

## KATHRYN SKYE

Nearly three years ago, you emerged from the security of my body and began your private journey from Hell to humanity. What you have been through in this time, very few can understand, and very few possibly, will ever experience. What a joy to see you now enjoying being; being with, and in yourself; with people, doing anything; living — not existing.

First born — what a joy! A much-wanted daughter for Keith and Heather. Rather non communicative, we put it down to your difficult delivery and the after effects of the epidural. You didn't like light and only partially opened your eyes in semi-darkness. You ate and slept. At two days of age you were jaundiced and from then on a gradual panic descended, crescendoing at two weeks of age, with you fighting and being hospitalized.

Pronouncements of massive brain damage, or death, were made. We loved you and loved you to stay. We believed that past the physical pain the treatments inflicted, the (A) disease and its madness, the drugs and their side—effects, the essence of you remained, regardless of your unconscious state and inability to respond.

We talked with your spirit; we supported you, at first at a distance as you were “too ill to be touched”, then gradually you again experienced warmth and security through loving touch as you were cuddled through your days of indecision as to whether you'd stay or go.

You were off with the fairies — sometimes too drugged so breathe, and too out of it to receive nourishment. Life was forced upon you. We loved you to stay, and you did. What for? The doctors' interpretations of the brain scans were terrible — blindness, deafness, massive cerebral palsy, massive epilepsy, profound mental retardation — you would never fit into normal life. Live each day as it comes, learn to love her, don't expect anything of you...

The sanctity of human life. Modern medicine saved you for the existence outlined above.

What were we to do? Our precious daughter, much wanted and loved, to be an insensate blob, never to experience the fullness of life as we know it. A life time of nursing and heartbreak ahead, constantly to be reminded through normal life experiences, of what would have been you, what could have been you, and the cruelty of your prison — your body, your mind. No, we didn't accept the judge's decision.

We believed that your broken brain was as mendable as a broken leg, taking longer in time, and more effort than a physical fracture. Finding others with a similar line of thinking was a trick. Did those around us think we weren't accepting reality? They were right — we didn't want the “wait and see” reality — that leads to the self—fulfilling prophecy of “no good”. Action and understanding create change, and we went looking for all of these ingredients.

Within the quest for every and all alternate treatments and viewpoints, was the desperate hope that they were wrong. Hope, hope, hope, hope that tomorrow would be different. You'd awaken and look around, smile, reach out a hand, explore your world, be part of our world. Each passing day, the gradual and very slow to sink in realization, that now was all there was, and you were going nowhere. Time passed, and you stood still — growing bigger and more slug—like

How to breast feed and continually care for someone who responds to nothing and does nothing but eat, excrete, breathe and sleep? Someone who spends most of the time whimpering, screaming, being? The horror of watching a child not develop. The guilt involved in not spending every waking moment at attempting to stimulate some response. Knowing you were lying there doing nothing.

The only way I managed was to believe that you were there, and would be one day yourself, as everyone else is themselves, and that your broken brain in needed time, patience, and a lot of love. A test for my creative abilities as a person and a healer — a live—in, full time patient I could learn from, in order to blaze the way for others, as it seemed that nowhere was the way cleared for us to walk.

We believed you needed fixing, and every effort went into the task at hand. It gradually dawned on me to imagine your case as I had treated hundreds of others — the difference between “THE PROBLEM” and the “REAL ISSUE”. The obvious “problem”

was the brain damage and the “real issue” was “WHY”? Not on a “how did it happen” basis, but a “WHY — WHAT’S THE LESSON?” level.

Initially I saw it as a personal test, and gradually became accepting of the concept of letting go of the outcome — living today as the only moment, not thinking of whether you’d go to school, have friends, enjoy your life, be laughed at, be happy within yourself, being loved and being able to love others, and hopefully a special “other”.

I didn’t think these thoughts obsessively for the boys’ futures - why yours? They could be killed or badly injured in any manner of accidents or diseases, and yet I wasn’t dwelling on how I’d cope with that.

So I had to let go of the outcome — no expectations, no assumptions — just now. One day when you were particularly grizzly and “out of it” and I’d had more than enough, I recognized a pattern. You seemed to be following my lead. I thought of you as a useless, massively brain injured baby, and you were. So, the test. Within half an hour you were as responsive as you had ever been through my change of attitude, and being with you. Really being with you.

The breakthrough I needed — the realization that changes in me, through me, allowed you to be more of yourself. I accepted you as you were, and loved the “you” you were,

not could have been, would have been, should have been, just you now. The quality of “now” shaped the next minute, shaped the next one, shaped the next one.

A multiple choice getting more and more diverse away into the distance. The more I and others put in, like a bank, the more there was to draw on. Anytime I watched you do something new, and projected this forward to what could be, there was absolute disaster — you’d get really ill usually, and back would be the survival panic.

In looking back I wonder why I panicked. It was more the prospect of MORE brain damage, rather than death. Death was too easy; I felt I could handle that. It was the possibility of you being less than you were now that freaked me. The harder you resisted and hated us, the more we loved you. Past where I’d have thought possible, through vast illness on my part, domestic traumas, your illness, your autism your non—eating, your non—sleeping, your fighting sleeping to exhaustion your screaming, your terror — we loved you.

We loved you and loved you and loved you and loved you, through months of whimpering, comforting you, up most of many, many nights, and still there was more to give you. What was the alternative? We’d taken the path - Skye better at any cost. We felt that you’d come to us as we could do it, and therefore we would. Our trauma and hassle over it all seemed very small, relative to your reality. You fought sleep, you needed constant movement and rocking — if we dared stop moving, or sit down, the

nearly asleep, exhausted child would awaken to begin the screaming cycle all over again.

What was the terror? To be terrified of nearly everything - this was your private hell. Not knowing the love and bonding other infants do, knowing only that you didn't want to be here, you wanted to be left alone, you didn't want the programme, the medicine in your mouth four times daily by the clock, to awaken, to live life. You wanted out.

Each time you tried a new disease, or problem, we found creative ways of working through it. We wouldn't just let you be. We felt we knew best. We wouldn't wish to live the life you had and were heading for, therefore, as caring parents, we were intervening. Like any other situation where a child needs guidance, you needed it on a different level and degree, therefore we gave.

You were/are our precious daughter, and had as much right to the best available as if you had a broken leg. No educated person, who knew about these things, had anything sensible to say beyond, "wait and see", "live each day as it comes", "learn to love her for what she is'. There were arguments between Keith and me over whether you wanted to be left as you were. I decided that to be born home especially, meant that, if humanly possible, the task would be completed. By appearing, the task was there and would be done regardless of your thoughts on the matter.

We spent every moment stimulating your unresponsive body - tickling, pinching, massaging, singing and talking, trying to get eye contact with you. NOTHING back — if anything you avoided us.

A very selfish road. I wanted my life back. I was very proud of my children; their beauty, their intelligence, their sense of self, their being. How was I to handle an insensate blob, drooling, fitting, being there physically as a reminder of physical dependence every minute of the day?

How was I to continue my career, my life and be your full time nurse? I wanted my life and my future back again. I wanted my perfect children and my perfect daughter. Illusions and dreams. I now know I always had them. You were here for a non-average reason, as I'm a non-average person.

It may have looked like a selfless obsession to outsiders. It may have seemed cruel to make you do everything you have done. Our decision was that it was crueler to leave you in the “not living/not dying” space, so we pushed you. You resisted, you hated, we loved, we won, you won. You're here now.

We met many people on the way each with a message, a type of therapy to try. We explored and we listened, and we did what we thought was best. There were great arguments staged over my truth and your dad's wishes and beliefs. I felt I knew best. I

lived and breathed your progress. I breast fed. I was with you through your endless nights of screaming, whimpering, nothing, no sleep.

When you went into your "other" spaces, screaming, fighting sleep, wanting constant rocking and cuddling, not letting us rest and sit down with you, our constant movement, your arching back, fighting being, we rocked, cuddled, supported, loved you. What was the alternative? If we ignored it all, it wouldn't go away for you. If we placed you in someone else's care, it would still go on. If we got angry with it all, our stuff wasn't a patch on the terror you had. I doubt that you knew you existed in our world, so locked into yours as you were. Did you know we existed? We did our best.

Finding a group of Reiki channels to give weekly healing sessions started your road to acceptance of self and our world. Very gradually you were less angry and hateful, more trusting and more able to respond. The changes were so minute relative to what "should" have been happening, but so major as they were happening, and you were going through a process, however slow, towards the "normal" stages of development.

We bullied your body. It had to know it was there. The bombardment of light, sound and touch. The constant patterning, crawling, masking, encouraging, and loving. Teams of people in and out, weekly, monthly – all for you. You didn't acknowledge them in usual manners; positively. You worked out that different voices and energies meant work. You screamed, grizzled, knew how to evoke sympathy and scare new volunteers away with

you behaviour of active and passive resistance. You looked as though you were being tortured. Maybe you were in having to be here, to face whatever it was. Life.

Gradually over the years, you accepted us in your life. Gradually we became precious to you. Each tiny step forward is a gift. You let us I cuddle you in bed; you let us tickle you; you smile when we touch you; you run to us with open arms when you see/hear us; you now cry when you think you're alone, when a door shuts; you want to be picked up and comforted when upset. We are finally important in your life. Welcome into ours. It's been a long time coming.

Sometimes you scream and go into your other spaces still. Sometimes there's no reaching you. Where do you go? What frustration must you feel to be alone in our world. Are you alone? Are we kidding ourselves? We speak with other, but are we really with each other? Who is handicapped?

Your life is presenting you with your physical needs met. There are always new people to entertain you. Your mother's life is still revolving around your growth and development. It's changed though. I'm learning to let you dictate what's next. This is your life now.

Where do you want to get to? No longer are you the raw material to be molded. It's now a joint venture outside the bounds of a parent/child relationship. We must communicate

outside words. Sometimes you're there, sometimes I'm there, sometimes we're there together.

Do you know you're different? Do you care? Is this all you want right now from your life? I often look at you, totally in the now, living in this moment and see the beauty of simple existence – for the time you are focused only on what is. Maybe you're further ahead than us and here we are thinking we're helping you!

The gift of so many lessons you've bestowed on those who meet you and hear of our journey. Even if it is the gift of their recognition of what they have in their "normal" everyday children and existence, they then miss the point of it all. Such growth for us who choose to use it as such.

The lesson of unconditional loving and giving – expecting nothing in return, as you could not, would not, chose not to return it.

The lesson of acceptance of now as all there is.

The lesson of letting go of the outcome.

The lesson of trusting the goodness and abundance of the Universe.

The lesson of accepting assistance in every form from others.

The realisation that I'm not indestructible; not superwoman; not capable of coping under wet cement ENDLESSLY.

The acknowledgement of myself as a person; the standing back after fighting for your life; fighting for your quality of life; living life for you, and now letting you take it back.

The joy of seeing you emerge. You are beautiful. Thank you for being in my life, for my growth.

Was it your selfless gift for my life and those who will benefit from interaction with those you've touched? Yours is a story of love and acceptance. It is open-ended. We can't know where/why it all started from. We don't know where we're going. The only moment we have is now; your unfolding is your choice. You unfold at your own speed.

I'm asked, "Do you expect she'll talk?" You do now, it's just different, as you, as we are. "Do you expect she'll go to school?" You are now. Every moment on this earth you've been doing your time, your lessons. Not always willingly, but always with guidance and love from those who are gathered around you.

You are not where I'd hoped you would be at three years of age – my dream/illusion of a perfect daughter. You are that perfect daughter already. It's a question of whose eyes I look through; whose reality is real. What are you/we here for?