

Palliative Care and Optimism

A journey through India with David Oliviere



David Oliviere, North India

‘In palliative care the best teachers are the patients themselves – their stories are gold dust. What they teach us is life changing.’

So says David Oliviere with his customary humility. This gentle man is a leading light in palliative care, being former social worker director at the North London Hospice, Macmillan Lecturer at Middlesex University and Director of Education and Training for St Christopher’s Hospice from 2001. He is also a tour leader for Jon Baines Tours, which arranges specialist health care study tours to destinations all over the world. David has led previous palliative care study tours to India and is leading another one to South India from 14 – 27 February 2024.

David has a special connection with India; he was born in Kolkata and lived there until the age of 8, when he left to live in Britain with his family. ‘I never thought in a million years I would return to teach about palliative care,’ he said. ‘When I said goodbye to India I never dreamt I’d be asked back in a professional capacity.’

David was asked to accompany Dr Mary Baines, co-founder of St Christopher’s Hospice with Dr Cicely Saunders, to speak in his capacity as a social worker in palliative care in 1993. Dr Baines recounted she brought the first medical supplies of morphine into India, secreted in the depths of her washbag. This was David’s first trip back to India as an adult.

‘It made such an impact on me,’ he says. ‘We arrived at night and all I could see was what looked like dead bodies lying all over the streets. Of course, they were homeless people. When I stepped out the next day from my posh hotel to meet my conference colleagues for lunch, I could see this whole completely different way of life – children crossing dual

carriageways in a nappy, or being totally delighted with a plastic carrier bag and piece of string as a balloon!’

David was one of the first social worker/counsellors who went to India to teach palliative care and since then, he has returned many times – both in his professional capacity and more recently as a tour leader for Jon Baines Tours. David led his first tour for JBT nine years ago.

‘The last nine years have changed my life,’ he says. He adds with a twinkle, ‘I’m glad Jon (Baines) pursued me with such persistence.’

When Jon first approached David to ask if he was interested in leading a palliative care study tour, David had just retired from an ‘impossibly busy’ job as Director of Education and Training at St Christopher’s Hospice – the first modern hospice in the world.

‘I promptly said no, as I didn’t know anything about tour leading and I didn’t think I could do it gracefully,’ said David. ‘However, I also knew I probably wouldn’t get old sitting in my armchair watching *Neighbours*, so when Jon asked me again a year later (it impressed me that he hadn’t forgotten about it) I agreed to consider it. I’d talked to Jon and it was clear that it wasn’t just about business for him – he was so nice and obviously cared about offering people a rich experience within their own subject area.’

The rest is history. David is still in touch with people from that first tour and more recently met up with two Australian nurses who happened to be in London and wanted to reconnect after taking part in David’s recent tour to North India in February 2023.

David never expected that being a tour leader would change his life profoundly on so many levels. ‘The tours are full of golden moments,’ he said. ‘Patients are living with advanced disease with some enormous challenges, but there is also such joy in life. On tour we witness something precious.’

Whatever you say about India, the opposite is also true. This vivid, tumultuous land is like its mirrorwork, *abla bharat* - the ancient Indian embroidery technique of attaching tiny mirrors onto fabric. It reflects something different every time you visit.

Running underneath these contradictions, however, are some fundamental truths; such as a quote from Dr Ishita Gandhi, Medical Director of Palliative Care at CanSupport. She says, ‘It is not the space that matters; what matters is to have the heart in the right place.’

Over the years of teaching and tour leading in India, David has collected some unique insights. Here are ten things he has learned from palliative care in India and ways in which the tours have changed both his life and the lives of other participants.

1. Person-centred care at its best. Neglect at its worst.

The lengths to which professionals and volunteers go to ensure the best care for people at the end of their lives is extraordinary, stretching very limited resources to the limits. At the other end of the spectrum, you have patients with head and neck cancers, with no

resources, having sold all they own – cows, belongings, even their homes - to get to a city with healthcare. We see what I call ‘social death’ with isolation, ignorance, lack of financial means or any health insurance, poor housing, accompanied by society’s stigma and myths about cancer and other conditions.

One of the first home visits we did was to the home of a 35-year-old woman called Zita who had stomach cancer with multiple secondaries. The team had received an urgent call from her husband as she’d been sent home from hospital and was in a state of what we call ‘total pain’ – social, physical, spiritual and psychological pain. There was nothing more the hospital could do for her.

Zita and her husband were very poor – they ran a shop with just 8 items in a very impoverished area. She had two children living with family in another city, who were due at home the next day, and had lost another 12-year-old daughter in a rickshaw accident three years before. She had never spoken of the incident or her daughter since, such was her psychological pain. She was in terrible physical pain but wanted to live long enough to see her children the next day.

The team gave her morphine - which is not always medically available to patients in India - and the effect was near miraculous. You could see her body relaxing and her humanity returning. She was so grateful to the team – and to me, even though I’d done nothing but show an interest – that she asked her husband to take a Bic ballpoint pen (one of the few items in their shop) to give it to me. I had with me an enormous wad of Bic pens tied together with a rubber band as I’d taken a friend’s advice to carry them with me to hand out to the poor. Here was a dying patient giving me a gift of a pen to take back to London. Such little ironies can make you cry.



Boy with counsellor, CanSupport

So, we see good, patient-centred care at its very best, but we also see terrible neglect.

2. The tour group is a surprise factor.

The exchange of stories and experiences make each tour something unique. It’s amazing to be both at ease with highly experienced clinicians and with people who have had just a

brush with palliative care, all exchanging life stories and humorous incidents during the tour. In our work we have to be 'a voice for the voiceless' (as Cicely Saunders, Desmond Tutu and others have said) or better still, help people find their own voice. Sharing experiences is one way of doing this.

Also, we sometime witness very moving things and debriefing among the group is important.

3. The openness of our inspirational hosts.

Many of our tour hosts are pioneers in the palliative care field in India. They are passionate about what they do and are determined to push the boundaries to get better and better services. They do this in various ways - through advocating for improved legislation, in education or empowering family caregivers. They freely share their own journeys into palliative care and what keeps them going.

I could speak for India about the people we meet on tour, who are often extraordinary in small ways. On our last tour in February 2023 we visited Saroj Gupta Cancer Care, which is now run by Saroj Gupta's two children (one is an oncologist and the other works in education and developing new projects). There is a sign up in the tea area at the Saroj Gupta Institute that says, 'Life is like a cup of tea - the taste is up to how you make it.'

4. The remarkable places one sees throughout the tour.

Ancient monuments, palaces and places of worship; breathtaking lakes and lagoons; and people on every corner, living life in a thousand and one different ways! So often people are standing or talking with other people and there is a smile on every corner.

There are 22 different languages in India and also 22 different societies, it seems to me. It's not uncommon for people to marry with only the English language to unite them!

5. Family care in all its shapes and sizes.

With the general shortages of paid carers and residential care, families are the main resource for patients at the end of life. They have to learn new nursing skills and manage the intricacies of providing 24-hour-care. There is often excellent care provided within families, but of course this can also go wrong. Sometimes families will reinforce mistruths to a patient, or deliberately lie to a patient and isolate them, not allowing them to access hospital services, or even prevent women from being examined by a medical doctor at all or prevent them from making decisions about their own health issues. Families not uncommonly police issues around diagnosis and prognosis.

6. The role of volunteers, local communities and voluntary orgs/ NGOs within the cancer and palliative arena.

The outstanding use of volunteers to lead or supplement services is mind-blowing, especially in Kerala, which has the greatest intensity of palliative care teams in India. Grassroots organisations perform astonishing feats in under resourced communities, running services and voluntary NGOS that make a vast difference to people's lives.

7. Understanding the role of Ayurveda and other traditional holistic elements.

Traditional holistic systems are enormously important in healthcare and everyday life. Although only 1 – 4% of India's patients have access to morphine within palliative care, many more will experience traditional medicine in all its forms - meditation, yoga and gurus, etc.

Pain control is a central part of cancer care treatment and traditional methods play a crucially important role in this.

8. Palliative care as a spiritual experience.

This is very clear when you witness the cultural and religious aspects of living life and death in India. There is much less embarrassment around religious and spiritual beliefs in India and much more openness in proclaiming hope and faith. This is a vital tool in helping people to live fully until they die.

When I ask people in India, 'Is anyone religious here?', hands shoot up. When I ask the same question of British nurses, one or two might coyly admit to 'being spiritual'. We are much more secular in the West and very respectful of not plonking religion on people. However, one must never rubbish the belief systems of others, as this can be the one thing that keeps people going – especially as morphine doesn't reach the vast majority of patients.

9. The tour as a social, learning and spiritual experience!

Sample the philosophy and attitude of many of the inspirational pioneers and healthcare workers we meet; the patients and families we may come across and their generosity of spirit. Palliative care is so much about offering hospitality. On the tour we enter situations where we see people being 'guests' and 'hosts' to one another. A perfect example is the Street Children project where CanSupport invited two trained ex street children to cook, present and serve our lunch – this was very moving and a surprise to me and the group. This project teaches valuable skills in hospitality and cooking to street children. CanSupport are doing wonderful work in probably the largest home care project in India and possibly the world.

There are many levels of meaning experienced on tour as you 'unpeel the onion' – meeting hosts and seeing inspirational places, such as one visit where they had transformed one grotty room into a vibrant childcare centre for terminally ill children. I happened to mention that I loved the elephants in India and intended to buy some to take home for my grandchildren. On our last day at the centre, each child presented me with a paper elephant to give to my grandkids.

This is the Zita paradox – who gave me a pen when I'd taken every pen on the planet to 'help' Indian people – and similarly, these children at the end of their lives had thought to give me these beautifully made elephants to take to my grandkids.

10. Stepping out of one's own culture and context to witness another.

For me, stepping out of my own culture and context to peep at another is always inspiring, surprising and exhilarating, no matter how many times I've taken the journey. It is a chance to look at my life anew. But also, to witness the potential and possibilities of people.

‘There is an underlying optimism at the heart of palliative care,’ said Cherny in Monroe and Oliviere’s ‘Resilience in Palliative Care – achievement in adversity’ (OUP 2007).

I wholeheartedly agree.

There is just one room left on David’s next Palliative Care Study Tour to South India on 14 – 27 February 2024.

To book or find out more about this and other tours, contact Jon Baines Tours on 0207 223 5618, email info@jonbainestours.co.uk or visit www.jonbainestours.com.