, darkening with each sentence I uttered. Hope was bleak but they latched on to it. I could see it flickering in their eyes while in my mind I could see the rocky road ahead. Hope keeps us going and I did not and I could not take it away from them.

The next few months I kept seeing him on and off. He braved the chemotherapy sessions clinging on to hope. He lost his hair and his health at the same time. They turned up in the clinic again after completion of the chemotherapy with a repeat scan. The disease had progressed in spite of whatever drugs were fed to it. His omentum had caked and the peritoneum had studded. His stoma was still working well though and his gas was not bothering him.

He was subjected him to further chemotherapy with different agents. That didn't help though and the disease went on ferociously devouring him from the inside. It was after the second session when he came to me, completely tired out. He was still fighting bravely but had accepted his fate and knew his therapeutic options had depleted themselves. He was focused and did not want to talk about more options. I silently envied his courage and watched him walk out of the clinic with his wife. I wondered how life would be for him, waking up every day, watching himself deteriorate, feeling the hour glass empty, not knowing which day would be his last. Then again, we all live this finite life. None of us knows which morning is our last. At least he knew his time was near.

The dominoes started falling after that. He needed multiple admissions. The peritoneal studs became large deposits and the omentum eaten away by the tumour. It kinked his stoma from the inside, making the gas collect in his belly again. This was the reason for each of his subsequent admissions. Initially suppositories helped but later on I had to place a large caliber Foley's catheter which relieved his symptoms. In his last admission he had accidentally dislodged the catheter. Try as I might, replacing it was too painful for him. I took him to the operating theater and managed to put in a catheter under anesthesia.

Saleem passed away a few days following this and his last complaint was the same as his first one: he could not pass the gas.

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