

# barefoot

childrenpeoplearth

*This is an edited version of a longer interview with Seikan by Charlotte Young for Barefoot Magazine*

## **Please can you explain about your work with Melbourne Zen Hospice**

Well, we're an organisation dedicated to providing support to the dying. This also includes support for their carers and families. Our involvement isn't necessarily focused on doing something. Often our role can simply involve "being with" patients and families—regularly and without fixed ideas and expectations. When someone is approaching the end of their life, just being present and open to them can be the most comforting and appropriate way of engaging. It's easy to forget this because collectively we've become very focused on doing and fixing things.

Melbourne Zen Hospice is a young organisation. To date we've been specialising in outreach care only—which means that we visit and support patients in their homes and in hospitals and other care facilities. We're also now in the planning stages for a residential service—a physical hospice. It's a medium-term plan, something which we hope to establish in the next couple of years. At present our outreach area has a radius of approximately 15 km from the city. As we keep growing and our volunteer network expands, it's likely that our catchment area too will keep growing and eventually include Melbourne's outer suburbs as well.

My own role within Melbourne Zen Hospice has been as a volunteer within our great team of volunteers, and I'm still very much continuing in this role. I am also the organisation's director, which obviously brings additional responsibilities. My professional background as a therapist and clinician has been very useful in my different roles within the organisation—both for supporting patients and for supporting volunteers. My role as a Zen monk—its path and my commitment to it—has been similarly important at a core level. I don't mean this in a particularly religious sense, as Zen isn't particularly "religious" in terms of what's normally associated with that term. Much more simply, it's a practice of discovering this present moment, and of becoming more at one with it. There's certainly no motivation on my part to try and convert people to any kind of new ideology or belief system. Just being present in this moment is enough and perfect. As part of it, some of our selective resistances, our discontent or suffering, or our sense of restlessness can begin to settle and ease. So my role as a Zen monk is not at all "other-worldly", but here and now.

Our new patient referrals come to us from different sources. Some are "word-of-mouth", others are formal referrals from different organisations and agencies—including the hospital-based palliative care services. Referrals to Melbourne Zen Hospice can be made by telephone, in writing, or online via our website. Basically we're happy to accept suitable referrals from anyone and anywhere, regardless of background, age, gender, and individual circumstances. As our mission is to provide support in end-of-life situations, that's also our main criterion for determining the suitability of referrals. Sometimes people contact us seeking help for other situations—for example, depression and suicidal states—and in such cases we link them up with other appropriate support services. As part of accepting a new referral, we usually ask that patients have adequate medical support, as we can only provide complementary palliative care at this time. We're very conscious of our duty of care aspect, and obviously we want to ensure that all of our patients are safe and looked after in the best possible ways.

Following a new referral, we proceed with particular sensitivity as it can obviously be very challenging for a family in a vulnerable situation to let strangers come into their home. So part of our first visit is to allow those apprehensions to settle, and also to clarify any expectations that the patient and family may have. Dying is a new experience, and most families are unsure about what kind of support they'd like to have. Often what's most noticeable at first is uncertainty, fear, and sometimes denial. So we explain what we can offer. And we may also mention what we can't offer—for example, provide medical care, or help with house renovations. This is to protect both patients and volunteers, and to clarify the nature of our service.

One of the unique features of our service is that we don't bring any specific agenda. We're not delivering medical services, or anything in particular. We make enough time, so we're not rushed and time-stressed, and this is something that patients feel. Our approach is caring and empathetic, but without being part of any family dynamic. With loved ones, the experience of grief can obviously become intense as someone is dying. In such a situation, the simple presence of an outsider who is compassionate and relatively free of expectations can be comforting. Over time, people start looking forward to seeing us—funnily enough.

Usually we start out with weekly appointments, and we let the patient and family know that we're happy to sit and talk, offer guided meditations, reiki, respite for the carer, or even do some shopping or cooking. As the patient's physical condition deteriorates, and our relationship grows and becomes more trusting, there will then often be a request for more frequent visits. So once a week may become twice a week, and then every other day, and in the last weeks it might even be daily. Each visit usually goes for an hour or two, and carers are often happy just to let us in and use the opportunity to go for a walk or whatever. It's important that carers take some regular time out, especially if the dying process is a protracted one.

Most patients really seem to enjoy guided meditations, and sometimes carers will stay back and join in. The meditations are designed to provide patients with a greater sense of peace and comfort, including effective relief from physical pain. Through my time with the dying, I've developed a keen interest in using voice meditation and various tactile methods to assist in the dying process itself, including once a person enters a stage of only being partly conscious. Using voice and touch in particular ways seems to bring definite benefits in terms of connecting, easing the transition, letting go and reducing suffering. I've come to think of this as a kind of "midwifery" to dying. Like birthing, so the dying process too has become part of the medical system, and the medical system of course works from an illness model, so it's in a realm of both medical thinking and medical interventions. But from a certain point onward, it's not really useful to think of dying as an illness at all. Birth and death are natural processes that involve an act of letting go, and courage to merge with something larger—like drops in the ocean.

### **Is there a common feeling or sense that you have after somebody's died?**

I feel acceptance, and sometimes even uplifted. I probably wouldn't be doing this work if I had a very strong grief response to dying. When I sit with people, my sense is that we are in the same boat. Certainly I don't think that 'Here's this person and they're in a sick and sorry state and I'm healthy and I've come to try and make them better'. My sense is that it's a shared situation. Sure, our chronology and individual experiences may not be in synch, but essentially we're in the same boat. We are human.

To be sure dying can be a painful experience for someone losing a loved one. But at the same time, encountering our mortality can have a healing impact—open us up to what is timeless and connecting. Also, when people die, they've often suffered physically and mentally for some time, and so on that level too—and a lot of carers and family do remark on this—there can be positive aspects of release and relief. In my experience, death and dying can be an affirmation of life itself—beyond the person who is dying, and certainly beyond my own ideas about life. So, for me, it's somehow always a genuine inspiration—a reminder to let go of my small self, one moment at a time. All of our volunteers are very aware of this, that it's not just about us helping others, but that it's very much a two way process.

## **How do you think we could become more accepting of death or less afraid?**

Well, in one sense our fear of death is hard-wired into us. That's not a bad thing because without it we probably wouldn't be here now—as in you or me (laughs), or even as a species. So if we suddenly saw a dangerous animal appear, we'd probably run very fast for our life, or we'd fight to live, and our energy would come from that hard-wired fear. But despite our core survival instinct, most cultures before us seem to have had a much more open and accepting relationship with death and mortality. I suspect that one of the main reasons for this is that these cultures simply didn't have the means for making death as invisible as we've made it. I think that's where the answer to your question lies—the simplest way for us to become more open and accepting of death and dying would be to have a more regular and reasonable level of exposure to it. The fact is that people are dying around us all the time, but one wouldn't know it, because collectively we're choosing to make it invisible.

For this reason, our vision for a physical Melbourne Zen Hospice is about not only providing best-practice residential care for the dying, but also modelling a more open interface between those of us who happen to be near the end of life and the broader public. We're very interested in a new kind of social institution—combining palliative care for patients AND daily public meditation sessions, healthy meals to eat in or take away, public talks, performances, and exhibitions, not least to celebrate our patients' individual lives. Many people have recently started designating funerals as being “celebrations of a person's life”—but we'd rather have such celebrations while patients are still alive and in some way able to share them.

### **Sounds beautiful**

I really hope that we can realize it. Just because a person is in the process of dying obviously doesn't mean that they're dead already. Just like the rest of us, a dying person is alive in this moment, and that's as alive as we can ever be. Medical institutions generally do an excellent job in providing medical care, but by the same token they're not that good at treating people as anything other than medical patients. Our vision is simply for an approach that affirms more clearly and creatively that palliative care patients are indeed more than just patients. Those who may have been artistic all their life can have their work shown in a public exhibition. Others who have developed a special skill or expertise can give a short talk if they wish. Or a film night can be arranged with family and friends—whatever is appropriate in affirming our living and dying as the wonderful mix that it is. I feel that there are many positive opportunities here—and that the realm of death and dying generally holds so much living wisdom for our time.

Our original vision has been of a physical Melbourne Zen Hospice by 2012. Our initial approach to this—probably somewhat naively—has been to focus on delivering innovative best-practice outreach support to our patients and families, and to trust that in so doing we'd just keep growing naturally—like a child will grow up naturally. In one sense we still have this view, and we've found that the majority of people who've connected with our support have been very appreciative, supportive, and generous. As a result, we've been able to make ends meet for our outreach services, all of which we're providing free of charge. On the other hand, the path to setting up and operating a physical Melbourne Zen Hospice will obviously be another dimension altogether, and certainly require far greater resources.

So earlier this year we woke up to what now seems obvious—namely to take small steps in our growth, rather than wait for serendipitous leaps. So our first stage is just a small hospice, to be set up in the next two years, most likely by sub-leasing within an existing facility of compatible use. Once we've raised sufficient funds to cover the lease, we expect to be able to cover and resource most of the rest ourselves. We're not setting up a hi-tech medical facility, but just a small hospice with the very best of simple care—with a focus on people, emotional support, complementary therapies, positive ambience, good food, and meaningful engagement. This will be offered both for respite and as an end-of-life care option for patients who do not, or no longer, require intensive medical support—and that's most of our patients to date.

## **Don't these patients want to die at home though, or would it be that they can't?**

Palliative care patients who want to die at home and for whom that's possible are in a fortunate position. For these patients we will certainly continue to offer outreach support as an important part of what we do. But dying at home may not always be possible, even less so if intermittent respite care is not available. For example, if the dying process is a protracted one, carers can eventually become too exhausted to continue—both physically or emotionally. If and when that happens, a medical hospice is often the only remaining option to patients, even when it might not be their preferred one, nor the most appropriate one. As an alternative to this, Melbourne Zen Hospice is to function more like a “home away from home”—comfortable, warm, clean, safe, and non-institutional. This will not suit everybody, but it will provide a new choice where currently many patients would like to have a choice, but don't have one. I can easily think of several instances where now deceased patients would have loved to have taken up such an option, but it was not available to them, and they had no choice but to live out their life in a medical facility.

So that's the background, and what we're now doing is laying the groundwork to make the plan happen. I feel there's a positive momentum that's building. Not long ago, we've completed a new volunteer intake and training, which went very well. Our volunteers are really amazing—I don't mean “superhuman” (laughs), but truly amazing as ordinary human beings—compassionate, courageous, and genuine. So Melbourne Zen Hospice will certainly continue to offer our outreach program across Melbourne—and indeed we're hoping to expand it further. But it will also be very important for us to find a physical home—as an inner core to what we do and to our continued healthy growth, and as a centre for the organisation. I believe that this is important for us now.

**Great. Good luck!**

(Laughs) Thank you. My experience with Melbourne Zen Hospice has been that it is innately fortunate, and I believe it will do well as a matter of course. But even if fortune were not behind it, my commitment would be the same—namely to provide it with parental love and care so that it may grow up and be itself. In this way, may the Melbourne Zen Hospice go on and provide support to many, many people in need.

*For more information about Melbourne Zen Hospice, other palliative care services, or to find out more about Zen please go to: [www.zen.org.au](http://www.zen.org.au)*

