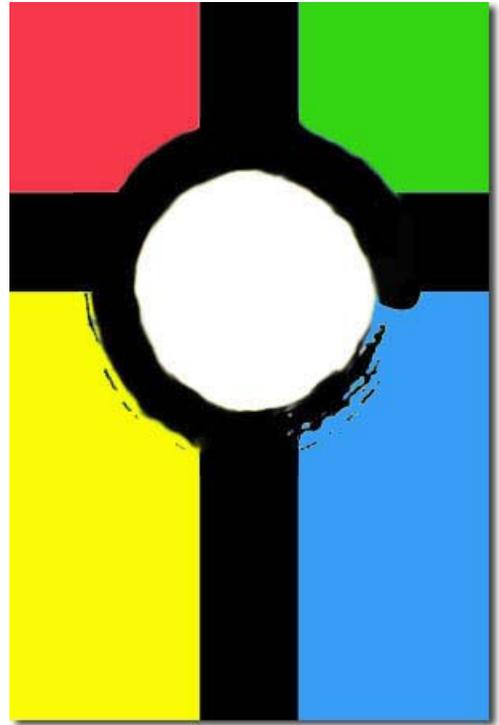


Metta María



End of Life Care
For Dying Children
with a Buddhist/Christian Foundation

www.mettamaria.org

By

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Abstract

The hard, cold fact is that in our society children are apparently not “meant” to die: yet on average every day, in Southern California alone, a child dies of cancer or some other terminal disease, often dying in agony arising from our society’s obsession with cure over comfort, and often in the sterile environment of an Emergency Department or a Pediatric Intensive Care Unit. The lucky few who are able to spend their last days at home, often do so in poverty-stricken conditions, too often without their parents or immediate family because they have been deported, and in circumstances that are far from ideal for what any compassionate person might see as those likely to contribute to a “good death.” One in four child deaths in California each year is due to cancer, and despite over a hundred hospice organizations in Southern California serving the elderly population, there is only **one** children’s hospice organization and they only serve patients in their own homes. Whereas Medicare and Medi-Cal cover one hundred percent of all medical care costs for the end of life care of an elderly person, there is no such coverage for children’s end-of-life care since they do not qualify for either Medicare or Medi-Cal. Even the best health insurance will not cover anywhere close to all of the costs of end of life care of a child dying from a terminal disease: costs that can often run into the hundreds of thousands of dollars, particularly where extremely expensive experimental chemotherapy and other drugs are used to try to extend the life of a child with cancer, regardless of the quality of that life so extended. Metta Maria envisions a series of philanthropist-supported children’s hospice care facilities, each located adjacent to acute care hospitals treating children at end of life, with the goal of providing as “home like” environment as possible for each child’s final days or hours, all designed and run from a foundation of the Five Buddha Families, the Three Tenets, and core teachings of both Buddha and Christ on the nature of compassionate care for the dying.

Dedication & Gratitude

*Dedicated to the merit of all those
working with sick or dying children.*

My deepest gratitude to: my wife, Cheri;
Roshi Joan Halifax; Sensei Alan Senauke; Maia;
Aine; Joshin; and to all the faculty of the Upaya
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all my fellow chaplaincy peers in the Upaya
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hospital and hospice I have been blessed to
have worked at. And last, but far from least,
backward bows and deep blessings to every
child and their family who's journey I have
had the great honor to share.

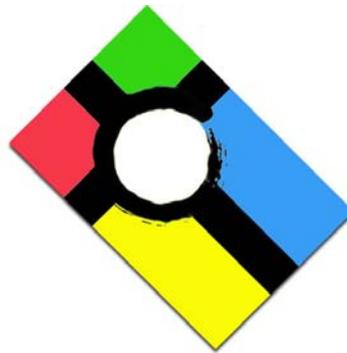


Table of Contents

Chapter 1. Introduction: The “Problem” of Children Dying

- a) The “problem” of children dying in our U.S. society 1
- b) The Dying Child and Modern Western Medicine 3
- c) Why both a Christian and Buddhist Foundation to Metta Maria? 6
- d) Buddhism meets Christianity – An Introduction to
the Wisdom Tradition 7

Chapter 2. Literature Review 16

Chapter 3. Methodology 25

Chapter 4. Findings

- a) Findings from working in hospitals and hospice 26
- b) Some examples of encounters with dying children 32
 - i) Case Study #1 – Yasser 33
 - ii) Case Study #2 – Jose 35
 - iii) Case Study #3 – Laquisha 38
 - iv) What did these three dying children have in common? 39
- c) Conversations and Interviews with Hospital and Hospice Staff 40

Chapter 5. Discussion

- a) The Basic Premise Behind Metta Maria Hospice Homes 43
- b) Design, Organization and Managerial Philosophy 44
- c) Greyston Bakery as the Model for Metta Maria 45
- d) The Five Buddha Families 50
- e) Staffing Metta Maria 53
- f) Physical Design of Metta Maria locations 53
- h) The Heart of Metta Maria 54
- i) Ethical Foundation 56
- j) Heart II: Agaspe, Selflessness, Compassion, Loving-Kindness 58
- k) Not Just for the Actively Dying Child – Who are Metta
Maria’s Target Demographic? 59
- l) Putting it All into Action 61
- m) Core Regulatory and Other Factors 61
- n) Funding Metta Maria 65
- o) Other Key Considerations 67
- p) The Primacy of Chaplaincy at Metta Maria 68

Chapter 6. Conclusions 69

References 71

*There can be no Doubt that a perfect Cure of
the Diseases of Children is as much desired by all, as
any thing else whatsoever in the whole art of Physick.*

Walter Harris, 1698

1

Introduction: The “Problem” of Children Dying



The “problem” of children dying in our U.S. society

The “problem” is that in our society, as in many western societies, children are apparently not “meant” to die. Dying is something that elderly people do, and it is perhaps understandably felt to be ‘unnatural’ for a child to die. Thus we have full support for adults over the age of 65 to die with financial aid from Medicare and from state systems such as Medi-CAL. But no such full funding existing to treat the terminally ill child, and no such support system is in place for dying children. I was frankly stunned to learn this as I commenced this path of being a Pediatric Chaplain working with very sick and dying children.¹ It also explained why there is only one hospice for kids in California (which has a limit of around 50 children it can care for at any given time), whereas there at least 195 hospices working with adults (which collectively serve over 81,000 patients each year²). Even that one kids hospice, *TrinityKids Care*, is, I understand, underwritten by the main adult hospice and the *Providence Healthcare System* in general, and perhaps could not afford to operate if it were a stand-alone children’s hospice agency. How truly sad is this?

¹ I have since come to appreciate that the problem exists for dying adults, too, who are under 65 and thus cannot get sufficient benefits to get proper end of life care. I have now experienced numerous dying adults 30-60 or so years old who cannot get beds in Skilled Nursing facilities due to not being Medicare or Medi-CAL eligible.

² Source: “Alliance for Advancing Nonprofit Health Care” data for 2006 as reported on NonProfitHealthCare.org <http://www.nonprofithealthcare.org/resources/BasicFactsAndFigures-NonprofitHospices.pdf>

There is some financial support for seriously ill and dying children, thankfully, but it is far from being full coverage. Medicare, for instance, will cover your child dying of end stage renal disease, but to qualify you must meet various criteria: You or your spouse must have earned at least six credits within the last three years by working and paying Social Security taxes; you or your spouse must be getting or be eligible for Social Security benefits; and your child must both need regular dialysis because his/her kidneys do not work or your child must have had a kidney transplant. The social justice issues here are rampant: one need hardly point out that no undocumented immigrant or migrant would qualify for this, and a large number of mainstream documented U.S. citizens would not qualify, too. And even this Medicare coverage is just for the narrow condition of end-stage renal disease, not for cancer, or any one of numerous other terminal or life threatening conditions and diseases.³

In California we have the “Medi-CAL Pediatric Palliative Care Benefit (also known as “the waiver”) that provides some financial support to seriously ill and dying children. But as far as I am aware, even this program is not available in all California counties, just some of them.⁴ Moreover, it would not necessarily help cover the full cost of a child dying, especially if that child requires extensive curative treatment such as experimental cancer drugs, radiation, bone marrow transplants, and so forth. Let alone, not covering a child to live in a residential hospice for the last weeks and months of their life.

The upshot is that if you have a seriously ill child, particularly if you are poor and/or an undocumented immigrant, your only option is to take your child to the emergency department of a local hospital. If your child’s condition is serious and specific to children, then you will either have to hope your local hospital will transfer your child to a hospital specializing in life

³ See: <http://www.medicare.gov/people-like-me/esrd/children-and-esrd.html>

⁴ See: <http://www.chpcc.org/education-research/hope-magazine/hope-magazine-2012/riding-the-waiver-2/>

threatening childhood disease (such as Childrens Hospital of Los Angeles, Children's Hospital of Orange County (CHOC) or UCLA Mattel Children's Hospital) or you will need to try to take your child to the emergency department of such a children's specialist hospital. Most of these specialist children's hospitals have a policy of turning no one away; thus if you take your seriously ill child to the emergency department of such a hospital they will take your child, and will give your child the care that hospital feels the child needs without cost to you – even though treatment of major cancers, for example, can accrue costs in the many hundreds of thousands of dollars (particularly if experimental drugs are employed). Such hospitals have it written into their budgets that a sizable percentage of their costs will not be recoverable because it is a known fact that so many parents, again particularly the poor and/or undocumented immigrant families, simply cannot afford to pay for services out of pocket, and they usually have no health coverage.

But the wonders of modern medicine does not bring all good news when it comes to a dying child and the decisions that parents – frequently, poor and often uneducated – are called upon to make regarding their child's treatment.

The Dying Child and Modern Western Medicine

Modern medicine: the good news, the bad news.

The good news is that through the amazing techniques we have developed to attempt to treat illness, patients in general are living longer than ever before. The bad news, due to the amazing medical techniques we have developed patients are living longer than ever before. Let me unpack this: the simple fact is that while it is amazing that on average patients live longer than they would have done even as recently as just a few decades ago, and indeed may now live whereas not too long ago they would have died, the by-product of this progress in medical techniques and treatments is that hospitals often trade-off *quantity* of life for *quality* of life,

making the former a priority over the latter. “Going for the cure at all cost,” often becomes the default position and this is heartbreakingly the case with terminally ill children.

Let us be clear, there is no doubt that our society has achieved absolutely wonderful results with modern techniques and medical treatments such that, for instance, children with Cystic Fibrosis (which disproportionately hits African American kids) can live a reasonably comfortable long life whereas historically they would have passed early with sizable pain and suffering. Similarly, we can work what seems at times to be miracles with brain surgery to remove cancerous tumors, and the recent developments in performing surgery on fetuses still in their mother’s wombs are incredible. Similarly, whereas in times past the “C” diagnosis (cancer) was synonymous with imminent assured death, now we can state with some confidence that if treated quickly and early, many cancers are survivable – for instance, so-called childhood “ALL” leukemia (Acute Lymphoblastic Leukemia) can be cured in around 90% of cases (with as many as 98% experiencing post-treatment remission), which is no minor fact given that ALL is also the most common form of childhood cancer accounting for around 35% of all cases annually.

The problems start when the standard treatments don’t show the promising signs hoped for. It is then that the sequence is likely to commence of proposing more aggressive treatments that may or may not lead to cure, and which may or may not extend life. Terms like “Clinical Trials” will likely be introduced as parents are asked if they would like their child to try a new drug or treatment plan that is still in development. And it’s worth pausing here for a moment to try to place ourselves in the shoes of a loving mother or father, let alone a parent who has had minimal education and for whom English is not their first language (and for whom *medical* English is not their language at all). When a physician says to you as this loving parent, “Would you like us to do everything possible to save your child, or would you like us to stop treatment and let him/her

go?” what parent would not immediately respond, “Of course I want you to do everything possible!”? Yet this is the situation that loving parents are placed in daily in U.S. hospitals across the nation.

Over the past several years of working with patients with life threatening conditions, time and again I have been present when doctors say this to the patient’s family. What I have never heard is a doctor present the choice in transparent, honest, realistic terms, such as: *“At this point we have a choice to either step up to more aggressive treatment, including perhaps trying a new experimental drug, in which case we may have some success in extending your child’s life a little but to be clear there is no possibility this more aggressive treatment will cure your child. Worse, in my experience, children who undergo this more aggressive treatment will likely die far more painful deaths and suffer greatly in the last weeks or months of their life. Alternatively, we can refocus our attention on ensuring your son/daughter is comfortable, manage his/her pain and discomfort, and by doing so probably extend their time with you and have a far greater chance of their passing peacefully with minimal suffering.”*

As I say, I have *never* heard any doctor say that to a parent, and yet in many cases this is the truth. Despite numerous studies showing that so-called “palliative” care, including the sub-set of palliative, hospice, can often lead to patients living longer, this fact is still widely ignored by the mainstream medical profession.⁵ I have sympathy for the doctors, though, since it seems very few of them receive training in medical school on how to present difficult decisions to families and loved ones; indeed, rarely do they seem to receive even basic training on bed-side manner, showing compassion, and so on. On the contrary, they have been taught that their job is to “save

⁵ “Palliative care helps cancer patients live longer and better,” <http://www.mayoclinic.org/diseases-conditions/cancer/expert-blog/cancer-palliative-care/bgp-20056303>; “Research shows patients may live longer with hospice and palliative care,” <http://www.nhpco.org/press-room/research-shows-patients-may-live-longer-hospice-and-palliative-care>

lives” and thus to determine that palliative or hospice care is a better course is, in their minds, “giving up” on the patient. Medical “success” in mainstream healthcare has become defined in terms of “cure” or if cure is not possible, then in terms of how long life can be extended (at the cost of quality of life). What is actually happening in many cases is that it is *not life that is being extended, but death that is being extended*. The patient spends a disproportionate amount of time dying (often in agony) in the name of “doing everything possible,” or “keeping up the fight.”

Why both a Christian and Buddhist Foundation to Metta Maria?

This thesis arose partly out of my calling to work as a chaplain with sick and dying children, and partly out of my observation (and stunned disbelief) that, despite a great need, there is no hospice facility for seriously ill or dying children anywhere in Southern California. The latter point is the core of this thesis, and will be unpacked below. First, though, an explanation for the title of this thesis (Metta Maria), which is also the proposed name of the envisioned hospice facility.

The name, Metta Maria, is designed to evoke both a Buddhist message of love and compassion (metta), and an iconic representation of love and compassion in the Christian tradition (Maria), which also takes into account the dominance of Latino families and patients in Southern California. The Christian teachings this proposal is based on, though, have much more in common with Buddhist teachings (especially Zen) than traditional, mainstream Christianity as it is usually understood in most churches. The Christian side of the foundation of this proposal is based on the “Wisdom Tradition” that Christ was a key exponent of, a tradition that either owes a lot to the spread of Mahayana Buddhism around 100 BCE to 100 CE, or is at the least remarkably similar to it in many key ways.

This thesis is also about establishing a residential hospice for dying children that is rooted firmly in the Five Buddha Families and the Three Tenets in particular. Thus this introductory section will provide a little about my background, a little about the Wisdom Tradition of Christ and how it relates directly to Buddhist teaching, and then some background on the plight of children dying in America in far less than ideal circumstances.

Buddhism meets Christianity – An Introduction to the Wisdom Tradition

To flesh out the context of this thesis, and the underlying Metta Maria, I need to say something about my personal Christian spirituality since it differs from traditional church teaching. It does, though, agree entirely with what is *actually* written in the New Testament, and is also supported by many current writers who have been sufficiently brave to risk the established Church's ire and write about what Christ *actually* taught.

Once one strips away the layers that have been put on top of the core teachings of Christ what one is left with is a core teaching that is very similar to that of Buddha. Now, I should hasten to add that I am not from the camp that thinks Jesus travelled to India, or China, or Tibet, but what we do know is that Mahayana Buddhism had its beginnings exactly around the time of Jesus' life (it commenced between 100 BCE and 100 CE). And we also know that the Silk Road opened up not just trade between the Middle East and the East, but also a flow of knowledge and spiritual teachings. The first Mahayana Buddhist collectives were started in the area Jesus lived and travelled at exactly that time in which he was undoubtedly hungry for any and all Wisdom teaching he could gather – be it from the Essenes, and other ascetics who lived in the desert (of whom, John the Baptist was one), or from any and all new religious teachings as they permeated the Middle East from India, China and points East. Including, quite likely, the newly forming Mahayana teachings.

This thesis is not the place for me to expound in great detail on this subject,⁶ but suffice to say there are sizable parallels between the teachings of Buddha and those of Christ (once you strip away what was later added or later imposed as Creed or Dogma). For instance, only Christ and Buddha are the two prominent teachers to use the medium of parable, approximately one third of Jesus' parables are nearly identical to those attributed to Buddha. It seems beyond coincidence that, for instance, both teachings should include the parable of the prodigal son, with the Indian version merely being somewhat longer and with a slightly different ending.⁷

What traditional Christian Church teachings tell us – indeed, I will go further and say you “must” believe in order to be a Christian – is that Jesus was the Son of God (that is the *only* Son of God), that he was born of a virgin, that he died on a cross and physically rose again three days later, that he died for our sins and that he, together with the Father and the Holy Spirit, form the “Trinity” of God in three persons, but “really” one essence, one substance. Traditional Church teaching also tells us that if we do good works in this life time then after we die we go to heaven – that is, heaven is a “place” we go to after we die – and that if we sin then we will go to a place called “hell” after we die.

The trouble is, *none* of this is what Jesus himself appears to have actually said or maintained to be true, according to the earliest writings we have that are closest to the time he actually lived and taught. Even the earliest writing we have about Christ dates from almost a generation after Jesus died. The four Gospels are made up of the first three so-called “Synoptic Gospels” (since they all tell a very similar account), and the Gospel of John that is quite different and clearly written much later. It is widely accepted now that the earliest written gospel is that of

⁶ I have a book in progress on the topic that is scheduled for publication summer 2015.

⁷ Here is one of many articles showing the strong similarity between the Buddhist and Christian version of the “same” parable: <http://www.comparativereligion.com/prodigal.html>

Mark, probably written between 66-70 CE, that is between 33-37 years after Jesus' death (and in a time when life expectancy of the average poor, non-privileged, male was just 38 years).

I don't mean to be dismissive of the Gospel of John, but if we are looking for clues as to what Jesus actually did and said during his lifetime, then John is unfortunately not the place for us to find it. Again, this thesis is not the place for a detailed analysis of this, but suffice to say that John was clearly written by someone who had a specific agenda, and was writing to a specific group of Christians, quite probably ones being persecuted. And, unfortunately, it is from John that many of the Christian creed and dogma that Christians and non-Christians alike find hardest to accept, is to be found: it is in this Gospel (and only in this Gospel, really) that Jesus is portrayed as the Son of God, it is only in this Gospel that Jesus is purported to say things like "No one comes to the Father except through me." (John 14:6) This quote unfortunately has been used to support Christian imperialism and primacy, which is to be deeply regretted.

Even the Synoptic Gospels were clearly added to over time, and what we find added are once again the aspects of Christianity that some modern ears find hardest to accept – the stories of Jesus rising from the dead physically, and of him being born of a virgin, and so on are likely added later well beyond the time Jesus actually taught and at a time when it became clear that the "Kingdom of God" that Jesus spoke of coming in his lifetime had clearly not come and did not appear to be coming soon.

Stripping all this away, what we are left with is a teaching and depiction of Jesus the Christ, that is strikingly similar to the teaching of Gautama the Buddha. And I use these terms in parallel deliberately, since just as Gautama was a Buddha, not the only Buddha, similarly, it is now becoming accepted that Jesus was a Christ, not the only Christ. And that Christhood is in

real terms like Buddhahood – a state of being that anyone can attain to (and which we all already have achieved but do not yet realize it).

So, briefly, what did Christ actually teach? First, he taught that heaven is *within you*,⁸ at no time does he say heaven is a place you go to when you die (at least not when you die physically, but perhaps when you die to ego, die to the ‘self’ with a small ‘s’). He also taught that God is in heaven, and thus God is within you (not in some place in the clouds “up there” but an intimate God that is “closer to you than you are to yourself”⁹). He taught that in order to get into this “heaven” – which was clearly a state of being and not a “place” – you must give up attachment to worldly things and become like a child in wonder and open awareness, living in the moment. The famous “It is easier for a camel to get through the eye of a needle than it is for a rich man to enter heaven,” is much like a koan, but one that has a clear message that someone attached to belongings and to dualism cannot enter the state of being known as heaven.¹⁰

Moreover, this “Kingdom of Heaven” is clearly a communal space, one where Sangha is of primal import, and the teaching emphasizes that everyone is interconnected (“I was hungry, and you gave Me *nothing* to eat; I was thirsty, and you gave Me nothing to drink; to the extent that you did not do it to one of the least of these, you did not do it to Me” (Matt 25:42-45)). Many of Jesus’ aphorisms focus on the interconnectedness and interdependency of everyone. He also taught, quite daringly for his time, that everyone is equal. Like Buddha, he worked with the outcasts of society and promoted the rights of women as equals. Just how radical his teaching of equality was is shown by a passage in one of the Synoptic Gospels that many Christian priests

⁸ Luke 17:20-21

⁹ To paraphrase Acts 17:23-31 and other commonplace sources including the Qu’ran. (Surat Qaf 50:16)

¹⁰ Matt 19:24 – The term “camel through the eye of a needle” was a common term at the time meaning “impossible.”

and theologians try to skip past since they find it too troubling. In our earliest written gospel we have this pithy teaching from Christ (Matt 3:31-35):

³¹ And his mother and his brothers came; and standing outside they sent to him and called him. ³² And a crowd was sitting about him; and they said to him, "Your mother and your brothers are outside, asking for you." ³³ And he replied, "Who are my mother and my brothers?" ³⁴ And looking around on those who sat about him, he said, "Here are my mother and my brothers! ³⁵ Whoever does the will of God is my brother, and sister, and mother."

Elsewhere Jesus says that whoever follows him (to enter heaven) will have to give up mother, father, brother, sister, home and belongs.¹¹ This is radical teaching on equality—we are all brothers and sisters, absolutely equal. And, most important, note that in all these teachings Jesus includes himself in this—he does not describe himself as someone above others or special, but as being a brother and sister with everyone. He teaches, “Our Father in heaven” not “My Father in heaven.” Nowhere in the synoptic Gospels does Jesus say he is the Son of God, and certainly not the *only* Son of God, rather he emphasizes we are all equal in this state of consciousness that he called “heaven on earth,” and all equal daughters and sons of God.¹²

There are, then, strong parallels between the teachings of Christ and those of Buddha. One key difference is that Christianity clearly has a theistic base (God is central to the teaching), whereas Buddhism has no stance on “God.” I believe it is more accurate to say when asked Buddha was silent on the issue—that is, is non-theistic—rather than to say that Buddhism is atheistic. An atheist is sure there is no God, whereas a Zen Buddhist may be centered in *not knowing*. While some might say this makes Buddhism and Christianity totally different, and at odds with each other, in fact the difference is marginal to, I would say, almost nonexistent when properly considered. Many Buddhists have reported that in moments of awakening in nature, say

¹¹ Mark 10:29, Matt 12:50

¹² This comment is disputable, but the counterargument is based on the fact that all four gospels were subject to later editing which resulted in words being attributed to Jesus that were certainly not said by him.

in a forest or on a mountain top, they have sensed a *palpable presence*. Or that in a deep state of Samadhi they have a sense that not only is everything interconnected, but that there is a sentience that is common to everything. Once one sees that for many modern Christians this is precisely how they perceive “God” (rather than as some elderly white man on a cloud somewhere with magical powers), then the differences between Buddhism and Christianity become more semantic than real.

Another difference is dualism: clearly Buddhism is non dualistic, but Christianity has wrestled with dualism since its beginnings as the so-called early Church Fathers tried to unpack Jesus’ teachings. The moment man (and I say man deliberately, since it was early male theologians) started to rationalize Christianity into creed and dogma, dualism crept in. God is three, God is one, since we cannot get our head around the idea that there is God the Father, God the Son and then some hard to describe God the Holy Spirit. Not only is the world divided, and thus dualistic, but even the concept of a God is divided. Then there is the common concept that God is transcendent and while God created the world, the world is not God it is separate from God. We, as humans, are separate from other “things” and from the world in general, and we are separate from God. In more recent teachings, thankfully, this dualism is going away and being replaced with a Christian teaching that is non-dualistic¹³ and it is to that view of Christianity – a view I would say is a better fit for what Jesus *actually* taught – that I subscribe to. A Christianity that is *very* similar to Buddhism indeed.

A third area of difference – although not as strong an area of difference as some writers have suggested – is ethics. As I say, the Ten Commandments of the Jewish faith that Christians also hold to are very similar to the Ten Precepts. Again, this thesis is not the place for an in-

¹³ Recent writings of Marcus Borg, Cynthia Bourgeault, Fr Richard Rohr, as well as older writings such as those of Thomas Merton or, even further back, those of the remarkable Meister Eckhart (1260-1328).

depth comparison and discussion of Buddhist and Christian ethics¹⁴, but there are key parallels that are pertinent to this project since it is of course founded on a strong ethical basis and I anticipate ethical questions arising often since they go hand in hand with end of life issues.

While this thesis is not the venue for an in-depth comparison of Buddhist and Christian Wisdom teachings, it may be of interest to note some broad similarities. In Zen when we realize our Buddha nature then all the precepts become obvious, since once I fully appreciate the interconnectedness of everything and who I truly am, all the precepts follow naturally from that realization. In Jesus' teachings, Love is the main commandment and from that all others flow, thus following the commandment to love God and love others as your self (Mark 12:31) then all of the ten historic commandments of the Jewish faith inherited by Christianity naturally follow from this one commandment to love. Thus both traditions have their highest goal as a singular state of being from which all the other precepts/ commandments follow naturally. The traditions diverge more, perhaps, when we consider karma in contrast to the Christian alternative. However, the traditional view of doing good to get into heaven when you die is out of date. In a clearer appreciation of Jesus' teachings we learn that our sins are forgiven and thus there is no real question of some people "going to heaven" and some not; in this clearer, now widely accepted, teaching hell is thus also not a place you go to after you die if you have been "bad," but rather is a state of consciousness in which you lack a connection with God. The revised wisdom teaching of Jesus, then, which is understood to be what he actually taught, is about a "heaven on earth" (that is, a state of being) which you can't enter unless you get rid of the ego, which in turn starts to sound very like Buddhist teaching. As to what happens after you die, Buddhists have a variety of beliefs as do Christians, but Jesus didn't say anything about an afterlife and Zen Buddhist's often don't believe in reincarnation *per se*, so once again we have some parallels.

¹⁴ Although I shall of course return to this question of ethics later in the chapter on running the hospice.

The bottom line, though, is an absolute necessity in end of life care to respect and honor what the patient and the family believe – if they believe in an afterlife, or in rebirth, then that belief is what must be respected and supported. Metta Maria will not be a place where the views or beliefs of the care staff are forced on patients or families, but rather are lived in our daily lives.

What Christ actually taught was the art of what the Greek writers called *metanoia* which is best translated as “going into the larger mind.” No, I didn’t just switch to Buddhist teaching, this is academically researched hard-core *Christian* teaching, it just isn’t the Christian teaching about which you are used to hearing. Christ further taught that the goal of his way of oneness with God, is to enter your center, and this center was described by the apostle Paul as *kenosis* – which is derived from the Greek term *kenosein*, which means “to let go” or “to empty oneself.” Again, I didn’t just switch to talking about Buddhist teaching, this is core Christian teaching to be found in the New Testament.¹⁵ It just isn’t the traditional Christian teaching that the Church has presented as mainstream for centuries – but these are the Greek terms used by the Gospel writers, we’re just not to reading them. As I say, when looked at clearly, Christ’s teachings are remarkably similar to those of Buddha.

Arguably, at the center of Buddhism is compassion, and at the center of the more pure teaching of Christ is Love – but this is Agape, not Eros. It is a non-sexual love that might better be called *deep compassion* (what Jesus described as the selfless love of a Father for his only begotten son, and which we may now find easier to portray as a Mother’s love for her only child). Notably, in Christ’s teachings God is Love (is compassion), not that God has the attribute of Love, or shows Love, is “loving,” but is Love. That Love, that deep compassion, that is at the root of both Buddhism and Christianity is what calls those who go deep in the path to ministries of social justice, to looking to care for those at the margins of society, and draws us to give up all

¹⁵ Cynthia Bourgeault, “The Wisdom Jesus.” Shambhala: Boston, London; 2008. P 62ff

else to follow this path. And it is what we do for others that shows the depth of our spirituality, not what we profess to believe in or profess to hold true, or what accolades or awards or titles or worldly merits or worldly wealth or possessions we may accrue.

2

Literature Review



The term “hospice” has the same root as the word “hospitality,” and the concept of a hospice as a physical facility can found as far back as medieval times when there were small dwellings for weary or ill travelers. However, the first modern use of the term hospice is attributed to the English doctor Dame Cicely Saunders who launched the first hospice of modern times, St. Christopher Hospice, in London in 1967 (Watson, 2009). Based on meetings she had with Saunders in the 1960s, Florence Wald along with two physicians and a chaplain founded Connecticut Hospice in Branford, Connecticut in 1974 (NHPCO). The year 2004 both marked the passing of an early pioneer in the field of death and dying, Elisabeth Kubler-Ross, and the point at which more than 1 million Americans had been served by various hospices (ibid).

Despite this dramatic increase in the awareness of the need for hospice care, it was not until 1982 that the first hospice for children was launched. Once again the innovation came out of the UK, and Helen House in Oxford, England, became the first hospice dedicated to serving children (Children’s hospice). Yet it was not as if the launch of this first children’s hospice lead to a rush to create such facilities; it took more than a further decade for the first Scottish children’s hospice to open (Rachel House) and about the same time for the next English children’s hospice to open near London (ibid). In the United States, rather than open physical hospice facilities for children, entities like Children’s Hospice International, founded by Ann Armstrong-Dailey, began collaborating with the United States Department of Health to get hospice services in general extended to include service to children as well as dying adults. In 1983, of the

approximately 1,400 hospices in the United States, only four were authorized to accept children and it was not until 1996 that Armstrong-Dailey started collaboration to get children more widely included (ibid).

Now, some 20 years later, most of the approximately 3,000 hospices nationwide in the United States will at least consider accepting a dying child, and it is purported that as many as 450 these actually have specific programs of one kind or another for dying children. This has not, though, translated into a radical increase in the number of actual physical facilities where a dying child may live out the remainder of their life (ibid). In common parlance, the term hospice has often been confused with physical locations, whereas in almost all instances the term hospice in the United States means a service that is either performed in the patient's own home, or at some kind of assisted living facility (nursing home), or occasionally within a hospital setting. But perhaps because of the medieval origins of the term as a physical dwelling, the idea persists that hospices are physical buildings.

There have been a few independent children's hospice homes launched, such as: George Mark Children's Hospice in California opened in 2004; Ryan House in Arizona, opened in 2010; Dr. Bob's Place, opened in Baltimore in 2011; and a handful of other potential hospice homes across the national that are in development (ibid). This is not the picture, I would wager, that the average person has of how we are coping with the deeply sad challenge of properly serving our children suffering with life threatening disease.

In terms of hospice services focused on working with dying children, there are very few nationwide (ibid). The only children's hospice service in California is TrinityKids Care Hospice operating out of Torrance, near Los Angeles. And, to be clear, this hospice is purely an in-home service that attends to children primarily in their own homes. TrinityKids does not own or

operate any physical hospice home for kids (the Providence Hospitals, of which there are several throughout the West Coast, do not have beds reserved for dying children). The reason for the rarity of children's hospices was discussed above, and even TrinityKids relies for its financial existence on the fact it is a subsidiary of Providence Health Care System, and of Trinity Care Hospice (for adults), which is well funded both by Providence and Medicare out of its service of elderly patients in the final days of their life. It is almost certain that TrinityKids Hospice could not exist if it was not reliant on being essentially a subsidiary of Providence from which it gains its financial support.

It has been covered elsewhere above that there are significant financial barriers to offering hospice and palliative care to children, and in particular to opening hospice homes dedicated to children. But is there a more fundamental barrier to offering hospice and palliative care to children? For instance, is there any evidence that children and their family or caregivers do not benefit from palliative care? On the face of it, this seems an absurd question to even ask: of course dying children benefit from medical palliation and also from hospice and palliative care in general. Moreover, of course the parents, caregivers and family members of dying children will also benefit immensely from the support given by hospice and palliative care services, and by palliative care pastoral assistance in particular. But here is the truly sad fact: it is easy to make this statement based on working with dying children and their families, but it is harder to support these simple facts by citing written works or research data.

The Oxford Handbook of Palliative Care, a go-to textbook on the topic, doesn't cover the idea of pediatric palliative care until some 529 pages into the volume, and even then it heads the section "Who needs pediatric palliative care?: The emergence of a new specialty." (Watson, 2009). There are relatively few books written on children's hospice and palliative care – few

compared to the many written on the same topic for the elderly – and there is currently only one book dedicated to the pastoral care of children (Grossoehme, 1999)¹⁶. Of the few books written, the ones that stand out include *Hospice Care for Children* (Armstrong-Dailey and Zarbock, Eds; 2008), *Palliative Care for Infants, Children, and Adolescents* (Carter and Levetown, Eds; 2004), and *When Children Die* (published by the National Academies Press; 2003).

The Oxford Handbook of Palliative Care reminds us that because of the immense strides made in the past 100 years to eradicating childhood disease, it is rare for a child to be so seriously ill that it might die (Watson, 2009). Terminal illness in children thus often goes inaccurately diagnosed, and while some terminal illnesses has curative treatment options, in many cases such treatment fails for reasons that are not always entirely clear to physicians (Watson, 2009). On the other hand, children are also known to make unexpected recoveries, which makes working with childhood terminal disease more unpredictable and hence potentially more even more stressful than working with serious adult illness (ibid).

Children as young as three can usually appreciate that something is dead, and the majority of children understand the irreversibility of death by the age of five to seven. But it is not until around age ten that children gain a more complete understanding of death. It follows, then, that working with children under ten who are facing life threatening disease is inherently difficult since the patient is not likely to have a clear understanding of what is happening to them (Faulkner, 2008). This is a double-edge sword, since along with this lack of full appreciation about mortality can come a lack of fear on the part of child patients compared to working with adults facing death. Often, then, it is the parents, family and adult friends who may require the more substantial pastoral support. Not unusually, it will be the child who is taking on a support

¹⁶ Koenig's book is a very slight volume, in paperback, which sells for well over \$50 and seems priced to dissuade purchase. My own book on the pastoral care of sick and dying children is scheduled for publication summer 2015.

role for the parents and family, since often they have less fear about what is happening than the family do.

In practice, medical palliative care of children with terminal illness is largely about pain management, particularly in the final phases of the disease. While pain may only be present 25% to 50% of the time during the active curative phase of the disease, this can rise to as high as 88% during the final terminal phase (Huff, 2008). However, it is interesting to note that in general children tolerate pain better than adults do, and in fact children's tend to tolerate pain better as they get older (Huff, 2008). A key issue, though, is that children often find it very difficult to tell you where they hurt or what the nature (kind) of pain is that they are experiencing. These factors, in turn, impact the general care of the kids, especially when they reach the hospice phase of their illness, and impact not only the children themselves but their families, too.

The psychological impact of dying on children varies according to age. Seriously ill toddlers, for example, have a tendency to become withdrawn. Preschool children, by contrast, have started to have vivid imaginations and may believe that their illness is due to something "bad" that they did or thought (Gibbons, 2008). For this reason, this age child may need repeated reassurance that their illness is not due to anything they did wrong. The school age child will have a much more sophisticated appreciation of their illness, and may be more aware of the terminal nature of their illness than caregivers or parents believe they are. By adolescence, there can come a sense of flawed identity (ibid) and a severe loss of self-esteem. By late teens, most boys and girls are normally future focused, just coming into their own as proto-adults, and thus it can be devastating for them to have a terminal diagnosis just as they are set to emerge from the cocoon of teenage. By this age it is more likely, too, that the child has developed a spiritual life and is asking questions like "Why is God doing this to me?" (ibid). Another reaction noted in older

dying teens is denial: rather than face the disease and all that this means to them, they will go into a phase of simply denying that there is anything seriously wrong with them (Fitzgerald, 2000). Needless to say, all these issues present a multitude of challenges for the chaplain for pastoral and palliative care of the patient and their family.

Other factors play into the support that a dying child or their parents may need: for instance, the tender issues that arise from a neonatal death, the particular issues arising from death from HIV/AIDs or from a disease transmitted through or caused by the parent (alcohol or drug poisoning *in utero*), or the additional issues that arise from a child being LGBT or facing some form of societal discrimination that layers on top of the news that the illness they have is fatal (Naulty, 2008; Wiener, 2008). And then, of course, there is the care for the grieving parent upon the patient's passing (together with the anticipatory grief that naturally arises in the phase prior to passing), and the pastoral support of the care staff who will be working with these dying children. (Sumner, 2008).

The issues surrounding the financing of palliative and hospice care for children has received a little coverage in the literature. The Institute of Medicine, for instance, summarizes how biased the medical system has been toward only supporting the payment of care of the elderly dying (Field, 2003). No child is covered at all by Medicare, and insofar as a child may have coverage at all for his/her care, it will come from a multitude of sources such as state Medicaid and private insurance plans of one kind or another (ibid). While there is a growing trend of medical insurance companies to include hospice coverage for children that mimics the coverage Medicare gives to the elderly, it is still relatively rare that a child will have adequate coverage for a stay in a hospice home (ibid). State coverage through Medicaid may help so long as the family can plead poverty (less than \$14,630 income per annum as of 2002), but this does not help, of course,

in the case of undocumented immigrants who compose a sizable portion of the families in the Los Angeles region that is the focus of Metta Maria.

Finally, returning to the psychosocial and spiritual needs of the sick child and their family. Families with seriously ill children often feel they are travelling the road alone, since this is uncharted territory for virtually everyone (Orloff, 2004). Even who comprises the family can be a wide variation in modern life: it may be the traditional two parent family, it may be a single parent (in many cases one parent may leave as the child becomes more sick, stating that they cannot bear to be around the child when they are so ill), or there may be close or even distant relatives looking after the child rather than the biological mother or father (ibid). Indeed, in my own experience I have often encountered the sole family member at the child's bedside being the grandmother or even great grandmother, or perhaps a distant aunt or cousin in the instance where the child's parents have been deported.

In some instances, and as a group Latino families tend to fall into this category, there will be an extreme belief that a miracle will take place such that the parents are in denial that the child will actually pass (Chong, 2002; Irish, 1993). This can, in turn, lead to great challenges to the grief support phase when the child then passes since in many cases one is not only dealing with a parent's loss of a loved one, in addition the parent may feel they have lost their religion – that God either cannot exist (or else why would he have let my child die?) or a crisis of faith that leads them to feel that God is punishing them for something they did (ibid).

In her seminal book on the topic, *Being with Dying*, Roshi Joan Halifax points out that death in our United States culture can often be a response to the idea of “a good death” that arises from fear, and too often ends up being life-denying, antiseptic, drugged-up, tube-entangled, institutionalized (Halifax, 2008). As sad as this fact is for adults dealing with a terminal disease,

in practice it can be exceptionally sad to see this same response to children dying. When a parent learns that their child is to die, it is not just uncharted territory that the parent enters (ibid), but it is entering a territory that ought not to exist and which seems contrary to the laws of nature. Children are not meant to die before their parents; that is just not the natural order of things. When a doctor treating your dying child says there is a potential new curative drug that might just help your child, what parent can say no to that suggestion? And even when a doctor is advising that it may be just best to “let nature take its course” and allow your child to peacefully pass away, who can blame the parent who feels they have a right to insist that the doctor continue all possible treatment? (Butler, 2013). The mere suggestion that a parent might consider quality of life over quantity of life and meet with the palliative team invokes for many the idea of “death panels” and the fear that the system doesn’t care about their child (Byock, 2012). This is the tender realm one enters when taking the journey with child and family from the moment the news breaks that the illness is likely terminal.

Researching books on death and dying quickly leads one to the conclusion that the literature is dominated by either Buddhist texts (particularly Tibetan, due to the prominence of *The Tibetan Book of the Dead*; Trungpa, 2010) or Christian literature. Groundbreaking works by Joan Halifax and Ira Byock, as well as significant contributions to the literature on Buddhist chaplaincy work (for example, *The Arts of Contemplative Care: Pioneering Voices in Buddhist Chaplaincy and Pastoral Work*; Giles and Miller, 2012) have greatly enhanced our understanding of what it is to be a pastoral presence to those who are dying. As Jennifer Block says, “Buddhist chaplaincy is in the formative stage as a modern-day discipline and profession at the intersection between Buddhism, chaplaincy, and suffering.” (Block, 2012). As she goes on to point out, the three most common causes of people needing healthcare today are old age, sickness and dying. And it is

noteworthy that these are the very same that inspired Buddha to reach beyond the familiar to find a greater truth in happiness. She goes further and argues that in a real sense the Buddha was a chaplain, or rather than any Buddhist chaplain who gives compassion to others is walking in the steps of Buddha. Trudi Jinpu Hirsch goes one step further and argues for the Four Noble Truths as forming a framework for contemplative care of the sick (Hirsch, 2012). She notes that whereas chaplaincy started out as a Judeo-Christian discipline, gradually the idea of Buddhist chaplains is taking hold. Hirsch notes that in 2012 she is able to reflect back just twelve years to when she became the third ever Buddhist chaplain to be certified by the Association of Professional Chaplains (APC) and went on to become the first Buddhist supervisor certified by the Association of Clinical Pastoral Education (ACPE).

It is arguable that there is a key point where Christian-based chaplaincy and Buddhist chaplaincy diverge—or at least have the clear potential to diverge. And this point is on the issue of suffering: for in the traditional Christian view suffering is just quite simply associated with disease (“dis-ease”) and one can comfort someone who is suffering with your presence and with prayer. Buddhist teaching, on the other hand, is more radical in that it tells us that whereas suffering arises from dis-ease, there is a path to end this suffering. Thus palliative care from a Judeo-Christian perspective has tended to involve pain management, comforting words, and companionship, but no vision that the core suffering involved can be truly alleviated, let alone ended. Yet, the mindfulness movement that has been taking hold in hospitals worldwide has caught many in the health professions by surprise by offering clear evidence that suffering can be alleviated, and potentially ended, by meditation and concentration (see Sundquist, 2014).

3

Methodology



The approach taken to investigate the need for, and viability of, a Metta Maria Hospice Home was a combination of several hundred hours of site visits, volunteering, hands-on chaplaincy work and interviews with key people involved in the end-of-life care of children. The information was gathered from a combination of: receiving chaplaincy training at Childrens Hospital Los Angeles (CHLA), Millar Children’s Hospital Long Beach and Little Company of Mary Catholic Hospital Torrance; volunteer work at TrinityKidsCare Hospice in Torrance and at Children’s Hospital of Orange County (CHOC); paid work as an interfaith (Buddhist and Christian) chaplain at CHOC, Little Company of Mary, and Kaiser Permanente; and speaking with key personnel at all of these hospitals and institutions. In addition, I work for St Christopher Hospice in Hollywood, California, which is a start-up hospice serving the greater Los Angeles area. Speaking with those forming St. Christopher Hospice—named after the first ever hospice in England started by Dame Saunders—was particularly helpful since they were able to articulate why they were initially not going to accept child patients, only dying adults.

The majority of the data was thus gathered from direct observation of working with sick and dying children and other patients throughout the Los Angeles and Orange County areas of Southern California, and talking with the nurses, doctors, spiritual care staff, and fellow chaplains.

4

Findings



I am minded that Marc Bekoff wisely quipped “*The plural of anecdote is not data.*”¹⁷ The findings here, then, while solidly based in personal observation and experience, and in tapping the experience of others through informal interview, do not amount to hard scientific data, nor do they pretend to do so. However, the observations are of merit since there is a remarkable—if sad—consistency to them regarding the need for a hospice home like Metta Maria. I will present my findings in two parts: observations arising from work in hospitals and hospices, and what I gathered from speaking with key people in the field of working with the sick and dying.

Findings from working in hospitals and hospice.

I worked with child patients in each hospital that I was attached to, either as a paid chaplain, or a chaplain in training, or as a volunteer. Naturally, child patients were my sole focus at CHLA, CHOC, Millar Children’s and TrinityKidsCare. First, the observations I make here should not be taken as criticisms of the hospitals in question: they are fine institutions with incredible staff. They are, though, part of the current healthcare system in this country which has systemic problems when it comes to end-of-life care, in particular the emphasis on curative treatment over quality of life (or so-called comfort care). In each of the hospitals I worked in, to one degree or another, referring a patient to the palliative care team or to hospice was seen by the primary doctors as a mark of their failure. Over and again, almost without exception, I witnessed

¹⁷ Marc Bekoff is the Professor Emeritus of Ecology and Evolutionary Biology at the University of Colorado, Boulder.

each primary doctor take the stance that their job was to either cure the patient or to extend life as long as possible by curative treatments. It was intriguing to me how consistently primary care doctors were interpreting their Hippocratic Oath as “do no harm”¹⁸ solely as a call to cure if possible, and were rarely focused on the harm that is often caused by—and the intense suffering that can arise from—so-called curative treatments. Pain, nausea, immunity compromise, extreme fatigue, depression, and so forth were most often seen by primary doctors as the unfortunate but necessary side-effects.

In one hospital I worked at as an interfaith chaplain, the tension between the oncology doctors and the palliative care team was palpable.¹⁹ I witnessed oncology doctors become visibly angry at the suggestion that their pediatric cancer patient might benefit from being visited by the palliative team, since to him bringing in that team was tantamount to admitting he had failed the patient, and failed the child’s family. When he was reminded that curative measures continue in full force while a patient is under palliative care, he pushed back that he did not need a separate team to tell him to help manage the patient’s symptoms of pain, nausea or shortness of breath. He was, he protested, already doing all he could to provide palliation to those issues. He was blind to the psycho-social and spiritual dimensions of palliative care, and felt that any comfort the child or the family might need was being more than adequately met by the wonderful (if over-worked) nursing staff and an occasional visit from a priest for prayer. He was also unable to see that curative treatment—whether chemical or radiation—could be balanced with comfort care without impacting the goal of the core curative treatment regimen.

¹⁸ The oath in its modern form—as The Declaration of Geneva—is, of course, far more than a statement to do no harm. It is a call to treat patients with conscience and dignity, to keep the health of the patient as a primary concern, to maintain a respect for human life, and so forth. But it has an undefined emphasis on the ‘health’ of the patient and respect for human ‘life’ while wrongly assuming all doctors fully appreciate what these terms mean in their deepest sense.

¹⁹ I am not stating the names of the hospitals out of respect and due to commitments to confidentiality.

Perhaps one of the most systemic issues I identified in each hospital was a tendency to label a patient by their disease. If a child was diagnosed with Acute Myeloid Leukemia (AML) then they were quick to say that even a single remission meant the child would eventually die. The child then became a lost cause from fairly early in the treatment process, with the medical staff just doing their valiant best to extend life (or, more accurately, extend death), as long as possible regardless of the suffering caused to the child or their parents. While there was much talk of each child being a unique individual, the reality was that in rounds (the meetings behind closed doors where the care staff discuss patients) all patients with a common diagnosis were often merged together, especially where that diagnosis, *in the opinion of the lead doctor*, indicated a dire prognosis. Less time was spent discussing these patients; they were seen as lost causes.

One issue that I encountered which was unexpected was the apparent pressure that doctor's felt not to permit a patient to die within a certain period of time after coming under their charge. The fear seemed to be partly legal (that they might be deemed personally responsible if the patient died relatively soon after being operated on by them or receiving key curative treatment from them), and partly merit based (that they would receive demerits that could impact them in various ways if a patient were to die). Perhaps understandably, the doctors were not willing to discuss these issues openly with transparency, but such factors were decidedly present. Such factors as how many deaths a given doctor was deemed "responsible for" (that is, occurred while he or she was the named primary physician) in a given calendar year, contributed in some cases to the focus on keeping children alive as long as possible, by intubation and other artificial means, if necessary.

A common cycle of events emerged in many cases where the terminal disease was considered to have particularly poor prognosis with life expectancy of weeks to months. At first

there would be an intensive round of curative treatment, usually accompanied by good attention to symptom management and in particular pain control. In many cases, since the patient was probably in pain prior to hospital admission, this phase brings with it great hope for the patient and family alike. Many curative treatments lead to initial promising outcomes, including at least the appearance of the cancer, say, going into remission. In these more sad cases I'm referring to here, the cancer then returns, often more aggressive than it was the first time. A new curative technique is tried, often showing promising initial results, but also often at the expense of the child experiencing severe pain, nausea or other symptoms that are side effects of the chemical or radiation treatment (not of the cancer, per se). Attempts at cure become merged with attempts to extend life as long as possible (often with the parents not being clear that the treatment they have agreed to has little hope of cure), with the result that the child's immune system becomes very compromised. Immunocompromised fungal infections then may occur, or septic shock, or pneumonia, or some other side effect of the state of the child's system post-curative treatment, and these can then lead to the child's passing, rather than the child passing of the underlying terminal disease, per se. In some cases, the suffering caused by these side effects of the curative treatment can be far greater than the suffering that the child would have experienced if permitted to allow a natural death, and die of the underlying cancer, say, while being treated for comfort measures only.

In these final phases of life where prognosis is poor, ethical issues come to the fore. As I mentioned above, what loving parent when asked if they want everything possible done for their child does not then answer "Yes, of course I do."? Hence, when an oncology doctor talks of possibilities that might be gained by getting the patient on a clinical trial, what the parent hears is "There is still hope!" and any attempt by the doctor to make clear that the treatment will not cure

their child just does not register. The ethical issues then arise, to what degree should a doctor actively seek to dissuade a parent from agreeing to a clinical trial that cannot possibly cure the child and may instead lead to a more agonizing death? Or should a doctor always promote hope, no matter how remote, that a cure may occur? And if a parent chooses to hear “There is a one in a million chance this new drug could cure your child” as “There is hope for a cure for my child,” does the doctor have a moral and ethical responsibility to truly emphasize to those parents that what they are being told is that statistically there is no hope? As chaplains, we always keep hope alive—and can be criticized by doctors for giving what doctors call “false hope”—yet over and over again I have witnessed doctors side step the issue when parents mishear a suggestion that a new drug might extend life for the doctor saying a cure is still possible.

In its final phases, the terminal illness with poor prognosis often followed a predictable path in my experience. There is constant pressure on hospitals to free up beds where possible, and thus to discharge a patient if it is reasonable to do so. With some such terminal diseases, as the child is discharged the doctor is fully aware that it is a matter of when, not if, the child will have a relapse and a crisis moment that could lead to death. And that it will be random chance as to whether that results in death occurring at home, or in the ambulance on the way to the Emergency Department, or in the Emergency department, or in the Pediatric Intensive Care Unit (“PICU”), should the child’s condition be sufficiently stabilized to transfer to the PICU.

From what I observed, there were two most common tracks a dying child might take owing to this systemic emphasis on “cure at all cost.” Where the aggressive attempts at cure were unrelenting, most likely the child did pass in the PICU if they were “lucky” enough to make it back into hospital when the final crisis occurred. Otherwise, the child died at home or in transit to the hospital, having never been referred to palliative or hospice care. Where referral to hospice

happens in such cases, it so late that death then occurs within hours or days of the child going on hospice service. Indeed, a leading hospice doctor reported that the average length of stay on hospice prior to death for their service is less than ten days. Since by Medicare definition a patient is supposed to be diagnosed as having six months to live in order to qualify for hospice care, the evidence is overwhelming that the healthcare system is leaving it too late to refer dying patients to hospice care.

Where a child is referred to hospice, however, before the illness (or side effects from the curative treatment) has progressed too far, the picture was consistently in contrast to the agonizing deaths witnessed in the first group pursuing “cure at all cost” or “extend number of days of life remaining at all cost.” Over and again, I witnessed these children move into comfort care and then in many cases live far longer than six months. Indeed, in many cases some degree or other of curative treatment continues in hospice—something that is unique to pediatric hospice that does not happen with adult hospice. The result being that in many cases the children in hospice can live for years, and are far more likely to have “good deaths” that do not involve extremes of agonizing pain, nausea, shortness of breath or other fear and anxiety provoking symptoms. I was fortunate to be able to see both sides of this picture by working and volunteering in both the hospitals—including extensive work with extremely sick children in PICUs—and in a pediatric hospice setting.

What I frequently observed, though, was the child’s death either occurring in the clinical largely uncompassionate environment of a hospital Emergency Unit or PICU, or death occurring in far from ideal circumstances in a home. The reason for this was simple: the family had no alternative open to them other than either having the sick child at home between hospital visits while on a curative regimen, or having the dying child at home for home-based hospice care,

since there are simply no hospice homes or other facilities other than hospitals where a very sick or dying child can go. The choice thus becomes binary in practice: either the child dies at home, or they are rushed to the hospital in a final medical crisis (even though hospice advises parents not to do so), such that the child dies in the clinical environment of an ED or PICU.

What I mean here when I refer to less than ideal home environments include homes that are already over-full with perhaps a dozen members of an immigrant family living in poverty in a small two bedroom home. It was heartbreaking to see how with no space really available to properly accommodate the dying child, space was nonetheless cleared for the child to have as their own, making life for the rest of the extended family almost impossible. In other instances, the child's parents had been deported, and the child had no near relatives in the United States. In testimony to the love that can be present in some extended families (more common with immigrant families than traditional European well-educated and wealthy families), the second and third cousins step in to take care of the child. But again, this was often in incredibly crowded, under-resourced, situations with far too many people living in a tiny home, or in some cases, homes with no running water, or electricity. But unless the sick child is actively dying—is actively going through an immediate medical crisis—then the child cannot return to the hospital to receive care, even (or especially not) comfort care.

Some examples of encounters with dying children.

If you are sensitive or squeamish, I should warn you some of these details are not easy to read, and you may wish to skip forward to beyond these case studies. Please note that in the interest of privacy no real names are used in these studies and the details have been changed sufficiently to protect the identities of those involved or the hospitals in which they occurred.

Case Study #1: Yasser

Yasser was a 14 year-old Muslim boy when he arrived in the emergency department exhibiting signs of what his parent's thought was a moderately bad case of influenza. To be fair to the parents, even the ED doctor who did the initial examination of Yasser also believed he might have flu. But blood was drawn, urine samples taken, and further tests were run. With an uncertain result, Yasser was admitted to hospital for what his parents believed would be a quick 24-hour stay for observation and treatment. A day later further results came back in: the provisional diagnosis was AML – Acute Myeloid Leukemia. Whereas its “sister,” ALL, is the more common leukemia in children, with a very high 5-year survival and cure rate of 90+%, AML has a noticeably worse prognosis. The 5-year survival rate is estimated by some researchers to be as low as 65%. AML impacts only about 500 children in the U.S. each year, and Yasser was one of those unfortunate few.

I followed Yasser as he went through a six-month course of chemotherapy, which he dealt with very well only occasionally suffering from nausea or weakness. At first, the symptoms seemed to have gone, but within a month they were back and Yasser was back in the hospital – rushed in through ED since his parents kept putting off accepting the reality that their son was not cured on first treatment. Further treatment options were discussed with the parents, but because Yasser was still technically “a child,” at the parents request the full details of what was happening to him, and what his treatment options were, was kept from Yasser. The parents heard how the chemotherapy their son had just received was the cutting edge therapy currently being given to AML patients. The next step, they were told, would be for Yasser to have a bone marrow transplant. The parents were informed that there is a longer shot of the transplant curing Yasser completely, but that cure has been known to happen. What the doctors did not make

clear, though, was that Yasser's chances of being cured by the transplant were minimal at best, and the chance that his life would be extended significantly was also remote. Instead, Yasser's parents were given hope by the doctors, and one thing I have learned as a chaplain is to always support hope.

Yasser was given some basic idea of what would happen to him, and given to believe that there was a good chance this would be a cure and he could come home to live a normal life again. By a great coincidence, Yasser's younger brother was a perfect match for the bone marrow, (which is not always the case). Now, in order to do a bone marrow transplant the hospital moved Yasser to an isolation room where no one could enter the general area unless they first "scrub in" (wash aggressively) for 20-minutes to try to avoid bringing any germs into the rooms. Even the nurses and doctors do not go into the patient room if they don't have to, but instead interact by putting their hands into plastic extrusions in the plastic wall sheeting, minimizing human contact and risk of infection. To visit Yasser, his family would have to not only scrub in, but also wear head to toe protection including a full-face mask, surgeons hat, booties over their shoes, gown, and gloves.

The process of bone marrow transplant can be brutal – and for Yasser it was. His body was bombarded with chemicals and then with powerful radiation in order to destroy the infected "bad" bone marrow before transplanting his brother's good marrow into his system. Yasser's body did not react well to this. Fairly immediately he started to suffer intense headaches that had him calling out in pain for help – calls that I could hear two corridors away. The bone marrow transplant completed, his body recovering somewhat from the intense onslaught that essentially destroyed his immune system, Yasser was transferred back to Intensive Care (known as PICU, or Pediatric Intensive Care). There it was soon found that a fungal disease had taken hold of his

system, undoubtedly because his immune system was decimated. He started to swell in the most grotesque way, his eyes almost literally popping out of his face with the pressure.

After over a week in agony, moderated somewhat by powerful pain medication that rendered Yasser completely unconscious, Yasser finally passed away. Since his parents had “bought” the idea that this treatment would cure their son, they had refused to make him DNR (Do Not Resuscitate), instead they had said if his heart stops that the doctors should do all possible to bring him back to life. Thus when Yasser’s heart stopped they pounded on his chest for what seemed like an eternity to the family watching nearby, but it was all for naught. Yasser passed just over six months from when he was first diagnosed, and from when I first met him as a regular, very bright, teenager that I helped with his math homework.

Case Study #2: José

Like Yasser, José came to the emergency department with what everyone thought was a case of flu. Unlike Yasser, though, he was diagnosed with ALL and thus the anticipation was his chances of a complete cure should have been very high. But this is the thing about statistics: saying that 90% of children survive ALL means that somewhere out there are 10% of children who do not live beyond five-years. José was one of that 10%.

Around 17 years old at the time of admission to hospital, José was preparing to graduate high school and the biggest problem in his life was the homework he was trying to get through. What bothered him most about being in hospital was that he found it hard to do his schoolwork there. When I first met José I was informed he had already had two rounds of chemo and had now experienced two remissions (the cancer appearing to go away) and two relapses. The cancer was now back again, and José was being referred to as “refractory” to treatment (meaning treatment was not working for him). A Latino male with no family other than his Spanish-

speaking mother who had no formal education at all, José and his mom were close buddies as well as mother and son. There is little to no possibility that José's mother had any idea what these complex unusual medical terms meant, and it was apparent that José himself barely grasped their meaning.

Despite having been through two rounds of chemo and relapsing (having the cancer recur) twice, José was actually fairly non-symptomatic. He was not in any pain or discomfort, but he was suffering from some depression, which was quite understandable under the circumstances. While I wondered if putting José on antidepressants was a good idea, I have to admit that once he was on them his more 'normal' cheerful self returned and it was a delight to spend time with him.

The term "Clinical Trial" was brought up in a family meeting with José's mother (an interpreter, of course, being used). The oncology specialists explained that there is a new drug just being tested, and that there is a chance that José might be one of the first patients anywhere to receive this drug. José's mother was told that this drug is showing very promising signs of being a potential cure for leukemia. What they also told his mother – or, at least, I sincerely believe they *thought* they had told his mother – was that since it was a test of the drug there would be absolutely no possibility of it curing José. Indeed, they added, it would be unlikely that the drug would extend José's life, but it would give test results that could benefit other kids in future like José. Whether due to the issues of translation, the mother's level of education, or the way the doctors presented the information, regardless of how, I am in no doubt at all that José's mother did not "hear" anything other than this new, potential wonder drug might cure her son. Consequently, she gave permission for José to receive the new drug, and the news was conveyed

to José as a wonderful new possibility for cure. A chance at the miracle for which they had hoped.

What was *not* conveyed to José's mother, though, was what it meant to be on a "Phase One Drug Trial," and why it was that the doctors were so certain it would not cure José. In a phase one trial the goal is to test the drug for basic toxicity, to determine side effects, and to determine what a "safe" dosage level might be for commercial use later. What is often not made clear to parents is that in order to determine what a "safe" dose of the new drug might be, the kids taking part in a phase one trial need to by definition be given too much – that is, over-dosed – so as to determine what a more effective, non-lethal dose is. In short, signing up for a phase one trial is giving the physicians license to essentially knowingly poison your child with a dose that is by definition likely to cause significant harm. Worse, another purpose of the trial is to determine side effects, so there is awareness among the doctors, often I fear not adequately passed on to the parents, that there might well be very serious side effects not least since the child will be deliberately given a too high dose.

Before his mother gave permission for José to start the phase one trial of the new drug, I had discovered that José had somehow missed out on getting a wish granted to him by the *Make A Wish Foundation*. In my experience, any child with a poor prognosis is referred to *Make A Wish*, and almost invariably gets a wish granted. For some it is going to *Disney World*, for others it is seeing a wrestling match with their favorite wrestlers from television. But for some reason – perhaps due to the language barrier, perhaps due to the fact both José and his mother kept their hope for a miracle so high he was not classified along side other terminally ill kids – he had fallen through the cracks of the system. I noted this in time, and got José and his mother

connected with Make A Wish: and José made his wish to have a driving lesson in a really nice car, and the Foundation had confirmed they would set it up for two weeks time.

At the time he started the phase one trial of the experimental drug, José was not entirely well but he was free of pain and any significant suffering. Moreover, he was really looking forward to his wish of having the driving lesson. Within 48 hours of starting the treatment with the experimental drug, initial results seemed almost miraculous. José's cancer symptoms essentially disappeared entirely. I recall looking in amazement at the positive changes in his test results (his "vitals") and rushing to his bedside to find that he was better than I had ever seen him before.

But then, within just a further 24 hours, José went blind.

Then his white blood cell count swung wildly first in one direction, then in the other. He started to swell up and he went unconscious. He never woke up – within a further 24 hours he had died a most painful, agonizing death. He never got to enjoy his wish, not that he could have done so anyway since the test drug had rendered him blind.

Case Study #3: Laquisha

Laquisha was an eleven year old African American girl from a poor part of town. Like Yasser and José, she too was rushed into ED with flu symptoms. Unlike both Yasser and José, though, Laquisha actually did have a bad case of the flu. She was a large child, bordering on obese, but clearly prior to the onset of the flu she was a normal, otherwise relatively healthy child. Like many people, I suspect, prior to becoming a chaplain I was not used to considering flu as a particularly dangerous illness: sure, I had heard of the very old and the very young potentially dying from it, but surely not a healthy young pre-teen? This then was a learning experience for me, since from the moment Laquisha was rushed in to the PICU (pediatric intensive care unit) she continued to decline further, and further. After a few days there came a

point where the doctors broke the news to the shell-shocked parents at Laquisha's bedside, that she could not breathe well on her own for much longer, and the doctors recommended that she be put on a machine to breathe for her (a so-called ECMO machine: Extra-Corporeal Membrane Oxygenation). In addition, the parents were told that Laquisha clearly could not eat, and to avoid her starving to death they recommended that a "line" be put in to her chest to get nutrients into her body. Faced with being told your child might starve to death – just imagine how horrifying this would sound to any parent, not least a very poor African American family – the parents said yes to all possible being done to save their daughter.

Four days later, Laquisha was essentially in a vegetative state, with no discernable brain wave patterns. The parents are brought into a family meeting with doctors who inform them that Laquisha has all but left us already, and that this is perhaps the time to consider switching off the ECMO machine, and removing the tube that has been giving her artificial feeding. They are told that if the machine is not switched off, if the tube is not removed, then Laquisha could continue to 'live' as she is for some considerable time, but, they were asked "Do you really call this living?" Reluctantly, with much anger and tears, the parents finally said, "OK, disconnect our daughter." The care staff dutifully did so, and the parents then were made to wait a further 24 hours between brain scan checks for the doctors to finally declare Laquisha to have truly passed on. For the entire last four days of her life, Laquisha's face was creased with agony. For the rest of their lives, the parents had to live with the thought that, not the flu, but *their actions* had directly lead to their daughter's agonizing death.

What did these three dying children have in common?

In each of these three case studies, the child died a far more painful death, suffered *far* more, than if the doctors had not been so relentlessly focused on "cure" and on quantity of days versus

quality of life. In both the first two cases, too, the kids would have certainly lived longer – perhaps many months longer – and almost certainly passed peacefully with a minimum of suffering if the “do all possible” focus on cure had not been followed.

But they had one other thing in common, too: namely, they all died in the very clinical environment of a hospital pediatric intensive care unit, surrounded by machines, poked and prodded for the last days of their life, and in settings that were anything but conducive to loved ones being able to say their goodbyes in peace.

Conversations and Interviews with Hospital and Hospice Staff

The results of conversations and interviews with nurses, doctors, administrators and fellow chaplains alike, was remarkable consistent. Both chaplains and nurses reported to me that among the most traumatic experiences they had to deal with was the death of a child in hospital as a result of what they saw as overly-aggressive curative treatment and a resistance to allowing the child to pass away at home. They reported that they witnessed a mixture of what they felt were doctors not wishing to admit what they perceived as failure which lead to children being denied comfort care and/or being kept alive artificially, or actions arising from fear of a very legally based system that does not want to be accused of causing the child’s death by not trying everything medically possible to keep the child alive as long as possible.

Frequently, these people reported that they had witnessed over and over again how a child would pass in clinical, unfriendly surroundings of a hospital, sometimes without family present, simply because the home was not deemed safe to discharge the patient to (and there was no where other than home to discharge to), or because of a focus on using every medical instrument available to modern science up to the final moments of life, which meant such extreme technology-based care could only happen in the hospital environment.

Nurses in particular that I spoke to expressed real ethical dilemmas, and the trauma arising from them, that they faced when doctors insisted they had to administer a curative treatment to a child that was widely acknowledged to lead to a quicker death, or to delay death but do so at the cost of far greater agony. In some cases, this trauma arose from misunderstandings that could so easily be helped with education: for instance, a number of the nurses refused to give morphine for pain since they associate morphine with actively killing the patient (euthanasia). Why this was most often an educational opportunity is because while there is a common story told in healthcare that a loving way to end a patient's suffering is to give them an overdose of morphine, this does not mean that more moderate doses are not the loving and compassionate care the patient needs to control intense pain. Yet, due to these misunderstandings, I and other chaplains I spoke with witnessed patients being left in extreme agony despite being prescribed frequent doses of morphine, solely because the nurses in charge misunderstood the use of morphine as being intended to intentionally kill the patient. This would never happen in a hospice home environment, like the proposed Metta Maria, where pain management would always be well understood.

In discussing the situations I witnessed in Southern California hospitals with a psychiatrist and palliative care expert, and fellow Buddhist, based in a Toronto Hospital (Dr Mary Elliott), she commented that it sounds like care in Southern California is significantly behind the level of end-of-life care provided to children in Canada. Dr. Elliott said that in their Canadian hospitals a PICU will have a special more "home like" room in it where a child could be moved to for the remaining hours of their life, rather than pass in a clinical ICU room full of machines and with little space for family to say goodbye. She also reported that there are funds in the Canadian system for treating children at end-of-life, and a better flow of children out of hospitals into

hospice care, including hospice care facilities (not just hospice home health care), with a greater focus on helping the child “die well” than appears to be the case in California. She was alarmed to note that in the United States our lack of proper care for very sick and dying children is at the level of Congress, with laws needing to be changed for Medicare, or some real alternative, being able to fully and properly cover all dying children regardless of race, ethnicity, or socio-economic status.

In my experience, 100% of chaplains I spoke to, and over 80% of nurses, caregivers, and those working in home-based hospice services, all confirmed that what is lacking in Southern California is at least one dedicated hospice home facility for children. A number of those I spoke to mentioned that virtually no nursing home they know of will take a child since Medicare does not cover a child’s stay, and there were consistent reports of a hospice in the South Bay area that used to take teenage dying patients, but that this facility had to close down due to lack of funding. Another consistent repeated comment was that it was generally understood that there is only one children’s hospice (TrinityKids) and no kids hospice home facilities, solely because “there is no money in it” and a lack of full support from Medicare or Medi-CAL. The general advice given by those I spoke to was to ensure any hospice home for children is well support by financial donations or it will also suffer the same fate as other such homes due to financial difficulties.

5

Discussion



The findings from this study were clear and conclusive: there is a need for a hospice home facility in Southern California of the kind envisaged in Metta Maria. Clearly, there are children who are near end-of-life in the anticipated service area for whom neither hospital nor home are ideal locations for them to spend the remaining time they have. Yet up to now, there has been no alternative for such children. It also follows from the observations and discussions with experts that the key challenge Metta Maria will face is a financial one of being sufficiently well funded. What also came out of the observations and discussions was a clear opportunity for Metta Maria staff to work with the local hospitals in Southern California to encourage the discharge of a dying child into the care of Metta Maria at as early stage as is reasonably possible, or at least to transfer the child when they are actively dying so that they may pass in a more home-like, more loving and compassionate, setting. There could also be a role for Metta Maria management to become actively involved in seeking to change the nations laws so as to provide better medical coverage for the child who is at end-of-life and in need of palliative or hospice care.

The Basic Premise Behind Metta Maria Hospice Homes

Put simply, the goal is to build a liaison with hospitals – starting with those in Southern California, but with an potential nationwide goal – to encourage them to consider dying children spending their last hours or days of life in a comfortable, home-like setting rather than in a cold, clinical intensive care unit. As indicated in the past chapter with the case studies, Metta Maria is

particularly looking to children who have received aggressive care at the hands of western medicine, and reached a point where the ICU doctors have essentially decided there is no more they can do. Rather than prolong the suffering of the children, rather than intubating them (putting a tube down their throats into their lungs) and putting them on ECMO with a feeding tube into their chests, consider instead transferring the dying child a few hundred feet away to the Metta Maria facility where the focus will be on comfort care for their remaining hours or days of life.

The goal, then, is to create a space in which the child and their loved ones can spend those final hours or days in as close to a home-line environment as possible, free from all the machines, and other paraphernalia that the patient and family have come to associate with the high-stress environment of an ED or PICU. I believe that proximity to established hospitals, particularly those specializing in the treatment of life threatening childhood diseases, will be crucial. When, on some occasions, the child may only have hours to live from when the aggressive curative approach has finally been halted, it will be important that the child need only be transferred a matter of half a mile or less to a Metta Maria location.

Design, Organizational and Managerial Philosophy

We now come to the crux of this thesis: namely, the design, establishment and running of the Metta Maria facilities in accord with the precepts, the Three Tenets, and in particular the Five Buddha Families, as well as a focus on the compassionate teachings of Christ. The name of the project—and of the proposed actual hospice facilities themselves—is of course an intentional blend of the Pali word for loving kindness (Metta) together with a central inspirational name in Christianity (Maria). The reason for selecting Metta is perhaps self-evident, but the reasons for selecting “Maria” are more subtle. On the one hand, for many this is the name of the Mother of

Jesus, known as Maria particularly in Latino communities. But it could also refer to Mary Magdalene, thought by many to potentially be Jesus' "beloved disciple," and the one who quite possibly "got" Christ's teachings best of all his followers. It is not so important whether this is historically accurate (too much emphasis has been placed at times on so-called historical accuracy), but on the message being sent, and the symbolism of deep compassion from within the Buddhist and Christian traditions.²⁰

That all said, a key goal of Metta Maria, despite its name, will be to be inter-faith, or faith-agnostic. Any child, and any parent, should feel equally at home and entirely comfortable at a Metta Maria facility, not just Buddhists and Christians. For this reason, too, the presence of any religious or spiritual imagery will be very carefully selected so as to be welcoming and inspiring to anyone from any religious or spiritual background, as well as also to those who self describe as "spiritual but not religious," or those who proclaim no faith or belief system at all. It is a crucial, central tenet of Metta Maria that absolutely everyone feel welcome and, as far as is possible, relaxed and at peace in the facility.

Greyston Bakery as the Model For Metta Maria

Bernie Glassman's Greyston Bakery²¹ along with his Three Tenets,²² and the teaching of the Five Buddha Families, come together to form the core model for Metta Maria. The *Three*

Treasures (as put forth in the ZPO rule) are:

- Buddha, the oneness of life
- Dharma, the diversity of life
- Sangha, the interdependence Buddha and Dharma

²⁰ The name was also selected for the simple reason that Metta Maria rolls off the tongue nicely, arguably better than, say, Metta Mary. Given the high population of Latino families, and hence Latino patients, in Southern California, Maria was also thought to be a preferred name, conveying comfort to this key target demographic.

²¹ <http://zenpeacemakers.org/zen-peacemakers/who-we-are/greyston-mandala/>

²² As well, of course, as the Three Treasures, the Four Commitments and the Ten Practices, and the Bodhisattva Vow - <http://zenpeacemakers.org/zpo-rule/>

The Three Tenets:

- Not-knowing, by giving up fixed ideas about ourselves and our universe
- Bearing Witness to the joy and suffering of the world
- Taking Action that arises from Not-Knowing and Bearing Witness

The Ten Practices:

1. Recognizing that I am not separate from all that is. This is the precept of Non-Killing.
2. Being satisfied with what I have. This is the precept of Non-Stealing.
3. Meeting the diversity of life with respect and dignity. This is the precept of Chaste Conduct.
4. Listening and speaking from the heart. This is the precept of Non-Lying.
5. Cultivating a mind that sees clearly. This is the precept of Not Being Ignorant.
6. Bearing witness to the offering of each moment. This is the precept of Not Talking About Others Errors And Faults.
7. Speaking what I perceive to be the truth. This is the precept of Not Elevating Myself And Blaming Others.
8. Using all the ingredients of my life. This is the precept of Not Being Stingy.
9. Bearing witness to emotions that arise. This is the precept of Not Holding On To Anger.
10. Honoring my life as a Peacemaker. This is the precept of Not Disparaging The Three Treasures.

The Four Commitments of ZPO:

Living The Ten Precepts I commit to:

1. A reverence for all life;
2. A sustainable and ethical economy;
3. Equal rights for all;
4. Stewardship of the Earth.

Together with these, Meta Maria blends the cornerstone of Christian ethical teachings:

The Ten Commandments:

1. Worship only God.
2. Not make false gods or let anything take God's place.
3. Use my words to praise and honor God.
4. Save one day a week for rest and worship.
5. Listen to my father and mother and obey them.
6. Not hate people or hurt others with my words and actions.
7. Respect my body and the bodies of other people.
8. Not take what doesn't belong to me.

9. Tell the truth.
10. Be thankful for God's good gifts.

And Christ's "Amendments":

"The Greatest Commandment"

Jesus was asked: "Teacher, which is the greatest commandment in the Law?" Jesus replied: " 'Love the Lord your God with all your heart and with all your soul and with all your mind.' This is the first and greatest commandment. And the second is like it: 'Love your neighbor as yourself.' All the Law and the Prophets hang on these two commandments. Matt 22:36-40 (Amp)

"The Golden Rule"

So in everything, do to others what you would have them do to you, for this sums up the Law and the Prophets. ((Matt 7:12 NIV)

And, last, a cornerstone part of Christ's teachings that pertains to working with the sick and dying:

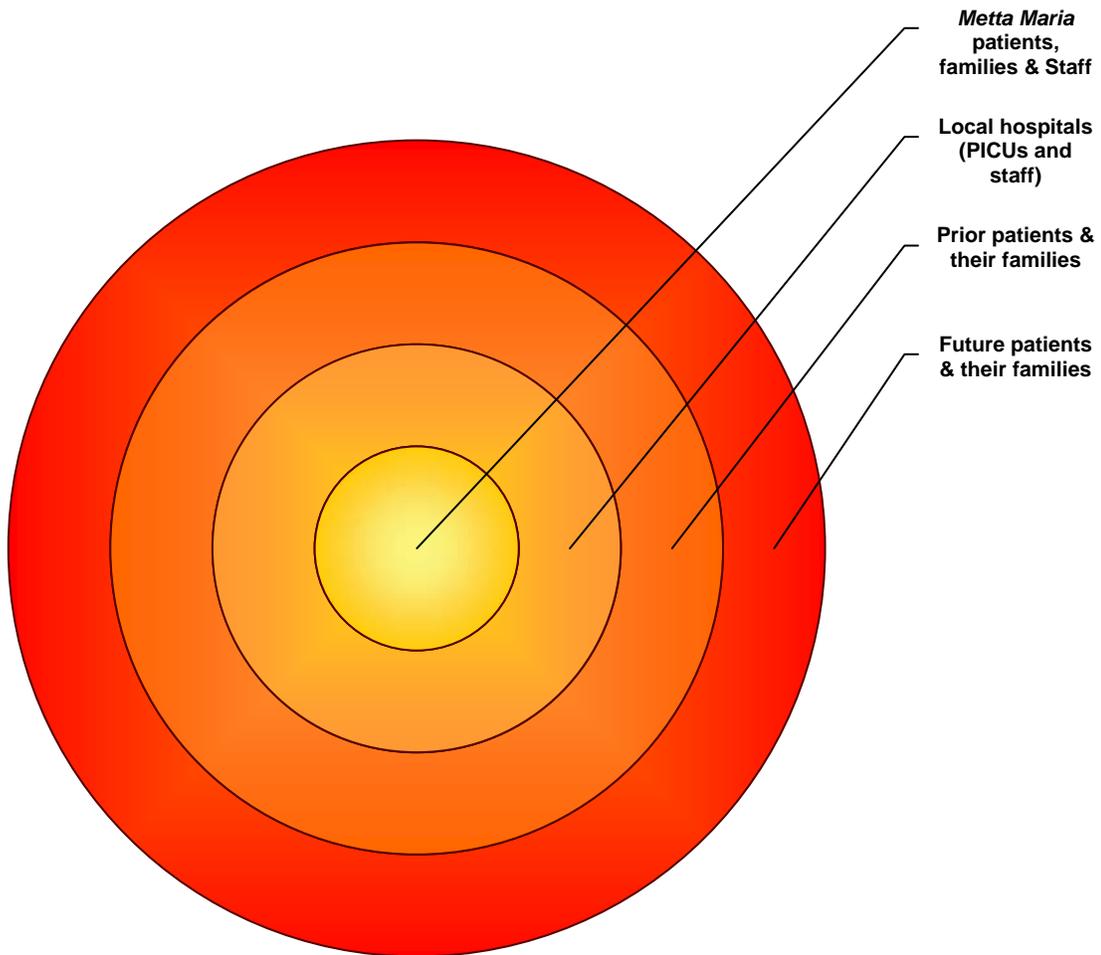
*'I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a stranger and you invited me in, I needed clothes and you clothed me, **I was sick and you looked after me**, I was in prison and you came to visit me.'*

'Lord, when did we see you hungry and feed you, or thirsty and give you something to drink? When did we see you a stranger and invite you in, or needing clothes and clothe you? When did we see you sick or in prison and go to visit you?'

'Truly I tell you, whatever you did for one of the least of these brothers and sisters of mine, you did for me.'
(MATT: 25:34-40 NIV).

In turning now to apply these precepts, tenets and practices to Metta Maria, clearly we honor the Buddha and the oneness of life. We who work in a Metta Maria facility are one with the patients and families of the patients who stay with us. We dwell in and respect the diversity of life, including cultural diversity of our patient families, and the diversity that comes with degrees of health and sickness. We also fully hold to the Sangha(s) of Metta Maria, not only the

immediate Sangha of those working at the facility, the patients, families and visitors, but also the Sangha that includes the nearby hospitals (especially the pediatric intensive care units and all their staff), and the Sangha of all those prior patients who have passed and their families, and finally the Sangha of all the patients who have yet to come to Metta Maria, and their families:



Staff of Metta Maria will be asked to sign their agreement to a commitment that has some similarity to the Zen Peacemaker Order's rule, which is largely a summary of the above put in a format that staff can commit to follow.

Turning to the three tenets, clearly all who work for Metta Maria will need to abide with a clear sense of non-knowing at all times. If working with cancer and other life threatening illnesses has taught me anything, it is that such illnesses are a superb example of how not-knowing is the only sane frame of mind to have when working with this population of children and their families. Terminal illnesses are rarely entirely predictable, and they give hard lessons to those who would think they are certain about the path an illness like cancer will take. It will be central to, and vital to, the care of the dying children that everyone involved in their care be fully present in the moment with the child and their suffering. And in order to be *fully* present it is vital to come to the patient's room with not-knowing. Bearing witness to suffering is clearly central to what Metta Maria is about, but it is also about bearing witness to joy, too. It may be the joy that a child is at peace and no longer suffering to the degree they were in the PICU, or it may be the joy that is shared with parents who get to have more time with their loved one than they anticipated. Certainly, there will be sadness and suffering—they go hand in hand with end of life care—but just as surely there will be joy, as a child shows signs of remission or recovery, or perhaps a long-hoped for milestone met, and Metta Maria staff will need to bear witness to it all. Perhaps most important—naming the elephant in the room—the staff will need to bear witness to the passing of each child that dies at Metta Maria, working with deep compassion to support all family and loved ones at that most tender of times, and following up with grief work and bereavement counseling in the days and months to come.

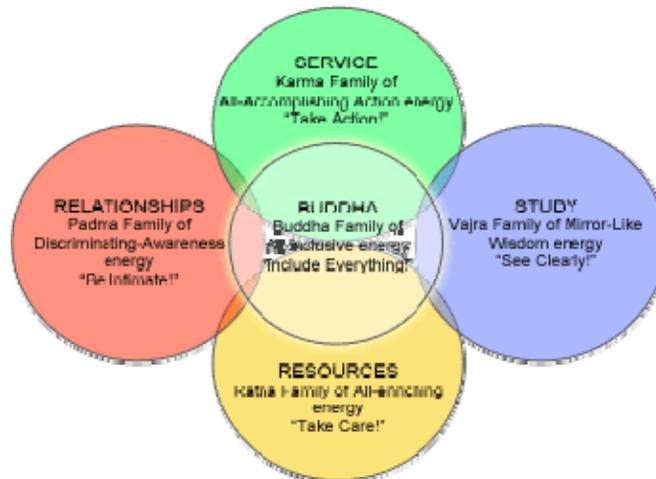
The actions the staff at Metta Maria take will have as its goal action that arises from Not-Knowing and Bearing Witness—these will be our guiding principles that shape not only what actions we take and decisions we make, but also how we take them and how we make them.

The Five Buddha Families

Traditionally, the five Buddha families have been represented like this in Tibetan art:



The position of each of the five Buddhas (north, south, east, west and center) will vary from depiction to depiction in mandala paintings, and which color is attributed to which Buddha can also vary. But the generally accepted names, colors and locations for the Buddhas is²³:

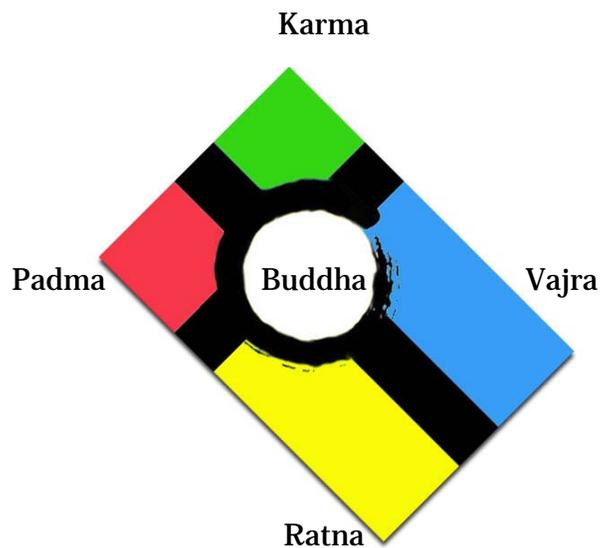


²³ Source: Zen Center of Los Angeles website; www.zcla.org

For Metta Maria the same color scheme was employed having first blended a Zen enso with a simple Christian cross to get a merged iconic image:



This image was selected for Metta Maria not only because it is evocative of a Christian Cross depicted in brightly colored stained glass, but it is also in the colors of the Five Buddha Family mandala. Correcting the directions of the mandala so that the Karma family is at the top (north), we get the orientation the logo is also used in:



Here are the poisons and antidotes and other characteristics of the families:

BUDDHA FAMILY: VAJRA (water)	BUDDHA FAMILY: RATNA (earth)	BUDDHA FAMILY: PADMA (fire)	BUDDHA FAMILY: KARMA (wind)	BUDDHA FAMILY: BUDDHA (space)
POISON: ANGER	POISON: PRIDE	POISON: DESIRE	POISON: ENVY	POISON: IGNORANCE
ANTIDOTE: PATIENCE	ANTIDOTE: EQUANIMITY	ANTIDOTE: COMPASSION	ANTIDOTE: JOY	ANTIDOTE: WISDOM
WISDOM: MIRROLIKE	WISDOM: EQUALITY	WISDOM: DISCRIMINATING	WISDOM: ALL-ACCOMPLISHING	WISDOM: DHARMA-DHATU

Further, in her book *The Five Wisdom Energies*, Irini Rockwell²⁴ lists the following attributes to people who fit into these five personality categories²⁵:

VAJRA QUALITIES	RATNA QUALITIES	PADMA QUALITIES	KARMA QUALITIES	BUDDHA QUALITIES
Clear-minded, precise	Hospitable	Engaging, charming	Efficient, practical	Receptive, content with just being
People: leaders, diplomats, surgeons, engineers.	People: kings, queens, Jewish mothers, cooks	People: “people people,” performers, therapists	People: military personnel, laborers, workaholics	People: spiritual leaders, dignified peasants, visionaries
Expression: wanting to know, pacifying, intellectualizing, mental, conceptual, fear of intimacy.	Expression: wanting it all, enriching, overbearing, needy, hunger for more, center of attention	Expression: wanting to feel, communicating, emotive, public speakers, addiction to intensity, desire to please.	Expression: wanting to do, creating and carrying out projects, driven busyness, direct, straightforward, taking control	Expression: wanting to just be, spacious, minimal, one-pointed, nose to the ground, absorption, ample, simple
Concepts: having an overview, logic, reasoning, critical, philosophical, intellectual.	Concepts: being comprehensive and thorough, retaining large amounts of information, doing research	Concepts: being intuitive, discriminating fine points, communication, pleasure.	Concepts: bringing thought into action, making sure things get done, seeing how things work, doing by trial and error	Concepts: nondoing, repetition using simple basic concepts, sleeping on it, osmosis, client-centered

²⁴ “The Five Wisdom Energies: A Buddhist Way of Understanding Personalities, Emotions and Relationships,” by Irini Rockwell. Shambala: Boston&London, 2012.

²⁵ The first line is in fact drawn from www.mogawa.net, the remainder are from Rockwell’s book, Appendix A.

Staffing Metta Maria

The goal will be to get a well-rounded staff that represent as far as reasonably possible the entire mandala of the Buddha Families. Clearly, the nurses hired to work with the children will probably be in the Padma realm, although the key managerial staff member, the person running the location on a day to day person, will likely be an RN (Registered Nurse), but one who is more in the Karma realm where the necessary good management skills are present. The project overall – not necessarily every location of Metta Maria – will need someone to spearhead marketing and community and national awareness, and such a person will be drawn from those with Padma qualities, perhaps some other qualities (such as Ratna or Vajra). The Project will also need at least one person in the role of researcher, helping Metta Maria stay at the cutting edge of whatever is current best practices for operating or furthering hospice facilities for children, and this person would be drawn from the Ratna realm, naturally. As the visionary behind the project, it will be in part my job to take on the Buddha realm role, with the goal of guiding the entire enterprise from a non-doing, centered – “still point of the turning wheel” – foundation of the Three Tenets.

Certainly, the core antidotes to the give poisons above summarize the key qualities we shall be seeking to exhibit at each Metta Maria location: patience, equanimity, compassion, joy and wisdom. Hiring the right staff to convey these qualities will be essential.

Physical Design of Metta Maria locations

The Five Buddha Families come in again in a key role of guiding the design and color scheme of each Metta Maria location. At the heart of the building or group of buildings should be areas that arise from the Buddha Realm—thus, predominantly white and minimalist, forming a central meditation room as well as an outdoor garden of tranquility, areas that families, staff

and patients (if they are able) alike can retreat to and recharge as well as to further a core practice of meditation that will be encouraged for all staff.

A balance of color schemes for the patient rooms will be sought, with an emphasis on using colors that promote tranquility and comfort. Managerial areas may be, for instance, colored green to promote the Karma realm of efficiency, although there is an argument for other color schemes – such as blues to promote clear mindedness and clarity. Similar consideration to the Five Buddha Family colors will be taken into account in designing the interior and exterior décor of the physical plant of each facility, with the goal of a common consistent theme that easily identifies a location as being a Metta Maria one.

The Heart of Metta Maria

In this section I deal with the heart of Metta Maria—heart in at least two key senses of “center, root, core, foundation,” and in the sense of “agape, selflessness, compassion, loving-kindness.” First, though, a statement of the heart of the project as being committed to being non-profit, with a philosophy of attracting volunteer work where possible, but of paying a fair market rate for those core staff (primarily nurses and a nurse manager) that will be very much at the heart of Metta Maria.

Primary to the foundation of Metta Maria is The Three Tenets: Not-knowing, Bearing Witness, Loving Action. Without consciously realizing it, many end of life healthcare specialists I know operate out of a state of not knowing when dealing with dying patients. Indeed, anyone who is stuck with fixed ideas about themselves or the universe will likely have significant problems dealing with dying patients in general, and dying children in particular. Each time my ego has stepped in and said “I’ve seen this before, this kid won’t survive through the end of this day,” the child then rallies and is with us a year later. Similarly, each time my ego has said “This kid is fine, she’ll be with us a goodly length of time yet,” the child then expires within the hour.

Death, like life, is not predictable, and yet it is an easy trap to fall into to start thinking that it is predictable.

In order to be fully present for each child and their family who is admitted to Metta Maria, it will be vital for all care staff of the facility to come from a place of not knowing. And the second tenet is at the core of why Metta Maria facilities will be founded, namely bearing witness to the joy and suffering of the dying child and their family. I say joy and suffering rather than just suffering, since like anyone who has worked with dying children I have witnessed moments of great joy amid what is ostensibly a very sad scenario.

Then the third tenet wraps up the definition of what Metta Maria will be all about, namely loving action towards ourselves and the patients and their families. This loving action is not just being a “nice person” who gives off a veneer of compassion and sympathy, but a deep *sincere* loving action that arises from deep compassion, deep love (agape). And this love, this loving action, this compassion, can call for very difficult decisions at times that may involve a loving action of aggressive pain medication to provide comfort, or some other necessary loving act that may be called for to help the child pass in peace, or to help the family be at peace with the passing of their child. Or at the least, to help the child and their family to cope, and make meaning of what is happening. Meaning making – which is at the core of chaplaincy work – is a great act of loving kindness, loving action.

The Five Buddha Families are also at the core of Metta Maria, as discussed in the prior chapter. A focus on balance, with balance in the staffing, the running, the admitted patients and families (where possible), a balance with the communities of care, the communities of support (Zen Centers, Christian Churches, and other supporters), and the extended communities of past and future patients and their families, sister-organizations both locally, nationally and

internationally. In all, there will be a goal of balance and of acting out of community that is represented by the Five Buddha Families, in a similar fashion to that described by Bernie Glassman in his description of the foundation and running of Greyston Bakery and the Zen Peacemaker Organization (for further information see Bernie's book, *Instructions to the Cook*).

Ethical Foundation:

What is also at the core of Metta Maria and its operations is a vital ethical foundation, both in Buddhist and Christian ethics. Transparency, honesty and integrity will be essential foundations of the project as a whole, and of each location. The ten essential precepts – the *dasa-sila* – are central to the project and its operation:

1. to not kill but rather to cultivate and encourage life;
2. to not take what is not given, but rather to cultivate and encourage generosity;
3. to not misuse sexuality or relationships, but rather to cultivate and encourage open and honest relationships;
4. to not lie but rather to cultivate and encourage truthful communication;
5. to not intoxicate self or others, but rather to cultivate and encourage clarity;
6. to not slander others, but rather cultivate and encourage respectful positive speech;
7. to not praise self at the expense of others, but rather to cultivate and encourage self and others to abide by their awakened nature;
8. to not be possessive of anything, but rather the cultivate and encourage mutual support;
9. to not harbor ill-will, but rather to cultivate and encourage loving kindness and understanding;

10. to not abuse the Three Treasures of Buddha, Dharma and Sangha, but rather to encourage awakening, and the path to awakening and a community that takes refuge in awakening.²⁶

Some of these precepts may seem a little odd in the context of working with dying children – to not kill but rather to promote life? But this is where wisdom comes in when looking at these precepts: even this first precept is so very appropriate as we unpack it and see that it speaks to us of allowing a child to not be in that foreign country of “one who is dying” but rather here in this present moment as someone, just like us all, who is living and trying to be fully alive in the moment, until those moments cease at passing. To relegate a child to the category of “dying” is to enter what I see as that hungry ghost realm of seeing the dying person as somehow a second-class citizen, to be pulled into anticipatory grief that prevents being fully present for the child in their last hours, days, and so on. To not kill also means to not kill hope—this is crucial. There is no room in the presence of a dying child and their parents for someone who believes that it is a loving act to say that there is no chance of a miracle, or that hope should be abandoned. All *Metta Maria* staff will be there to support hope, to keep hope alive not kill it.

Similarly, the staff will take a clear stance on being honest with families, and transparent, as hard at times as it may be to be candid. This is a fine line, to be sure, to be walked carefully so as to not be seen as destroying hope, but it is a line that experienced end of life care givers are accustomed to walking.

In addition to Buddhist ethics, Christian ethics will also be followed by all *Metta Maria* staff. The sources of these ethical guidelines include scripture, tradition and reason. We look to Biblical scripture for guidance as to what to do in a given situation—which can often be a useful tool to have when our Buddhist teaching guides us to be, say, generous or promoting of life, but

²⁶ With acknowledgements to the San Francisco Zen Center. www.sfzc.org

we meet situations with a dying child when these words of wisdom in the precepts leave us unclear as to what right action is in the moment. Similarly, there is Christian tradition as a reference to guide actions, and determine right action. For some this can just be asking “What would Jesus do?” but anyone who has tried to follow that simplistic guideline often soon hits obstacles. Jesus was strangely silent on when to use a modern drug or when to not use a modern medical instrument or technique. Then there is the Christian belief in reason—that is, that we can use reason along with prayer to gain insight into what the ‘right’ thing is to do in a given situation.

Heart II: Agape, Selflessness, Compassion, Loving-Kindness

This “heart” of Metta Maria arises spontaneously out of the third tenet – loving action – and arises, too, from loving kindness, which in turn arises from right action, right living, concentration and centering prayer. From a Christian perspective, this is what arises from Christ’s teaching of *metanoia* (going into the larger mind) and *kenosis* (to empty oneself), thus seeking the goal of peaceful selflessness, putting others first and self (ego) last. In Christian terms, we say this is putting God first, or put another way, realizing our divine nature (that God is within us and not separate from us) so that our ego does not get in the way of our being truly loving to others. From this practice arises *agape* – divine, Godly love – which compels us to, and arises concomitant with, selfless, loving action. From a Buddhist perspective, the parallel of right concentration and meditation leading to a state of Samadhi, which in turn leads to a deep compassion out of which spontaneously arises loving kindness for others. This deep compassion that naturally arises is in contrast to the ability each of us has to become more *compassionate*.²⁷

Metta can also be a concentration practice of its own leading to a greater ability to be

²⁷ I draw a distinction here between the deep compassion that is our natural state (Buddha nature), and being *compassionate* as a skill that can be acquired, knowing that not all Buddhists—and certainly not even all my teachers!—agree with this distinction. I do, though, argue strongly for it since I find it to be true from my own experience and my own Zen practice.

compassionate. And there are training systems such as Joan Halifax's G.R.A.C.E. that seek to train people to be more compassionate.

The teachings, then, are remarkably similar, both achieved by a routine of practice at Metta Maria locations that is a mixture of meditation (Zazen) and centering prayer and mindfulness-based stress reduction techniques, all with the goal of ensuring the facility's staff are centered and focused on loving action. This central core of practice and discipline is also a key way in which Metta Maria staff will embody good self-care, since if self care is not given a priority, then we cannot fully and properly care for the patients and their families.

Not Just for the Actively Dying Child - Who Are Metta Maria's Target Demographic?

This topic will be dealt with in more depth in the next chapter on putting the idea in action, but it seems appropriate to give a brief summary of who is the anticipated target demographic for these locations. Thus far the focus has been on the key "resident" being an actively dying child, perhaps one who has between hours to—at most—days to live having been transferred from a nearby hospital Emergency Department or PICU (Pediatric Intensive Care Unit). But for reasons laid out in the next chapter, it is likely that it will not be practical to limit those staying at Metta Maria locations to just those children who are actively dying.

However, it is not just regulatory issues that suggest a broader audience of child be permitted to stay at a location, it is suggested, too, by considerations of balance which once again goes to the foundation of The Three Tenets and the Five Buddha Families. It also goes to consideration of the 'climate' of the location were it to only admit children who have a few hours to days to live. While there will be an important focus on staff self-care, and both compassion training as well as training on how to avoid empathic burn-out, still the reality is that there would be a considerable burden on staff that comes with only admitting children who then pass almost immediately.

For all these above reasons, then, each Metta Maria location will also admit at least two and possibly three other patient demographics:

a) **Respite patients** – these are patients who while they are on hospice – and hence, technically, have only six months to live according to a physician’s estimation – are in fact reasonably stable but their parents or caregivers would like some time off from the role of caregiver. These patients will usually be admitted for just 24 hours, so as to give the family or the core caregiver staff some needed respite. On occasion, at the discretion of a site manager, these stays may be extended to 48 hours or perhaps 72 hours, but in general are specifically designed to be relatively brief and on a “as needed” basis (say once or twice per annum if the child is continuing to thrive, as many on hospice, now free of the brutal curative medicines and therapies, find they are).

b) **Terminal but not actively dying patients** – for regulatory reasons, it may not be possible to limit admissions to solely those children who are actively dying. Thus the intention will be to have some beds available for longer-term hospice patients who are in need of a “home like” environment, but who, for whatever reason, cannot be home for the final phases of their illness (perhaps, as often happens in Los Angeles, the parents have been deported, or the home is a single-bedroom house with 10-15 people living in it, with no room to take care of an actively dying child).

c) **Non-hospice, at-risk children** – as will be clarified in the next chapter, there is a possibility that for regulatory reasons again each Metta Maria location may not be permitted to only have hospice beds. If this is the case, then each location will also have beds reserved for at-

risk children particularly young children in urgent need.²⁸ Children with an imminent threat would be given priority, such as those with failure to thrive for medical or other reasons, those in danger of violence—whether because they are LGBTQ, or at risk in a drug dealing/taking environment, at risk for gang violence, at risk for sexual exploitation, homelessness, or similar.

Both the precept that Buddhists do not permit intentionally any sentient being to come to harm, and the Christian teaching to reach out to the less fortunate with compassion and love, are driving factors in wanting a broader residency than just those kids imminently dying, although they are an exceptionally needy demographic that are currently underserved by the “system.” The issue will be in knowing where to draw the line with which children are admitted, and for how long. This will, in turn, be guided to a large extent by regulatory issues such as the number of beds permitted by code, or the issues arising from the challenges of funding a larger number of beds or staffing a larger concern.

Putting it All in to Action

There are clearly a number of key hurdles to being able to open the first such Metta Maria location. Among the key issues are necessarily, regulatory issues, other permissions, identifying suitable building(s), raising funds for the initial launch and to ensure the location is stable ongoing, staffing each location, and building rapport with nearby hospitals to ensure suitable candidates for transfer to Metta Maria are indeed actually transferred in a timely manner.

Core Regulatory and Other Factors

When I first investigated the idea for this project I was not prepared for the numerous roadblocks that stand in the way of anyone seeking to provide care for dying children. It becomes clear fairly quickly why there is only one children’s hospice in Southern California

²⁸ The statistics for the rate of homelessness among children in Southern California are frightening: one source estimates that there are as many as 63,744 homeless children in Los Angeles County, with sizable homeless children numbers in all the other Southern California counties, too. Source: www.schoolonwheels.org

(Providence TrinityKids Care) which exists primarily because it piggy-backs the well funded adult hospice service, *Providence Trinity Care*, which itself is supported by the larger Providence group of hospitals and related out-patient service organizations.

Hospice began as physical locations like hospitals, with many of the early hospices being in the United Kingdom, such as the *Friedenheim* in London which had 35 beds by 1892, and in Ireland, the Religious Sisters of Charity opened *Our Lady's Hospice* in Harold's Cross Dublin in 1879 and was reputed to deal with as many as 20,000 patients suffering from such disorders as tuberculosis and cancer. In 1905 St Joseph's hospice opened in London, again a physical hospital like building with numerous beds, and in the 1950s Dame Cicely Saunders, a British lady, developed what are now considered to be the foundational principles of modern hospice care- which again at this time in the 1950s was primarily in buildings called "hospices." In recent decades, though, in both Europe and the United States, "hospice" has come to refer to a service that is provided, not physical buildings. And the service that most hospice agencies provides is in many ways based, here in the U.S., on Medicare guidelines and what various health insurance companies will pay for in end-of-life treatment. Indeed, for many "hospice" has become part of Medicare, operated by private entities that call themselves "hospices." It is amazing, though, that many people are unaware of this, such that I have lost count of the number of elderly patients I have worked with as a chaplain over recent years where, when the term "hospice" is raised, the response from the family and the patient is usually "I don't want to go to one of those places" as if they were still physical hospice buildings. Certainly, that is not the case in Southern California.

The closest one comes to physical hospices these days are perhaps the "Skilled Nursing Facilities" (SNFs, referred to in the health care community as "sniffs"), which often will take some hospice patients. However, it is rare that these SNFs will take any patient under 65 years of

age since Medicare coverage is crucial to the way these facilities operate (and of course, you have to be 65+ to qualify for Medicare). Yet even if you are in your late 60s, many SNFs will not take you even if you are formally designated as a hospice patient (that is, a doctor has determined you probably have no more than six months to live, since this is the definition of hospice eligibility), since the SNF will argue that despite the doctor's opinion you are still relatively young and may live well beyond six months. As heartless as this might sound, there is some regulatory and financial sense to it, since many times Medicare or Medi-CAL or various health plans, will only cover someone to reside in a SNF for up to 100 days. Beyond that there is no funding for your stay in a SNF in many cases, and the SNF's do not wish to be placed in a situation where they cannot in good conscience discharge a dying patient just because the Medicare or health plan has stopped paying and the family are unable to pay out of pocket.

As you can imagine, the situation is thus far worse for children, since they are not remotely close to qualifying for Medicare. There is some basis for getting Medicare funding (in special circumstances outlined above), and some possibilities for other sources of funding such as Medi-CAL, but rarely from private health plans, which simply do not cover such costs of treating a dying child. It is thus very hard to even finance a hospice agency – that is, an entity that simply arranges for care at home – let alone an actual physical hospice facility. And, as I've said, it is thus perhaps no wonder that there is only one children's hospice service in Southern California, and very few at all in the entire U.S.²⁹

Forming a hospice organization in California is a long and laborious process that usually takes many years to complete, and many entities do not get approved. Since 1991 hospices

²⁹ As mentioned elsewhere in this thesis, while many of the some 3,000 hospices in the United States will now consider accepting children, as few as around 450 have any specific programs for children. The number of exclusively child hospices is not reported anywhere that I could find, and perhaps TrinityKidsCare in California is the only one. Certainly, there are very few physical hospice homes for children, as summarized elsewhere in here.

started to get their own licensure process separate from home health organizations, prior to that they were all run as home health entities. Commencing the process toward becoming a formal “hospice” involves writing to the State to request licensure and certification, it also involves getting Medicare and Medi-CAL clearance and approval, and a requirement to be compliant with numerous Federal regulations even before the State can commence an investigation of whether your entity meets all the regulations to be approved as a hospice.³⁰

For all the above reasons, the likely logical route – perhaps the only practical route – to establishing Metta Maria in the relatively near future as an operational facility is to start each location as a “Group Home” for children which gains permission to have some hospice beds. Group Homes are usually aimed at housing foster children waiting on a foster parent, or perhaps in need of a place to live when a foster placement is not working out. There are far fewer regulations pertaining to the establishment of such a Group Home, and it is easier to obtain permission for such a home to have a number of hospice beds (that is, beds reserved for hospice patients). That said, there is a possibility to be researched that Metta Maria might piggy back on an existing hospice – and for children that really only means TrinityKids Care – with that hospice providing the necessary permissions to establish the physical facility for kids to live.

For these reasons, then, partnering with a hospice will likely be essential, and while this may limit the options to TrinityKids Care, it is possible that another existing adult hospice organization would consider expanding care to children³¹, if Metta Maria could convince that entity that there would be adequate funding to support it. If TrinityKids Care is not the hospice agency partner of Metta Maria, then it will be vital to have a good working relationship with

³⁰ For a glimpse as to how torturous this process is, see: www.cahsah.org or the Federal regulations website which is: www.access.gpo.gov/nara/waisidx_05/42cfr418_05.html. Or this page for the Federal Law relating to forming a hospice: www.ssa.gov/OP_Home/ssact/title18/12861.htm

³¹ I have had exploratory talks with one such adult hospice and the investors in that hospice have expressed an interest in expanding coverage to children in the foreseeable future.

TrinityKids since many referrals for patients are likely to go through TrinityKids, particularly for the kids who would be likely to stay longer rather than those just being transferred from an ICU for remaining hours or days of life.

Funding Metta Maria

By now it is clear that founding Metta Maria is not for the faint of heart, and funding it is a key challenge. With the exception of the remote possibility that Providence (which funds TrinityKids) might underwrite Metta Maria, or that some other independent hospice agency funded by wealthy benefactors might also fund the project, the fact is that Metta Maria will likely need significant financial support from benefactors and philanthropists. While there would be ‘some’ financial help for running a group home from local and state sources, and some help from Medicare and possibly Medi-CAL, the fact is that if Metta Maria needs to partner with a hospice agency, then they too will need a share of the limited funds from such sources, too. And such funds are usually small—\$500-\$750 per day per child—which falls far short of running a state-of-the-art facility for actively dying children.

Certainly, the facility will not need to be anywhere as well equipped with medical equipment as a hospital, or particularly an ICU, but there will need to be basic equipment such as medical beds, oxygen supplies, perhaps some degree of ability to monitor vitals, as well as code issues such as ramps, grab-bars in hallways, specially equipped toilets and showers, and so forth. But the need for funds is complicated by another real-world factor, namely that, in practice, unlike dying adults there is not likely to be a continuous stream of actively dying children. The need for such care is sizable – at any one moment at least 100 kids are on hospice care at any moment in Southern California, but perhaps well over a 1,000 who perhaps ought to be on it. But that does not mean that Metta Maria’s beds will always be full every day, every week (and, let’s face it, that is how we want it to be – no one is hoping for children to die). But this factor is another

reason why the project will attract longer stay kids, such as those on hospice but likely to live many months to year or several years, and at-risk kids who may also stay for at least one year.

There will thus be a need for a significant fund raising activity, and one that is ongoing for the life of the endeavor. The Padma realm marketing and fund raising staff will be put to good use here. The belief is that with careful promotion and an aggressive fund raising campaign, key sources of funds such as Hollywood money, should be accessible for a need so worthy as dying children.

Because funding is likely to be a challenging issue, the project would likely commence with a relatively small five-ten bed facility, of which perhaps as few as two-three beds would be reserved for hospice patients due to regulatory restrictions. This initial facility would also have a skeleton staff, which would at core be primarily two registered nurses and one additional nurses assistant or other similar general help. Employing a full time manager or director for Metta Maria at first may be impractical, and those involved in fund raising may have to be initial required to offer their time on a volunteer basis. Of course, since the facility is a 24/7 operation, even the minimally staffed location would need at least two RNs for day-shifts and a further two RNs for evening/night shifts.

While deeper financial analysis of necessary funding needs yet to be done, initial calculations suggest the Project would require in the region of a minimum of \$200,000-\$250,000 in initial funding to establish the physical facility, but perhaps realistically closer to \$500,000, including necessary code modifications and decoration, etc, to make it “home like” for the kids and their families, and to then fund the basic running costs for the first year if the operation was run “lean.” To have a reasonable buffer, then, suggests Metta Maria would likely need to raise initial

funds of in the region of *at least* \$500,000-\$1,000,000, with ongoing commitments from key benefactors for further support.

In line with the fundamental philosophy of Metta Maria, crowd-source funding will be explored, taking the funding into a larger sangha, a larger worldwide community.

Other Key Considerations

As already mentioned, it will be vital to establish good and close relations with any hospice dealing with children (and primarily TrinityKids). Further, it will be essential to establish close relations with key staff at local hospitals that are likely to transfer dying children to our facility. Since part of what Metta Maria will aim to do is support a child who may only have hours to live, it will be vital that the facility be geographically very close to a key hospital. For this reason, a minimal plan for Metta Maria has to include a vision for several such locations, each located close to key hospitals dealing with the most acute children's conditions – such as Childrens Hospital of Los Angeles (Hollywood), UCLA Mattel Hospital (West Los Angeles), Miller Children's Hospital (Long Beach) and Children's Hospital of Orange County (CHOC – in Orange). Later, extending coverage south the Rady Children's Hospital in San Diego, and elsewhere proximal to other children's hospitals, will be a key goal for what might be seen as “phase three” of Metta Maria (phase one being the establishment of an initial facility, likely close to Childrens Hospital of Los Angeles, and phase two being expanding coverage to the Los Angeles and Orange County hospital locations).

Hiring expert staff with substantial experience in palliative and hospice care of children is essential, with at least one such RN having excellent managerial skills to run the operation on a day-to-day basis.

A key goal is to have the rooms of each Metta Maria location be as close to “being at home” as possible for the kids, or perhaps more accurately, “being at an idealized home” since in many cases the kids may not have a home or may have a home which is far from ideal. To achieve this end, the Project will employ an expert interior designer and will also rely heavily on identifying the successes in existing facilities where such home-like décor for dying children has been done. Key facilities that will act as models for Metta Maria include George Mark Children’s House in San Leandro (near San Francisco), Ryan House in Phoenix, Arizona, and *Helen & Douglas* House in Oxford, England (which is my home town, and a facility I am familiar with and inspired by—and which also inspire the creation of Ryan House in Phoenix).

The Primacy of Chaplaincy at Metta Maria

Not surprisingly, it will be essential to the running of each Metta Maria location that there is excellent pastoral care support, not just for the patients, but also for their families and for the Metta Maria staff. Such support would be through a highly trained inter-faith chaplain, and ultimately, a team of such chaplains. Because of the underlying basis of Metta Maria being both Buddhist and Christian, the initial pastoral support would particularly draw from these traditions. At the very start, then, since I have both traditions as key to my chaplain training and work as a chaplain, I would likely personally be covering the initial facility for its launch period.

However, shortly into the life cycle of the Project there will be a key need for at least one further chaplain, ideally one who is also dual-empowered and dual-trained both as a Christian and as a Buddhist, or alternately, the Project will need to fund two half time positions, for two different chaplains. It is likely that this first chaplain, or this first pair of chaplains, will be able to serve most of the locations envisioned in the second phase, as Metta Maria rolls out to have locations adjacent to all key children’s hospitals in the general Los Angeles regional area.

6

Conclusions



An urgent need was identified for children's hospice home facilities in the Los Angeles area and throughout Southern California. Reviewing the literature and data on dying children in Southern California revealed that a substantial number of children die each month either in a clinical uncomfortable hospital environment of an Emergency Department or a PICU, or in far from ideal circumstances in a home that is over-crowded, or otherwise unfit as a suitable environment for a child to die in.

The philosophy behind the design, funding, establishment and running of such hospice facilities was discussed, and an essential foundation in the Three Tenets, the Ten Precepts, the Christian commandment to Love, and a clear basis in the Five Buddha Families as exemplified by Bernie Glassman's Greyston Bakery, was determined to be essential to the formation and running of each Metta Maria location.

The issues that are likely to arise in establishing even the first of such hospice facilities was discussed, and the need for key benefactors as well as funds from crowd sourced funding, and other core financial support was identified.

The centrality and fundamental foundation to Metta Maria of the Three Tenets, the Five Buddha Families, and an essential basis of Loving Kindness and Christ-like Compassion, was emphasized, as was a need to have all Metta Maria staff acknowledge support for such an approach, and commit to practice that will fuel this basis for the establishment and running of each hospice location.

Finally, the essential need to center each Metta Maria facility in community, and to ensure that each is firmly rooted in community and the interconnectedness of everyone and every thing, was emphasized.

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