

Focusing on the Unfocused

Keratoconus! A difficult term to pronounce, also known as KC, is a rare disease that prompts the thinning of the cornea. Spacing occurs between the tissues due to severe deficiency of collagen in the fiber.

I had been diagnosed with KC, in 1999. Here is a nineteen (19) years long summary of "My journey through KC". It is a synopsis of late diagnosis, of finding out what were the best ways of treatment, the remedies, the tyranny, the trials, the changes and the challenges, the shift, the pain both physical and emotional, the struggle to make people know what it does to you, how it happens, how it would be taken care of, and an endless, tedious process of training one's self for the dreadful journey one is 'NOT- so- ready' to embark. It is a battle, a war with the situations it brings you to, and another one that continues within you. It is a long tiresome journey. A tale of the suffering and a lot more that came to invade my existence.... with this one word "KC".

It is not about a disease that is rare in itself. It is about "focusing on the unfocused". It is to see the world and its people, how they actually look like. I see them as ghostly images and ghostly shadows. As fading streaks of light when the end of the tunnel closes and as pillars of bright beams when it opens again. I see the obvious and the oblivious and I am uniquely blessed, as not many people around me can have such a sight. I see the stars where there are pebbles and six or eight moons where there is just one. I see halos in every possible form of light and I see just flattened discs of lights where there are bulbs. I pour sugar outside of the jar and spill milk on the table top. I place the knife on a part of my finger instead of the object as that seems placed at a different angle. Smoke and smells bother me.

At work, life isn't any different. I sit in front of a faded, blurry laptop screen for hours. I squeeze my eyes until I'm strained to a point that I no longer can handle the stretch. I feel I am squinted but I have to work. I have to go, I have to grow and I have to be!

The glare oh well! It is the worst of all. The beautiful façades might just appear as a plain huge placards with nothing on them. A dimly lit room, fizzles, of what is left of, my ability to work. I love bright and sunny days but the night-time or after dark gives me fears of insecurity, inability, falls and a brand new fray to deal with.

My passion for colours die, when I see smudges and smears of colour everywhere and wonder where the actual, beautiful colours have disappeared. I love nature but only to see giants of light and dark shades which were once trees. Mountains look like leviathans. I see fog where there is none and an oasis in the middle of a freshly tarred road. It gives me hope and eases my journey.

I feel that an ardent love affair with books, is ending with a sad, painful break-up, when the pages I so loved to read are just felt by the tips of my fingers. The smell of recycled paper and printing ink, is all that has been retained of years of reading and imagining and becoming a lot of the characters that I once would be, through those books. I am left with memories to cherish for as long as I can and for as long as I am not able to read again. This is not trivial.

I am thus far, virtually, legally blinded and more so, emotionally then physically. I am not able to explain to the world around me, as to how it can best fit me, amidst all its insensitivity and unawareness of my condition.

After the most pinching question: "Why don't you use glasses?" comes yet another one: "Why don't you drive?"

Then a series of them chase me from time to time and day to day. Some say I need to "focus" on carrying less stuff and others advise to use flat shoes. How do I tell them that I lose my footing.... no matter what! There's no FOCUS!

INDEED! There is NO focus, but there is remedy and there is treatment. There is hope and well some light too. I embark to yet another journey, trying to discover how to begin it. To experience how to seek medical help and how much of it would eventually consume me.... all in various ways?

- The remedy: Rigid Gas Permeable (RGPs) or hard contact lenses. Not an easy path to take. But very promising as far as the vision is concerned. The right eye could not enjoy this aid but the left did to a full 15 years. By the time I was actually diagnosed with KC, in a year and half, the cornea in the right eye had developed lesions and the RGP only tend to make it worst. It needed immediate grafting.
- The treatment: Corneal transplants. Since the cornea is devoid of a main blood stream (only fine blood capillaries are there), the chances of rejection are few to none. Corneal transplants are thus one of the most successful forms of transplants.
 - a). **Penetrating Keratoplasty (PKP):** is a procedure which involves the replacement of the eye's damaged cornea with a donor cornea. The need for a corneal transplant is usually due to disease, injury, infection, previous eye surgery, or other problems.



PKP



DALK

- b). **Deep Anterior Lamellar Keratoplasty (DALK):** Part of the DALK procedure is removing any overlying stromal tissue. Penetrating Keratoplasty (PKP) generally has a high success rate, but the risk for immunologic endothelial graft failure has led some **corneal** surgeons to DALK, where host endothelium is preserved. This has become a more preferred method.
- The concern: Pakistan lacks the privilege of an eye bank. I discovered later, that due to socio-religious refrains there is NO eye bank in Pakistan. It is alarming for the patient to know that a thing on which his/ her entire treatment depends and something that is the only means of a new life to the patient, is not available at all. Nowhere near you! The scholars have thought of it to be insignificant as it is NOT life threatening..... BUT to get into a disability and that too where the world which you are so used to seeing, in all its beauty, starts to fade first and then gradually disappears from your ocular sphere. Disappointed and dissatisfied by the reasoning, I went into depression.

The ways and means of acquiring a cornea for my right eye were nonetheless not approachable. I came across agencies which had dealers who would get the tissue for the patient.

- The worry: Quality of the tissue. Specifications: unknown. Cause of death of the donor: unknown and the handling of the tissue was a threat in itself.
- The hope: Like I said, a ray of light beamed from the crevices in the ceiling. I was directed to an Institute that offered much more than I had expected. One of a kind, with state of the art architecture, facility, faculty, treatment and technique, The Aga Khan University Hospital had support, counselling, treatment and guidance. No later was I booked for the surgery. The tissue (cornea) was booked by the hospital. I landed in the hands of one of the best people and finally on my right eye, a PKP was performed on 23 July 2001. The recovery was amazing and in less than five (5) months I could not only see but also read the registration plates of cars, the hoardings,

newspaper headings and much more. Life was partially back. Slowly I gained sight and focusing in my right eye. The aftermath, well a new altered lifestyle to live with a graft!

The surgical sutures which were in the form of an undulated movement around the graft, remained inside the eye for a whole year and at the end of the eleventh (11th) month, one end broke being a sign of the removal of the sutures. For the left eye, however, half of them were removed after six (6) months and the other half in twelve (12) months' time from the date of the surgery. The removal of the sutures too is a surgical procedure. Why I mention the stitches here with great significance, is the need to understand that as the stitches are removed, the vision gets corrected by a few points.

While the stitches are there, the set of caution is tremendous, although the doctor creates a very relaxing life mode for the patient but it still doesn't mean that one can go overboard with things, especially where it is important to take care.

This is a whole new SOP (standard operating procedure) for me to follow and to dwell upon, for the rest of my life.

The left eye was operated upon in 2016. 21 March 2016 to be precise. DALK was the methodology but dark remains the result. In two (2) years, I am still struggling with recovery and an emotional and psychological healing. The RGP lens is back. This time, however, more methodically set to suit the graft.

There is caution and precaution implemented at every step. A great deal of DO's and DONT's which I have to comply to. Living with and taking care of two grafts (foreign bodies), for which my body does not have a defense mechanism, is what leads to a lot of caution and care. It is a brand new experience of a fresh start to a totally different journey.

It is a brand new life!

As far as the society is concerned, around me not much has changed. I see people of how they really were and how they really are. Less in their knowledge, low in their thinking, yet driving one, to be like the way they want him or her, to be. Why can't they say, "Fall freely... you will be held."? Why can't they drive cars with less beams? Why can't they make arrangements for sufficient light in a room or an office or on the streets? Why can't they stop smoking in public? Why can't they change their ways, when I can't change mine? Why can't they change their thinking and perceptions to be more accommodative? Why can't they be more acceptable towards disabilities? Why do they judge? Why do they look mercifully at a disable and in the process become more merciless than ever before?

These are the few questions out of many, which I would like to ask them. And more on how they can help if they think on this other set of questions:

Why can't they educate themselves and later others around them to pledge their organs? Why can't they live after they are long gone... through me and through many like me? We need the organs that would be buried for the scavengers to be fed on. Why can't they pledge these to us instead? They can help us to create our personal legacies while they create theirs by pledging the organ donation.

I can still easily skip a step or in the ugliest of moments, an entire flight of stairs. I don't know how it happens but I surely know WHY it happens. Each time I rise after a fall, I prepare myself to fall again and rise to remind myself that there is more to come!

Every day I renew my passion for life and for living it as it comes!