Newsletter 2

Make Do Tell 2018

Artists in Community International inspire and educate communities, individuals and leaders to be creative in and through art-making. We provide engaging programs and projects that are inclusive, challenging, dynamic and joyous. Our work is contemporary art-based with international flavours – inspired by our roamings and backgrounds.

Make Do Tell is an annual project we run in Nepal and /or India. We provide our services, the project is funded through the generous donations of many supporters.

Public hospitals in Nepal function very differently from public hospitals in Australia. Like many aspects of life here, the hospital experience is a very public one, the whole family is likely to be involved, very often staying in the hospital alongside their sick relative. As wards are shared, a number of families will witness and experience each others lives as they deal with a cancer diagnosis and treatment.

We arrived in Bharatpur and met with our colleague, Dr Krishna Sharma, to plan our ten-day program in the Paediatric Haemo Ward (with children who have leukaemia) and in the Palliative Care / Hospice Unit. I spend the morning in the Palliative Unit, and Alex (Jyoti) and I are in the Children's ward in the afternoon.

We first met Krishna last year and learnt of his struggles to get treatment for Paediatric cancer patients. Until recently, the hospital board believed that a child's chance of successful treatment was so low that the money would be better spent on more curable child illnesses. Krishna's dedication and tenacity is inspiring. As the childhood blood cancers are being successfully treated, there is more recognition, at board level, of the particular needs of children with cancer. However, as specialist cancer treatment has only been available in Nepal for 23 years, there is still a long way to go.

The Palliative Care Unit is new, another hard-won battle. I admit to a little uncertainty about how the art program would go there - would the children be so sick and near to death that an artist would be an intrusion into a very private and possibly physically, and emotionally painful time?

The Unit has six beds, although they were never all occupied. Walls are brightly painted with attractive designs created to make the room feel more relaxed. Now that 15 hours a day load-shedding is not a daily endurance in Nepal, there is light and warmth as well as power sockets to charge phones, run my speakers and iPad ... an unbelievable change in just a year.

I met two girls around 12 years old, one is very unwell and coming to the end of her life, and the other bright and in the middle of her treatment. A 3-year old boy with end-stage leukaemia is tiny

and lies listlessly across his young mothers' lap.



Saroj is very ill; both he and his mother enjoyed drawing and when he was too tired to draw he like looking at photos on the iPad. I also downloaded a drawing program for him which was easier to manage when he was tired.

His mother drew whilst he slept lying across her lap.

All the young people had family with them, and many other family members come to visit. The siblings are amazing in all they do to support their loved one; we were moved to witness their gentle and generous care, yet we see an intense look of anxiety in the faces of those parents whose child is so ill.

We started with a simple invitation to draw. Circles, shapes and patterns. Nothing particular, nothing complex, just paper and colour and time. Everyone joined in. It felt like a merciful relief from months of nothingness ... I put on some gentle *Ali Farke Toure* music from Mali and fill the room with a quiet Oud music that flows over us all, without barging into us.

On some days, drawing is interrupted by eating. As far as we can see, the hospital does not provide food but there is a canteen in the grounds that does a great dahl bhat, takeway. Some families take a room nearby and bring in tiffins of home-cooked meals, and others have small gas stoves on which they cook rice, dhal, greens and other Nepali food. It's a kind of curious way of operating on one hand, but on another, I was astonished to see how much the young patients ate and it made me wonder whether there is something about home-cooked food that is so much more appealing that hospital food – but we know that already, don't we?



A young patient preparing food with her father on the porch outside the ward. In Nepal is quite normal for many activities – including preparing food and creating art – to happen on the floor.

Most families are not local – many have travelled 100s of kms over difficult terrain and are unable to return home during treatment. The disruption caused by the diagnosis is immense, parents cannot work, yet their financial responsibilities (such as rent) remain, and increase with additional costs of medicine etc here, children are pulled out of school to help care for a loved one. It amounts to a very worrying time for them. One father told me about his financial stress at the end of the project, and that creating the art helped alleviate his anxiety. He said that "art should be in all the wards, and the materials should be given for free". Such was his passion.



Over the ten days, the iPad and speakers get quite a workout. We play music, look at pictures and rather than being gloomy and ominous, there was such a feeling of community, care and warmth. As I was putting some pictures on the wall one day, I did a funny little dance – like all my dances – and Rampyari and her sister Sagun saw and laughed. Dancing! Next thing I know, the music is changed to something upbeat, and Sagun and I are dancing; all of us falling about with laughter.

Rampyari's cancer is in her leg, so her best option was bed dancing; I am pleased to say she now has a good grip on many fine dances from the 1960s, including the swim. The aged cleaner joined in with a very saucy dance, then as Jyoti (Alex) arrived, he was drawn into a dance with the girls' father. Other family members hovered at the door, intrigued and laughing ... Who would have thought, and in a palliative care unit!

The fun, friendly and dancing cleaner.

Once again, I am reminded that no matter how sick, when someone is alive, they want to be alive, to participate in life ... in some way, no matter how small.

As I said, life is public in the public hospitals, everyone joins in or watches. I love it that the nurses have time to spend with patients, and make art and the cleaners in both areas are actively interested and join in.





The nurses are outstanding in both wards and have time to join in.

In the children's ward, the cleaner is responsible for teaching us how to say "I don't speak Nepali" as well as enliven the environment with her larger than life personality.



This cleaner in the palliative care unit realises the turtle is missing some toes and adds them before the work can be put up.

During the next ten days, the children come and go from the unit, spending a few days in a small unit in another part of the hospital to receive their chemo. I pop in and give them art materials or have a chat. Art making provides a welcome and enjoyable way to spend the hours and days when otherwise there is nothing to do.





Sagun, the dedicated and lovely sister of a young patient, Rampyari, adds to her drawing as her sister receives chemotherapy.



Rampyari's uncle and father, Nara. Nara was a keen participant and created beautiful pictures – he was able to relax and forget his problems for a while.





I grew very fond of the patients and the families. Being connected with them via Facebook has been a lovely way to keep relationships going for a little longer.



This mother's anxiety for her daughter was palpable, some days she felt physically sick. Yet she always joined in because she had discovered that the art helped settle her mind, and relax a little.



The children's ward is on one side of a small corridor, an adult haemo ward is on the other side, At the end is the nurses station is, and alongside that the communal area with a family sized table, around which a lot of eating happens. This becomes our art table.

We were warmly greeted by the nurses and delighted to see most of the pictures from last year still on display. At that time, there was a bit of concern about putting the drawings on the walls; it's funny how management can be so precious, despite the joy the pictures bring to the creators of it, and others. I have experienced the same thing in hospitals in Melbourne – you might almost be put in the stocks if you dared put anything up on the whitest of white walls at the new Peter Mac cancer hospital there, even though so many patients told me that felt overwhelmed by the starkness of the whiteness and the 'hospital' feelings it evoked. And I won't even start on nursing homes ...



Anyway, it was not a problem we incurred – in fact, I was heartened to notice a nurse slap glue onto the back of a picture and paste it onto a wall after I had run out of BlueTac. I am pleased to say that by the end of the ten days we had pretty much redecorated the ward ... so that lovely pictures greeted children at the weighing station, by their beds, in the corridor, at the entrance to the entire unit, and in the communal eating area. Even in our absence over night – a new picture or two would be put up. It made our hearts sing.





Art on hospital walls makes these places feel more humane and less scary. Patients and families spend months at this hospital, so their environment is especially important to them. Art around a child's bed personalised their space and made them feel proud of their achievements





Parents enjoy precious 'normal' time with their sick child at the art table, and relax together.

The ward has about 8 beds. There was quite a range of ages of patients- from babies to young people up to about 12. The children seem remarkably stoic, but clearly, the parents are anxious and fearful. Over the ten days the art table provides a relaxing time for them – as soon as their duties are over, they hesitantly come over and hover until I invite them to join in the community painting or drawings that are happening at the table. It can take a few days, and many requests for them to overcome their shyness; others like to take a few materials and sit on the floor and do their own drawing, or work quietly with their child. Making art together is a great way to be 'normal' and do things not related to illness or treatment.

Children from families whose parents are being treated next door also join in. One 16 year old confided her fears for her father who has leukaemia. She needed re-assurance, and that is another thing the artist can offer. A friend of mine made the observation that simply providing pencils and paper in a cancer hospital does not alleviate the anxiety or encourage people to participate – it is the role of the artist to invite people in, and be part of a community, for even the shortest time, that makes a difference at this enormously difficult time.



Rayam is the uncle of a young patient. His humour, care, English skills, and bright personality brought so much joy and help to the art table and beyond. We were so impressed by the resilience and compassion of these young carers.





Little Sister with her collage and painted mask.

The stay in hospital for family members, especially children, is scary and boring. A younger sister in this family was just so delighted by the art program - the nurses would tell me that my "little sister" was looking for me.

We introduce different art styles, materials, and themes – encouraging participants to try new things and introduce them to Aboriginal art, working with colour, collage, drawing, and painting

with watercolours and acrylics. Art from the Western Desert Aborigines from Australia totally caught the imagination, and a completely new form of art to them. We jumped off from those images to create our own mostly doing circles using dots. Everyone joined in, and seemed to really respond to the focus required; as I have so often observed when people are totally immersed in their art making, they cannot think about all their problems and fears - they relax and the art gives them time and space to revive.





Two young boys around ten years old especially loved painting; we were amazed as both these boys' focus as well as careful attention in doing their artwork ... their proud smiles says it all (even though smiling for photos is not de rigeur here).







As you can see, I love to take photos and people here like to have their picture taken. I got a pile of them printed and gave each person a photo of themselves ... I got my first smile from my little 3 year old friend in the Hospice when I gave them to him.







We have been invited to return to the hospital to assist Krishna establish a program that will exist for patients throughout the entire year. He wants to include art as well as other activities and services for children and their families.

So, to the question from the first newsletter. How long did it take to return from Bharatpur to Kathmandu?

The answer:

Seventeen hours to travel one hundred and forty one kilometres.

It took ten hours to travel the first forty kilometres. This is partly because the road is being remade. However, as this is the only road south and southwest from Kathmandu, it is always very busy with trucks and buses. In turned out that this particular Saturday was a holiday weekend so there was much, much, more traffic than usual. It was bumper-to-bumper, with overloaded trucks, buses, and private cars winding their way up and down this narrow and treacherous road. At times, it would turn into a dirt track with massive potholes, with a huge drop down to the river on one side.

The traffic ground to a halt for hours to make way for the hundreds of trucks and buses coming in the opposite direction. There nothing we could do. We played Patience on the iPad until the battery ran-out. We tried ringing our accommodation host in Kathmandu, but our local phone was out of range. There was nowhere to go to the toilet with any privacy, hard enough for men, but near impossible for women. Jyoti read, while Anne did some sketching. She completed eight sketches. This series will be known as the traffic-jam collection.

While planning the return trip to Kathmandu, we contemplated taking the flight, which takes about forty minutes. However, we decided it was an extravagant waste of our budget, as the flight is notoriously unreliable, time wise. During this arduous journey, we discovered that morning's flight had been delayed four hours. It made us feel a little better.

By the end of the seventeen hours, there was a unanimous decision of the members of the Artists In Community International board, (both of us), that when we returned to the cancer hospital in Bharatpur, we would take the flight!

We are freelance artists, available and interested in project and teaching work. Contact us via our website.