

Mending Bodies, Healing Lives



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When we started the CanSupport home-based palliative care programme in 1997 in collaboration with the Institute Rotary Cancer (IRCH) at the All India Institute of Medical Sciences (AIIMS) in New Delhi, India, little did we imagine how far we would go. We did a trial run of three months,

visiting six patients who lived within a radius of 25kms from the AIIMS campus. There were two of us, a volunteer nurse and a counselor. We also doubled up as driver and navigator respectively. The response we received from these patients and their families was so overwhelming that in no time at all we had to employ a doctor, a nurse and a counselor as more and more patients began to be referred to us from the Pain and Palliative Care Clinic at IRCH. From the very beginning we were certain about one thing, this was a service for the less privileged and we were not going to charge for it.

Today, more than 700 patients are being cared for by our 12 interdisciplinary professional teams comprising doctors, nurses and counselor. They work out of eight field centres located in different parts of the city and adjoining areas referred to as the National Capital Region (NCR). It is hard work as there is heavy traffic congestion, the area and population to be covered is vast, and the work requires confronting human misery, squalor and poverty on a daily basis. We are fortunate, therefore, to have a dedicated team who see their job not as a burden but rather as a chance to connect with the highest within themselves as well as within their patients.

While giving the Second Hinohara lecture at the recently concluded Asia Pacific Hospice Conference at Penang, Malaysia, I referred to the work we do

at CanSupport as akin to that of rafoogars. I even claimed to come from one such family! I shall in what follows try to explain what I meant.

The rafoogars are a community that currently resides in several villages in northern India. They have for centuries been repairing ordinary damaged garments as well as preserving rare and treasured textiles and items like Kashmiri Pashmina shawls. Their skill lies in their ability to use techniques that make their mending invisible to the naked eye. A skill which it is believed their ancestors brought with them from Central Asia. Unlike other craftspeople, however, they have remained unrecognised over the ages and even today are marginalised.

I used the analogy of these brilliant menders of garments because I believe that the people with whom we deal at CanSupport need the services of a rafoogar in order to feel whole again. These are people who have been told by the experts that what began as a tear in one part of their fabric now extends to every corner rendering it beyond repair. This is often the point when most people turn to the palliative care team in the hope that their tools, though considered less sophisticated than those of the specialists, (in the case of the rafoogar, it is a simple sewing needle) will when wielded with love and compassion still be able to preserve the integrity of the garment that has been declared beyond repair.

This is a job that, as every rafoogar knows, besides skill, requires courage, self-confidence and a passion for one's craft. It also needs excellent team work as the rafoogar must from the outset have a thorough understanding of the nature of the fabric that he has to repair. He along with his fellow rafoogars will have to gather this information from a variety of sources using all the senses at their command. Experience and intuition too will play a part. They will each have to touch the fabric, they will have to look at it closely to understand its history, its pattern and its weave. They may even have to taste or smell it. What they will also need to know is the value the wearer places on the garment and how far he is willing to go to repair it.

... continued from page 5

Those of us who work in palliative care know that this is a process that cannot be rushed if it is to be done properly. It requires pacing oneself with the patient; allowing him to take the lead, listening in a sincere and empathetic way and responding when required. The intention always being to help patients identify those threads of their life that have had the greatest meaning for them so that these can then be teased out and woven together to cover the tear. This is an effort that also requires good leadership and management skills as many people and circumstances contribute to the life of a garment and they have to be all brought together in a meaningful way.



The test of the skill of the *rafoogar* lies not only in his ability to make the part of the garment that has been darned invisible to outside eyes but also to the much more acute and critical eye of the wearer. This last act requires a leap of faith on the part of both the *rafoogar* and the wearer of the garment. Theirs is a destiny that is now intertwined and if they are to fully experience the joy of what they have jointly created they will have to shift their gaze from the part that was damaged and has been repaired to the pristine and untouched beauty of the larger garment of which it is a part. It was in this context that I related an incident from the life of my father, a soldier in the British Indian Army, who fought in Malaya in the Second World War and spent time in a prisoners of war camp.

The War had just ended. A British War Crimes Investigation Team entered the camp where my father along with his elder brother and other Indian soldiers had spent two years as prisoners of war of a Japanese air force unit. My father's elder brother, who was commanding the prisoners, was summoned by the team and asked to identify those of their captors who had been particularly harsh to them; all of them were lined up in front. My uncle had already conferred with his men and had instructed them not to lay blame on any one. Having led them wisely and seen them through difficult times, they were willing to be guided by his advice.

Consequently, no one was named or pointed at. This is how my father described what happened afterwards: "After the members of the team left, the senior most Japanese officer, a Major General, drove up to our camp in his official car, with his flag flying and all that, and asked to speak to the commander (of the prisoners). ... (He) appeared in his usual torn and scanty attire, wooden clogs on his feet, and to our surprise, the Japanese Station Commander, resplendent in his uniform, bowed down low in front of my brother and with tears flowing down his cheeks declared in broken English "You bigger man than myself."

The lesson my father says that he learnt from this was that if you are kind and considerate you can win over even your worst enemy. Or perhaps there is the realization that there is no enemy at all. Finally, you are all on the same side – the human side – and that is what requires your attention.

We must, therefore, encourage our patients to become bigger than they are by letting go of past grievances, to forgive and to seek forgiveness, to express and to receive love freely before they say their final goodbyes. The *rafoogar*, too, must similarly be ready to feel deeply, to take pride in what he has accomplished and then finally cut the thread as he moves on to the next precious garment offered to him for mending.

This article was written by Dr Harmala Gupta as a reflection of her Hinohara lecture delivered at the 9th Asia Pacific Hospice Conference, July 2011.