VIEWPOINT

When doctor turns patient

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As a doctor I have given my patients news they would rather not hear. Then one day I was at the receiving end.

A routine check, on turning forty, showed that I had asymptomatic proteinuria. My nephrologist assured me vaguely, that this condition was very slow in progression. Other than following his advice of losing weight and controlling blood pressure, I did not bother to follow up with him.

I was reacting like most patients do by denying the seriousness of the condition and presuming that all would be well. I would have expected, in retrospect, that my friend and nephrologist should have been more emphatic with me and given more information. However, I was happy with this; the more you know, the less hope you have. It also illustrates the fact that doctors find it difficult to break bad news, particularly to colleagues.

Many years later, a routine check-up showed that my serum creatinine level was abnormal, and further tests showed that I had finally reached the end stage of my renal disease.

Transplant

As a candidate for renal transplant, I was an exemplary patient. I controlled my blood pressure, lost weight and took medications. I had a morbid fear of dialysis and was unwilling to suffer the disruption of life that this procedure entails. I felt that a renal transplant would be the ideal solution.

My wife Jayashree, an anaesthesiologist, spontaneously decided that she, and only she, would donate her kidney to me. We went in for the surgery with high hopes. Statistics show that transplantation wherein the wife donates the organ to her husband have a higher rate of success. However, complications followed, and the transplanted kidney soon shut down.

Then followed six months of haemodialysis, three times a week. It is a depressing and unpleasant experience to be dependent on a machine, and to be on it for four hours at a stretch. Nephrologists tout dialysis to be an *excellent* alternative for the treatment of chronic renel failure. Regretfully, this may be the *only possible* alternative. During the over 75 trips to the dialysis room, I saw, at close quarters, the agony that patients on dialysis undergo. It disrupts the tranquillity of the entire family and is a financial disaster for many.

I underwent my second transplant elsewhere, which was a success. This was followed by three months of dressing the wound, for what we thought was an infection. I moved around wearing a diaper to prevent soiling of my clothes. On exploring the non-healing sinus, it was found that I had a leak from the transplanted kidney and a block at the lower end of the transplanted ureter—exceptionally rare complications in anyone, but here, occurring at the same time in the same person. I was operated six times in 18 days, and the leak was successfully stopped.

I then understood what it was to have a dressing done ever so often. I could not tuck my shirt in and wear all those fancy clothes—little pleasures that we take for granted.

Doctor as patient

Doctors give advice, but rarely follow it. Had I been more proactive in finding out why I had proteinuria, I may have been able to salvage renal function for a longer time. Often, delay can be disastrous. I was in a state of denial, in spite of knowing the possible complications. When it dawned upon me that I was in trouble, I passed it away as a *fait accompli*.

Being a doctor helped me to cope better, I knew that the treating team was doing its best, in spite of the waves of complications that followed. A lay person would be upset, angry and even suspicious. I was offered the option of 'changing my team' or 'going to another institution', by my nephrologist, which I firmly declined. Many times doctors offer to back out—more in anger at the patient's insistent, sometimes justified, questioning of the correctness of the treatment being given. In my case, it was possibly out of anxiety and frustration that I was not getting well. My wife and I kept giving courage to our colleagues, rather than badgering them. I feel that faith in your doctor is of paramount importance. It brings out the best in both—the patient as well as the doctor. My wife had watched, at close quarters, our colleagues at work, and was confident that I was in safe hands. We have to accept the possibility of complications.

The uncertainty was terrible. After the second transplant, my treating doctors were anxious-a surgeon from another city was undergoing a second transplant. They did a post-transplant isotope scan after 24 hours, to be sure that all was well. Under normal circumstances, with a good urine output and stable biochemistry, this would have been unnecessary. This brings out another hazard for a doctor treating a colleague. He tends to be overcautious and this may cloud his decision-making process-the so-called 'VIP syndrome'. The doctorpatient must realise this and assist the doctor. Thus, being a colleague may, unwittingly be, disadvantageous. The complications of the second transplant were managed by the team that did my first transplant, with inputs from the second team. It seemed to me that my urologist needlessly felt guilty about the fact that the first transplant failed. To him, this was a personal failure, and he felt responsible for my unfortunate plight. He needed to be counselled by me.

There is a penchant for doctors to give their patients inappropriate hope. However, in my case, considering that I was their colleague, my doctors were honest with me and this made it easier for me to bear the stress.

Holistic approach towards patients

Oft-quoted statistics about success rates should be relegated to the books; they are of poor consolation. I had almost every possible complication. While I was always loathe to shoot statistics at patients, my experience strengthened my resolve to put statistics in perspective—they can only be an indicator of the possibility of success. While I have conducted innumerable workshops on communication skills and can wax eloquent on issues such as denial etc, I am now able to appreciate the truth better.

I now understand a patient's feeling much better. I believe I am more empathic and my approach to treatment is more holistic. As a general surgeon, I have also learnt some practical lessons, such as the advantage of liquid Cremaffin for a person on long-term catheter, how to move about with a catheter in you, and the comfort that nebulisation can give. I also realise the devastation and economic burden that CRF imposes on the lives of patients. A more robust and realistic transplant programme is needed, and this calls for a re-look at some of the ethical issues involved. One must also appreciate the fact that post-transplant care entails life-long treatment with expensive immunosupressants and the possibility of contracting severe infection.

Power of prayer and positive thinking

How did I cope? It was a combination of exemplary support from family and friends and the phenomenal power of prayer. I was convinced that I had come to this world with a purpose and the Master Planner (a word oft used by my dear wife) knew what He was doing. My wife was (and is) my guiding force and the greatest source of strength. Being a doctor helped me; I was able to understand what was happening to me, and therefore, my expectations were, I thought, realistic. This can also work the other way round, thus making doctors difficult patients. The positive attitude that I had made it easier too.

Many of us underestimate the importance of motivation and inspiration in the process of healing. The poem below and the many philosophical discussions I had with my wife, played a significant role in my getting well soon.

Paul Hamilton Haye's poem, which teaches us, as the *Bhagvad Gita* and other scriptures do, of the need for equanimity in life reads as follows:

Art thou in misery, brother? Then I pray Be comforted. Thy grief shall pass away. Art though elated? Ah, be not too gay: Temper thy joy: this, too, shall pass away. Art though in danger? Still let reason sway, And cling to hope: this, too, shall pass away. Tempted art though? In all thine anguish lay One truth to heart: this, too, shall pass away. Do rays of loftier glory round thee play? Kinglike art thou? This, too, shall pass away! Whate'er thou art, where'er thy footsteps stray, Heed these wise words: This, too, shall pass away

Things could have been worse. My zest for life has increased and I am much more spiritually inclined now. This should help me fight avascular necrosis of both femora which I have now developed. Please wish me luck.