

“A book of immeasurable value.”

Lin Jensen, author of *Bad Dog! A Memoir of Love, Beauty, and Redemption in Dark Places*

The Blue Poppy and the Mustard Seed



A Mother's Story of Loss and Hope

Kathleen Willis Morton

The Blue Poppy and the Mustard Seed

A Mother's Story of Loss and Hope

The Blue Poppy and the Mustard Seed

A Mother's Story of Loss and Hope



By

KATHLEEN WILLIS MORTON



WISDOM PUBLICATIONS • BOSTON

Wisdom Publications
199 Elm Street
Somerville MA 02144 USA
www.wisdompubs.org

© 2008 Kathleen Willis Morton
All rights reserved.

No part of this book may be reproduced in any form or by any means, electronic or mechanical, including photography, recording, or by any information storage and retrieval system or technologies now known or later developed, without permission in writing from the publisher.

Library of Congress Cataloging-in-Publication Data

Willis Morton, Kathleen.

The blue poppy and the musard seed : a mother's story of loss and hope / by Kathleen Willis Morton.

p. cm.

ISBN 0-86171-565-9 (pbk. : alk. paper)

1. Willis Morton, Kathleen. 2. Spiritual biography. 3. Grief—Religious aspects—Buddhism. 4. Buddhism. 5. Infants—Death. I. Title.

BQ996.I45 A3 2008

294.3'4442092—dc22

[B]

2008023221

12 11 10 09 08

5 4 3 2 1

Cover design by Pema Studios. Interior design by Dede Cummings. Set in Caslon 11.5/15.5. Cover and interior photograph © Lynne Jaeger Weinstein

“A Ritual to Read to Each Other” © 1960, 1998 by the Estate of William Stafford. Reprinted from *The Way It Is: New & Selected Poems* with the permission of Graywolf Press, Saint Paul, Minnesota.

Wisdom Publications' books are printed on acid-free paper and meet the guidelines for permanence and durability of the Production Guidelines for Book Longevity of the Council on Library Resources.

Printed in the United States of America.



This book was produced with environmental mindfulness. We have elected to print this title on 30% PCW recycled paper. As a result, we have saved the following resources: 27 trees, 19 million BTUs of energy, 2,369 lbs. of greenhouse gases, 9,832 gallons of water, and 1,263 lbs. of solid waste. For more information, please visit our website, www.wisdompubs.org. This paper is also FSC certified. For more information, please visit www.fscus.org.

A Ritual To Read To Each Other

If you don't know the kind of person I am
and I don't know the kind of person you are
a pattern that others made may prevail in the world
and following the wrong god home we may miss our star.

For there is many a small betrayal in the mind,
a shrug that lets the fragile sequence break
sending with shouts the horrible errors of childhood
storming out to play through the broken dyke.

And as elephants parade holding each elephant's tail,
but if one wanders the circus won't find the park,
I call it cruel and maybe the root of all cruelty
to know what occurs but not recognize the fact.

And so I appeal to a voice, to something shadowy,
a remote important region in all who talk:
though we could fool each other, we should consider—
lest the parade of our mutual life get lost in the dark.

For it is important that awake people be awake,
or a breaking line may discourage them back to sleep;
the signals we give—yes or no, or maybe—
should be clear: the darkness around us is deep.

—*William Stafford*

The Blue Poppy and the Mustard Seed

A Mother's Story of Loss and Hope

Still Moment of Mystery



There is only one truth, one law, in all the world
and the six realms of existence, too:
all things are impermanent.
—*The Buddha, to Kisa Gotami*

I WAS CHANGING MY SON LIAM'S DIAPER when I noticed his left hand and part of his arm had started to turn dusky-plum blue.

"Liam," tears came again, "you have to let go now, baby." My knees sank to the floor. I folded over the bed where he was lying and pulled him to my side. He was so thin it hurt me to hold him.

"Liam, if you need to go, you should go." I had been repeating that phrase for forty-five days when I could gather the strength. Every day, I knew it might be his last. I gave him permission to die. Hospice workers and Tibetan Buddhist tradition say to do that so the person can have a peaceful death. I was desperate to give back something to Liam even if it was only a peaceful death. Every night as I held Liam bundled up between his father and me in bed I thought, *Please not tonight. Just let him live until the morning.*

Every morning I didn't move until I knew that he was still breathing. Then I'd kiss him, and I'd think, *not today. I hope he doesn't die today.*

When I saw his hand was blue I knew it wouldn't be long.

"You can't hold on any longer, Liam. It's time for you to let go."

My father-in-law, who is a heart surgeon, had told Chris, my husband, and me that Liam's limbs might discolor eventually because his heart didn't circulate enough blood.

My voice was soft and shaky like a butterfly flying against the wind when I finally got Chris on the phone at work.

"Chris, you have to come home. His hand is blue. You have to come home."

"I'll be right there."

Chris had only been at work for a few hours, and it was only his second day back. He didn't want to go back to work, but we had no idea how long Liam would live—and we had to reach for some normalcy, now almost seven weeks after his birth. When we left the Neonatal Intensive Care Unit at Emmanuel Legacy Hospital, Liam's cardiologist had said, "If he's still here in a week, call me. I'll want to see him again."

When Liam had been home a week we decided not to call the doctors anymore.

"Will they be able to tell you anything that will make a difference in his condition?" my father-in-law had asked.

"No," we'd answered, remembering the grim diagnosis that was documented in his medical records:

The child has sustained extensive bilateral cerebral hypoxia. This seems to be a more global change that would suggest more of a global perfusion problem, rather than emboli . . . The prognosis, which is very limited for this child, has been discussed with his family. His prognosis is of such severity, I think the fam-

ily should be apprised of this in order to make decisions on his care.

I would support their decision either way, to avoid futile care (in view of his very serious neurological findings) . . .

Futile care. That was the phrase that hit me the hardest. How could it make sense that medical care for any child would be futile?

I FINISHED changing Liam's diaper and swaddled him in a blanket. I put a hat on his head even though it was June 27. He should have been fat and warm, bouncing and giggling on my knee. Instead, I took his temperature every couple of hours to make sure it had not slipped below ninety-two degrees. If it were really low, Chris would unbutton his shirt and undress Liam to his diapers. Then they would lay, bare chest to bare chest, under the comforter, with the light streaming in the bedroom window, until Liam was warm again.

Liam's eyes were dulled and glassy. He was somewhere trapped inside a body that, at the time of his birth, had looked perfect in every way on the outside. His skin was downy like a white peach. He had our coloring. His hair was amber, a subtle blending of his father's auburn-brown and my strawberry blonde. When he was born a plump 7 lbs. 8 oz. he resembled me. Then his cherub frame waned to probably less than 4 lbs. I had books on my shelf that were heavier than he was in the end, when he took on the sharp angles of his father's face. Inside—his heart and his mind, his wisdom and his skill—he had reached his fullest potential at almost seven weeks old.

"He won't walk. He won't talk. He won't be able to feed himself. You will be lucky if he recognizes you as his parents," Liam's neurologist had said at our initial meeting. With each sentence he spoke, the tide of my blood pulled back. I felt my face blanch, and

my jaw and body slacken. “He might not even be aware of his surroundings. And I’m not sure he’ll even be able to think. Let me make this really clear. I’m not talking about mild damage. I’m not talking about medium damage. This is severe.” His eyes were unwavering.

CHRIS ARRIVED HOME. But that was all we could do—just be with him. I didn’t want to put Liam down. I sat in the white chair by the bookshelf and held him. I picked up a thin copy of *The Life of the Buddha* by Venerable Dr. Hammalawa Saddhatissa, and I began reading it out loud to Liam. I sat, and read, and held my son all day because I couldn’t bear to let him go. I didn’t know anything else to do. I didn’t want to do anything else. I didn’t get up to eat or pee. I sat and held my son all day. Chris was across the room sitting on the couch for most of the day too. I didn’t fully notice what he was doing. I just felt the barely-there weight of my son in my arms as I read to him about an ordinary person who had found a way, a path, out of suffering.

That night, I lay next to Liam on the bed. I turned on the TV that was at the end of the bed. I didn’t really want to watch TV. I just didn’t want to watch my son die. The square room felt like a TV screen. I watched from outside myself. I saw Liam on the bed wrapped in his blankets: motionless, silent, still breathing. I sat next to him, propped up on the pillows, and stared at the happy everything-will-be-okay-in-a-half-hour world on TV. I was still on the surface like a calm ocean, but underneath I was dark and shifting restlessly. I felt I should be talking to Liam. I felt I should be doing something. I felt I should hold him and comfort him. I flicked off the TV and turned to him. Each breath could be his last. I didn’t want to miss it, but it was too hard to focus my attention on him. I tried to talk to him.

“Liam, Mommy’s here. Don’t be afraid.” Hysteria rose to the surface of my voice like a shark with obsidian eyes. I gasped and choked on my words. I couldn’t talk to him and stay calm at the same time. I didn’t want to disturb his dying. I didn’t want to distract him with my moans and cries that might hold him to this imperfect body and world. I turned the TV back on and watched every crisis resolve on the half-hour. I floated above my grief. Chris was upstairs meditating. My son lay dying beside me. Though I couldn’t look at him, I felt the rise and fall of his breath throughout that Thursday evening, and into the night when all three of us curled up under the covers and let the dark of the room enclose us.

That night I didn’t make my panicked plea for one more night. I just pulled Liam close and whispered with my lips touching his soft cool temple. “Mommy has you, Mommy has you.” I wasn’t sure he could hear me, but I hoped that he could feel my words.

The moment of Liam’s death came gently near dawn as he lay on the bed between his father and me.

I heard a little whine just as I was beginning to doze off. I was instantly wide-awake. “Chris, turn on the light.” I looked at the clock; it was 1:58 AM. Liam whined again softly. He took a breath, and then did not. I moved the blankets away from his body so I could see it. Chris and I were vigilant for I don’t know how long. Liam was lying on his right side with his right arm bent and his palm beneath his head. His left arm was folded across his chest with his other palm down on the bed. By chance it was the same position the Buddha was in when he passed into *parinirvana*. Chris and I were propped up on our forearms lying on our stomachs beside him. Liam’s belly and chest did not rise again. We were still. The world was still. It was the moment we knew would come. That mysterious moment that connects this life with the next. The only moment that all of us can be sure will eventually come someday.

We rose slowly and sat on either side of the bed. Every bit of warmth left his body as I sat reciting, as best I could, the Tibetan Buddhist prayers prescribed for the moment of death. I closed my eyes. I heard my cries as if from a distance. I forced myself not to cry so that Liam could pass away undisturbed. We didn't touch him. I didn't want to hold Liam back.

In that mysterious moment, this is what I remember seeing in my mind: There was amber light. There was warmth. There was a person with long hair and a beige dress with her back to me who squatted down, opened her arms, and scooped up a plump, pink, laughing baby who kicked and waved his arms. I thought the baby must be Liam though I didn't completely recognize him in a healthy body. The woman walked away, carrying the baby who was looking over her shoulder. I felt calm. I noticed I had stopped choking on my dammed-up tears and gasping for breath. As I slowly opened my eyes I heard a small voice say, "Mommy." With my eyes then fully open, a thought popped into my head. It was Liam, and he knew I would want to hear him speak just once. It hadn't occurred to me until just then that I would never hear my son call me *Mommy*. And yes, I would have wanted to hear it. Those were things—speaking, laughing, thriving—that he would never do, no matter how long he lived.

I turned to Chris and looked over his shoulder to the clock. It was 5:30 AM. Three and a half hours had passed into nothing.

"We should clean him up before he gets too stiff," I said. "Will you do it? I can't."

Chris had to do a lot of things I was not strong enough to do.

PRETENDING EVERYTHING WAS OKAY was something I could do, had to do sometimes, and was something I got good at faking for short amounts of time.

When Liam was four weeks old we had to buy him premie clothes because all his newborn clothes, hand-me-downs from my sisters-in-law and crisp new outfits from his baby shower, were all too big. We went to the same store where we had ordered Liam's blue-and-white gingham stroller with a chrome chassis and white-wall tires. The saleswoman recognized us. We had spent a long time with her while placing our order for the stroller and had spoken to her several times on the phone. As we looked through the small selection of clothes for premature babies she was silent. She didn't congratulate us. She didn't come over to dote on Liam. I could feel her sad eyes on us. She looked away when I looked up to meet her gaze. I tried to pick the cutest onesie from the sad assortment on the rack for my son who was not born prematurely—just dying that way.

Chris and I loved to push Liam in his buggy up and down Hawthorne Street by our home and pretend we were a normal family.

"Oh, he's perfect," the man at the Ben & Jerry's shop said. He put his arm around the pregnant woman standing next to him and gave her a gentle squeeze. What we couldn't see behind my perfect son's soft, dark eyes was the tremendous global brain damage that robbed my son of the most basic of human survival instincts: to nurse, to cry, and to respond to the world around him.

"Yes," I said to the man. "He's perfect."

We encountered another couple on the street. "Oh, a redhead. We have a redhead too," said a woman holding their two-year-old. "Just wait till he's this age," the man gushed to us. "They're such a blast."

"We can't wait," we beamed back.

Some people did notice that there was something a little different about Liam. "What a cutie," the owner of the bar on the corner said screwing up her nose. "He's got some snot on his cheek, though."

“No, that’s his feeding tube. He’s very sick.”

“Oh.” She didn’t skip a beat. “Isn’t it amazing what they can do with science these days?”

“Yeah,” we both said. We just smiled. We didn’t tell her that it was more amazing that science could do nothing for us, or for Liam.

“So, have you adjusted to the shock of being new parents yet?” she asked.

Chris and I stared at each other looking for an answer.

“I guess that means no,” she said.

We were in shock but not because we were “new” parents. Parenting a terminally ill newborn, assessing all the information the doctors delivered to us, and deciding what was best for Liam, we felt like we had done a lifetime of parenting in just a week. We had never had time to feel new.

CHRIS DID, however, take care of Liam with the adoring attention that any new father would, till the very end.

Chris went into the bathroom and ran hot water over a washcloth to clean Liam for the last time. He returned and pulled Liam, who was still lying on the bed, a little nearer to him so he could change his diaper. Chris turned Liam on his back. I winced and turned my head away. The right side of Liam’s face and the corner of his right eye were dark cherry-red with still blood that had begun to pool on the side of his body on which he was lying. His eyes were basalt, skin like lilies-of-the-valley, lips the color of gray-blue flannel.

As I stood up I saw Chris cleaning Liam’s bottom, wiping away the tar-like excrement released when his energy let go of his body. Chris held Liam’s cold feet and wiped him clean with slow, deliberate strokes, taking care to make sure he wiped away all the dirt, just like he did every day in the same gentle manner. He did not

grimace. If he was too overwhelmed, like I was, to touch his son's cold, dead body he didn't show it.

"I'm sorry you have to do that, honey," I said, "I just can't."

"It's okay. He's my baby. I love him, and I want to clean him." His voice was a thin trickle.

"I'll call Sharon," I said leaving them alone in the room. Sharon was Liam's hospice nurse who came over every other day. She didn't sound as if I'd woken her when she answered the phone, though it was dawn.

"Sharon, it's Katie." My voice was flat.

She said, slowly raising her voice to make the one word into a question, "Hi?"

"Liam passed."

Sharon exhaled. "Okay. Do you want me to come over now or do you want some time alone with Liam?" She knew some people were afraid to be alone with their dead children. We had talked about what would happen when the time came. She had to come over to officially pronounce Liam dead.

"No, you don't have to come now. He actually passed away at 1:58, but we didn't want to call you then."

"Okay, I'll come over in a couple of hours. Did you call the funeral home?"

"Not yet."

"Do you need me to call for you?"

"No."

"Okay, I'll see you in a couple of hours."

Chris called the funeral home. The man who answered told Chris that they wouldn't be open till 9 AM.

We were grateful to have a few extra hours with Liam. We lay on the bed with Liam between us.

"Maybe we should read him *Horton Hears a Who!* one last time," I suggested.

Chris's voice undulated with tears held back as he read. It was the story we read to Liam every day when he was hooked up to all the monitors and IVs for the first week of his life that he spent in the NICU, the Neonatal Intensive Care Unit. Chris dissolved into tears half way through the story when he read, "I'll just have to save him. Because, after all, a person's a person, no matter how small."

We reached over Liam to each other, and cried, and waited.