

# **YOGA TOWARDS INDEPENDENCE**



**Franky Lewis**

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Printed in New Zealand by

Yoga 4 U

Web: [www.yoga4u.co.nz](http://www.yoga4u.co.nz)

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The techniques described in this paper should not be attempted without the professional guidance of a certified yoga teacher and/or a physiotherapist.

Cover illustration: Franky and Keegan Lewis buddy walking.

*"We are all part of an incredibly vast, majestic and interconnected energy complex. Understanding this – and appreciating this! – is the basis and foundation of yoga. It is the knowledge required for living the divine life."*

(Schiffmann, p340)

## **YOGA TOWARDS INDEPENDENCE**

Research paper presented in partial fulfilment of the requirements for the International Yoga Teachers Association (N.Z.) Inc. Teacher Training Diploma Course, September 2006.

Franky Lewis

*Interdependence is and ought to be as much the ideal of man as self-sufficiency. Man is a social being. Without interrelation with society he cannot realise his oneness with the universe or suppress his egotism. His social interdependence enables him to test his faith and to prove himself on the touchstone of reality.*

Mahatma Gandhi, 1929  
(Cited in Wikipedia)



## **ACKNOWLEDGEMENTS**

Writing this research paper has been made possible first and foremost thanks to Keegan's precious co-operation. Thanks to him, his patience and willingness to participate, I am gaining some very priceless learning, which I am eager to share. I am most grateful to him for choosing me as a mother.

I am thankful to my husband Lew for his patience and support, for listening to my yoga 'stuff' and for being so understanding of the many hours I spend on my yoga mat and in front of the computer.

I am also grateful to my parents for introducing yoga into my life at a young age and to all my friends who have in their own way, and sometimes unknowingly, pointed me in the right direction.

I would like to extend my thanks to all the therapists who have worked with us for the last ten years and who have willingly shared their wealth of experience with me. Thanks also to all the members of our team of helpers, who readily support us and contribute to Keegan's independence.

I would also like to warmly thank my friend Philip Patston, whose insights on disability are helping me to understand Keegan from the perspective of a disabled person.

Finally, I could not have written this paper without the commitment and support of all my yoga teachers; a special thanks to my friend Trish Dye, my tutors Anne Scott and Jenny Fellows, all the tutors of the IYTA Teacher Training Course and Debbie Findlay who synchronistically made me realise that yoga could be adapted to all levels of abilities.

Franky Lewis  
September 2006

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## **PREFACE**

Getting caught into believing that living with a disability needs to be stressful and traumatic is an easy trap. When life deals us different and more challenging cards than our neighbours, we suddenly don't fit in the system anymore. We enter the fraternity of disabled people who have to fight and lobby for the most basic needs and rights: support for personal hygiene, accessibility to buildings, equipment for mobility... As we engage in ongoing battles, we can find ourselves reinforcing *maya*<sup>1</sup>, the illusion of separation. We feel that there is **them**: non-disabled people who have no or little understanding of our issues because of not living with them; and **us**: disabled families who live completely different lives but are trying to adapt to a society designed for able-bodied people.

I had always seen my son's physical impairment as a limitation to the practice of yoga rather than a tool to explore his abilities. This was reinforced by the fact that, apart from Jesus' teachings on healing<sup>2</sup>, the great yoga masters of our time have not left us a manual of detailed yogic practices for impairments.

Discovering yoga under the new light of *Patanjali's Sutras*<sup>3</sup> opened up new horizons for me and sent shivers down my spine when I realised the dormant potential for Keegan. It was then that I decided to learn as much as I could for his benefit, but also for the benefit of other people/children in a similar situation. This decision gave me an elated feeling of strength: instead of being a passive pawn of the traditional medical approaches, I was going to take an active role in my son's well being. I was also going to empower him to do the same.

Nearly three years have now passed since that decision and I can truly say that therapists, friends and family are all amazed at Keegan's development. He is ten years old and opening up to the world like a beautiful flower. There is no doubt in my mind that yoga plays a big part in the 'awakening of his potential'. For me, learning to detach myself from the illusion of **them and us** and from close-to-heart issues enables me to concentrate my energy on promoting Keegan's independence in a very positive way.

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<sup>1</sup> Sanskrit word.

<sup>2</sup> Yogananda, pp329-351 (Healing Power of Thought Transformation).

<sup>3</sup> Written in the Sanskrit language approximately 2000 years ago in Northern India by the sage Patanjali, they are a compendium of an ancient pre-existing oral yoga tradition consisting of both practical advice and theoretical context. Divided into four chapters, they consist of 195 *sutras* (aphorisms or statements), which have been extensively expanded by numerous commentaries ever since.

## INTRODUCTION

For the purpose of this paper, I have chosen to define independence as “the capacity to freely make decisions and to act on them”. Where society may assume that Keegan will always be dependent for all his needs, I am trying to teach him a meaningful way to find his own independence. By actively supporting and encouraging his mobility, I am, together with Keegan and a team of helpers, developing his independence and helping him to create meaningful personal interdependence with his environment.

Practically, this means distilling in him **awareness** at all levels: physical, mental, emotional, spiritual and social. Calling upon Patanjali’s teachings, my aim is also to show Keegan a way to peacefully accept the limitations of his physical body and to control the agitation of his thoughts in order for him to significantly develop his own personal skills and abilities. I would like to teach him how to detach himself from his frustrations and turn them into positive experiences toward his emotional and spiritual freedom. The higher his awareness, the more his spirit will be able to stand in its true identity and shine through his actions.

In this paper, I first set the background of Keegan’s extreme prematurity. I briefly explain his impairments, and inform you on the meaning of the New Zealand Disability Strategy in today’s *Aotearoa*<sup>1</sup> and its relevance to Yoga. I then propose to show you how I have researched and adapted yogic principles to Keegan’s specific needs in order to promote his independence. I look in detail at:

- ✓ *yamas* and *niyamas* (abstinences and observances)
- ✓ *asanas*<sup>2</sup> (postures)
- ✓ *pranayama*<sup>3</sup> (expansion of the life force)
- ✓ *pratyahara* (withdrawal from the senses) and relaxation techniques
- ✓ *dharana* (concentration).

I also cover briefly:

- ✓ *dhyana* (meditation)
- ✓ *samadhi* (self-realisation).

Finally, I share with you some personal insight on how yoga helps and supports me, as Keegan’s mother.

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<sup>1</sup> Maori word meaning New Zealand.

<sup>2</sup> According to Patanjali, *asana* is “that position which is comfortable and steady.” (Saraswati. *Āsana Pranayama Mudra Bandha*, p9).

<sup>3</sup> Not to be confused with breathing techniques, which are used to influence the flow of *prana* in the *nadis* or energy channels of the *pranayama kosha* or energy body.

I conclude that adapting yogic principles to Keegan's specific needs, as described in this paper, is helping him awaken to his potential, and more importantly is proactively promoting his journey towards independence.

The information has come predominantly from a combination of life-long experience with yoga and the medical knowledge I have gained from Keegan's therapists. It has been reinforced by the reading of numerous books, websites, articles and information sharing with disabled families and friends. Other sources also include: compact discs, tapes, yoga courses, lectures.

Time has now come to share the modest fruit of my research and bring awareness to the fore in order to help other people awaken to their potential, regardless of their abilities.



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<sup>1</sup> Lotus Flower: [www.kingtutshop.com/freeinfo/Lotus-Flower](http://www.kingtutshop.com/freeinfo/Lotus-Flower).

## **BACKGROUND**

### **Prematurity**

Born at twenty-six weeks of gestation (fourteen weeks early) and weighing seven hundred and eighty eight grams, Keegan is one of these miracle babies the press and the medical profession proudly talk about.



Keegan at birth

What is little known, because resuscitation of micro-babies<sup>1</sup> is still in its infancy, are the long-term effects on children as they develop through childhood and adolescence. Observing and supporting Keegan since birth has made me realise that there is indeed no miracle but an ongoing discovery of physical, mental and emotional challenges which are undoubtedly due to his extreme prematurity. He was resuscitated at birth with a poor Apgar score<sup>2</sup> of 4 at 1 and 7 at 5 minutes, had a possible brain haemorrhage, respiratory distress syndrome (RDS), pulmonary haemorrhage, feeding difficulties preventing him from sucking, inguinal hernias, irritability, slow growth, cognitive development issues and other significant conditions not relevant to this paper which I wish to keep private. He was diagnosed with cerebral palsy eight months after his birth and with epilepsy three years later. We are currently in the process of investigating Asperger's Syndrome (high-functioning autism) as another possible diagnosis. An EEG<sup>3</sup> and MRI<sup>4</sup> we did at the age of five show that the white matter of his brain is underdeveloped, which is consistent with a very premature birth,

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<sup>1</sup> Babies born under 1000g.

<sup>2</sup> The Apgar score was developed in 1952 by an anaesthesiologist named Virginia Apgar. It is designed to quickly evaluate a newborn's physical condition after delivery and to determine any immediate need for extra medical or emergency care. Five factors are used to evaluate the baby's condition and each factor is scored on a scale of 0 to 2: heart rate (pulse), breathing (rate and effort), activity and muscle tone, grimace response (medically known as "reflex irritability"), appearance (skin coloration). These five factors are added together to calculate the Apgar score. Scores obtainable are between 10 and 0, with 10 being the highest possible score. (Kids Health for Parents. [www.kidshealth.org/parent/pregnancy\\_newborn/pregnancy/apgar](http://www.kidshealth.org/parent/pregnancy_newborn/pregnancy/apgar))

<sup>3</sup> Electro encephalogram.

<sup>4</sup> Magnetic Resonance Imaging.

according to David Jamison, his paediatrician and head of Starship's Neurological Department at the time.

Recent studies have found a link between damage to the white matter of the brain, the myelination process<sup>1</sup>, cerebral palsy, a whole array of other conditions and preterm birth.<sup>2</sup> "According to research conducted by the National Institute of Child Health and Human Development, 25 percent of extremely premature babies have neurological problems at 18 to 22 months, and 17 percent will develop cerebral palsy."<sup>4</sup> Another study on prematurity of children born between twenty-six and thirty-three weeks suggests that by the age of fifteen, forty percent will have some type of neurological impairment<sup>3</sup>: behaviour and cognitive problems often accompanied by sensory and physical impairments.

As the brain, along with the spinal cord, is one of the main constituents of the Central Nervous System (CNS), any damage to it will affect the body's ability to manage the other systems. The efferent system, which regulates muscles and glands, struggles to communicate. This affects the control the body has on its musculo-skeletal system (muscles and bones) but it also has an effect on the endocrine system (glands).

This could explain an array of endocrinal issues such as:

- ✓ diabetes-type symptoms like fainting if not eating at a regular time
- ✓ slow growth
- ✓ poor sleep pattern
- ✓ constant dehydration with difficulty to control body temperature
- ✓ weak immune system
- ✓ epilepsy
- ✓ high tolerance to pain
- ✓ psychological issues (anxieties, mood swings)
- ✓ challenging cognitive development: constant need for reassurance of how he feels physically, mentally and emotionally.

Hence the importance of establishing and maintaining good blood flow around vital organs (including the brain and the spinal cord), in order to optimise systemic communication.

## **Cerebral Palsy**

Cerebral Palsy is a condition resulting from brain damage (usually around the time of birth) causing physical disorders and problems with motor control and posture, such as increased muscle tone and involuntary muscle movements. As explained hitherto, I discovered that the physical aspects of Keegan's impairments were not limited to his physical body, as the medical profession seems to believe through their symptomatic approach, but also have profound effects on his mental, emotional, social and spiritual personality. As actions,

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<sup>1</sup> The myelin is the insulating sheath surrounding nerve fibres in the brain and spinal cord.

<sup>2</sup> See Appendix 1.

<sup>3</sup> Impairment originating in the brain.

intentions and thoughts are generated in the brain, bringing them to fruition for Keegan invariably creates spasticity<sup>1</sup>, preventing smooth energy flow throughout his body.

Cerebral Palsy's main characteristic first appeared to me as muscular tension. As yoga is about letting go of tensions, it seemed logical to use this approach to help Keegan.

### **Asperger's Syndrome**

At the time of writing this paper, I am currently exploring this syndrome but many clues seem to indicate that it is affecting Keegan. This is reflected by a great difficulty to find personal equilibrium and to focus on what is happening in the present moment, generating an endless circle of continuous worrisome thoughts and emotions.

### **The New Zealand Disability Strategy**

The New Zealand Disability Strategy<sup>2</sup> states that "Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have."

We are either born with an impairment (due to genetic factors like Down Syndrome or due to perinatal brain damage like Cerebral Palsy) or acquire one (loss of a limb in a car accident or a stroke).

A majority of impairments are located in the brain and have very different impacts depending on the part(s) of the brain that is (are) affected.

We commonly see impairments as physical (affecting the body), mental (mental illness) or intellectual (affecting the intellect, our reasoning skills).

What is important to understand is that impairments have an impact on how an individual relates to his/her environment. We learn and grow through experiences, no matter how these take place. A person who is not able to walk will obviously have a different experience to a person who walks. This doesn't mean that his/her experience is any less than that of anyone else. The perception of our environment is just different. This perception is sometimes

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<sup>1</sup> "Spasticity has been defined as an increase in muscle tone due to hyperexcitability of the stretch reflex and is characterized by a velocity-dependent increase in tonic stretch reflexes (Lance, 1980)." (eMedicine from WebMD. [www.emedicine.com/NEURO/topic706](http://www.emedicine.com/NEURO/topic706))

<sup>2</sup> Office for Disability Issues. *The New Zealand Disability Strategy*. [www.odi.govt.nz/nzds](http://www.odi.govt.nz/nzds), p7.

exacerbated, leading to hypersensitivity, which occurs when one (or more) of the five senses is over-stimulated.

Another important challenge that a disabled person may face is frustration: barriers such as accessibility, being heard and understood... are very tough lessons indeed, quite often misjudged by our own ignorance.

The New Zealand Disability Strategy was written in support of the one-in-five New Zealanders who identify that they have a long-term impairment.

“Underpinning the New Zealand Disability Strategy is a vision of a fully inclusive society. New Zealand will be inclusive when people with impairments can say they live in:

‘A society that highly values our lives and continually enhances our full participation.’

Achieving this vision will involve ensuring that disabled people have a meaningful partnership with Government, communities and support agencies, based on respect and equality. Disabled people will be integrated into community life on their own terms, their abilities will be valued, their diversity and interdependence will be recognised, and their human rights will be protected.”<sup>1</sup>

### **Relevance to Yoga**

The New Zealand Disability Strategy is showing us how to open our minds and understand that we are all human beings instead of being categorised as either disabled, Maori, female or gay or.... a combination of these...

We all have many very different needs. Being able to demonstrate love and compassion, to use our listening skills and to put ourselves into someone else’s skin will help us to better understand the needs of a wide variety of people, more particularly those of us who, at a soul level, have chosen this lifetime as a huge learning opportunity for the human race.

We can learn to become inclusive and support each other, as a community, thanks to the creation of interdependent links. We can also learn to value everyone’s contribution to society and celebrate the diversity of life, Diversity within Unity. In doing so we all contribute to enhance the overall experience of our human race.

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<sup>1</sup> Ibid. p7.

**YOGIC MANAGEMENT THROUGH**  
**PATANJALI'S EIGHT LIMBS**

*"This is the teaching of yoga.  
Yoga is the cessation of the turnings of thought.  
When thought ceases, the spirit stands in its true identity as observer of the world.  
Otherwise, the observer identifies with the turnings of thought."*

(Stoler Miller, p29)

## **Yamas and Niyamas**

Moral principles (*yamas*) and social observances (*niyamas*) are the first two yoga practices which, according to Patanjali, can help us detach ourselves from the misidentification between unliberated spirit and phenomenal world (the source of our pain).

The application of the *yamas* and *niyamas* into Keegan's life is slowly taking the shape of a strong and positive base, which he will be able to use, I hope, as a platform when time comes to leap gracefully and happily into adulthood.

### **The five yamas or moral qualities**

#### **Ahimsa • non-violence**

Sutra II.35: When we are firmly established in non-violence, all beings around us cease to feel hostility.<sup>1</sup>

Some studies have shown that parenting stress is a risk factor for later behavioural problems in both preterm and other children.<sup>2</sup>

The stress created in trying to cope with everyday life for the parent of a disabled child is a factor that undoubtedly affects all disabled families. Parents become the buffers between a non-understanding society and a child who functions differently but who has so many talents, which are not often recognised by society.

For example, it takes Keegan two hours to get ready to go to school every morning. A last minute event, like having to change his clothes, inevitably adds an extra 15 minutes to our routine. As we have been threatened not to be able to use the taxi service to go to school if we are more than five minutes late, our mornings have become very tense.

In these instances, and because the consequences are significant (how would Keegan go to school?), it is very easy to become frustrated and display impatient behaviours.

Applying ourselves to demonstrate non-violent and patient attitudes toward Keegan is contributing to create a loving and caring atmosphere within our family unit. Feeling peaceful and respected, Keegan can express himself in a meaningful manner, without the need to mimic patterns of impatience.

*Ahimsa* is also relevant to Keegan's physical practice; wanting to push his body too far could be tempting but damaging.

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<sup>1</sup> Cited in Lawson, p7.

<sup>2</sup> See Appendix 2.

### **Satya • truthfulness**

Society often assumes that disabled people cannot express themselves or people

Sutra II.36: When we are firmly established in truthfulness, action accomplishes the desired end.<sup>1</sup>

find it easier and less time consuming to talk to the person accompanying the disabled person. People often forget to talk to the child; instead they speak about him to the parents, right in front of him and sometimes for long periods of time in the case of specialist appointments.

With Keegan, we are sometimes quick to make assumptions which reinforce the different aspects of his disability and which are therefore disrespectful, like for example telling him to concentrate better while buddy walking<sup>2</sup> when it is actually us (the person helping him) who is not supporting him properly... Observing Keegan when subjected to such situations is quite revealing; he either looks uncomfortable and becomes agitated or he switches off and 'removes' himself from the situation (he is physically there but his mind is elsewhere).

Allowing him to express the purity of who he truly is, is an important key to his emotional and spiritual development.

Letting him be 'part of the conversation', as he requests often, is giving him the opportunity to feel included in his environment and to learn how to positively interact with others.

### **Asteya • non-stealing**

For the last ten years, we have concentrated all our efforts on Keegan's physical well being.

Sutra II.37: When we are firmly established in integrity, all riches present themselves freely.<sup>3</sup>

This means that some other areas of his development now need to be addressed, like learning about his identity and property.

Keegan expresses his uncertainty by ongoing questions such as: "Are you my mother?" Or "Is this mine?" Even though these questions come across as a constant need for reassurance, they could also indicate that Keegan is affirming himself and learning about what belongs to whom.

Once he understands this concept, and possibly in the same process, he will comprehend the meaning of non-stealing.

Patently taking the time to respond to his numerous questions is important in order for him to understand this concept and find his place in society.

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<sup>1</sup> Ibid. p7.

<sup>2</sup> Supported walking as pictured on the front cover.

<sup>3</sup> Ibid. p8.

### **Brahmacharya • continence**

As the term chastity does not apply to Keegan (and to most of us), the application of this *yama* needs to be taken to its wider meaning.

As Keegan's senses tend to be easily over stimulated, his reactions sometimes seem to be out of control and out of proportion.

Teaching him moderation and how to detach himself from his senses will enhance his perception of the world and enable him to live life to the full without becoming addicted to the pursuit of pleasure or the avoidance of pain.

Sutra II.38: When we are firmly established in our search to know God, subtle potency is generated.<sup>1</sup>

### **Aparigraha • non-possessiveness**

Detachment from the senses also extends to material things. As we, Keegan and his support

team, are reliant on material things such as equipment for his mobility, we may come to identify with them and believe that we could not exist without them. With non-attachment comes the realisation and the gratefulness that we are very lucky to have the support of such wonderful technology, and the appreciation that happiness is in our inner self rather than in anything external.

Sutra II.39: When we are established in non-attachment, the nature and purpose of existence is understood.<sup>2</sup>

## **The five niyamas or personal observances**

### **Saucha • physical and mental purity**

Illness and attachment to persistent, incessant thoughts and emotions create pain, preventing the whole body from relaxing.

Physical purity for Keegan involves learning about his personal hygiene, proper diet and sufficient sleep, an appropriate exercise regimen including yoga postures and keeping his environment clean and tidy.

Mental purity is letting go of those worrisome thoughts and emotions.

The assistance that he receives in his daily life needs to be respectful of his desire to learn how to

Sutra II.40: Physical purity destroys identification with the body and brings freedom from contact with other bodies.<sup>3</sup>

Sutra II.41: From mental purity arises cheerfulness, mastery of the senses, one-pointedness and fitness for the vision of the Self.<sup>4</sup>

achieve these different aspects of purity without assuming that he is not able to. Creating awareness at this level empowers him to make decisions with regards to his physical and mental health.

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<sup>1</sup> Ibid. p8.

<sup>2</sup> Ibid. p9.

<sup>3</sup> Ibid. p9.

<sup>4</sup> Ibid. p9.

### **Santosha • contentment**

Constant mental agitation renders contentment quite

Sutra II.42: From contentment, unsurpassed happiness is gained.<sup>1</sup>

difficult to experience and could be a sign that Keegan is trying to find a way to connect with his infinite nature. At times, it seems to me that, ever since he was born, Keegan has been discontented with everything around him. I sometimes wonder whether it is his spiritual way of sharing with us the refusal of his present karmic life or maybe just a reflection of my own discontentment. Qualities such as love, patience and compassion can break through this shield of unhappiness by creating positive thoughts on how to be at peace with any situation at hand. This is reinforced through teaching him that resisting an experience actually reinforces the realisation of that experience. Paxton Robey reminds us of Jesus' words "Resist no Evil": "If it is true that reality is created by thoughts held in mind and emotions held in the body, what is created by being anti-war?"<sup>2</sup>

When we accept that we choose our experiences at a soul level and that the ultimate school (earth school) gives them to us as part of our karmic cycle, we learn to feel serene about them. Only then can we reach a state of happiness and peace. This dimension is very challenging but goes hand in hand with detachment (*aparigraha*) and non-violence (*ahimsa*) on the path to supreme bliss.

### **Tapas • austerity**

This *niyama* is an important parameter in the shaping of Keegan's personality

Sutra II.43: Through fiery aspiration and through the removal of all impurities, comes the perfecting of the bodily powers and of the senses.<sup>3</sup>

and strength of character. In this context, austerity is seen as the discipline that is necessary to work toward and achieve independence.

By drumming repetition into his daily routine in a gentle and caring but consistent manner, Keegan is learning to develop the courage and the fire needed to push himself toward his personal goals no matter what they are. As this powerful "burning" process is a gift from me to him, I need to carefully ensure to include temperance in my teachings to him. Combined with *dharana* and balanced by *santosha*, it becomes a valuable tool to teach Keegan equilibrium between his driving and steadying forces. Once counterbalanced, these forces will clear his way toward courage, wisdom, integrity and straightforwardness.

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<sup>1</sup> Ibid. p9.

<sup>2</sup> Robey, p20.

<sup>3</sup> Cited in Lawson, p10.

**Swadhyana • self-study**

Even though self-study involves the reading of

Sutra II.44: Self-study results in contact with the soul (or divine One).<sup>1</sup>

sacred scriptures, for which Keegan is too young yet, it also means the cultivation of the ability to read “energy patterns” in the self and others, to discriminate between the “not-I” and the transcendent Self (*Atman*).

For Keegan, it means discovering these energy patterns within his body, mind and emotions and how these forces interact with each other. Through his daily yoga routine, Keegan is learning to feel movements and shifts of energy within himself more importantly, but also within his surroundings. He is learning to observe these changes and adapt to them. This awareness is slowly bearing fruit as he is now spontaneously starting to apply his yogic experimental knowledge when required, for example to gauge people’s thoughts or emotions. This *niyama* works toward reinforcing the *asteya yama*; learning more about himself helps him find his identity within his environment.

**Ishwara pranidhana • self-surrender**

Surrendering to God or

*Brahman* is the culmination of our yoga practice. It is the reminder that, as we

Sutra II.45: From surrender to the Lord, the state of *samadhi* is perfected.<sup>2</sup>

choose our experiences at a soul level, we need to trust that these were chosen in full awareness of our Higher Selves, for the best of humankind evolution.

For Keegan, this translates into the challenge of accepting things as they are and learning to cope with frustration. It also means learning to live in the present moment and enjoying what that present moment has to offer. As Epicureans used to say: “Carpe Diem”<sup>3</sup>.

For his family and support network, it first involves accepting him as he is, but also supporting and encouraging him. Beyond that, it invites us to acknowledge the beauty of his soul.

Going a step further, we can all choose to transcend the *karma* that generated his birth by opting for happiness in every moment. When choosing happiness, we discard the guilt attached to *karma*, we become free to surrender to God and attain *samadhi*. When we surrender to God, we acknowledge our divinity. We understand that every part of our body, every plant, animal, object are expressions of God. We become All encompassing, we become One, reunited with our Creator.

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<sup>1</sup> Ibid. p11.

<sup>2</sup> Ibid. p11.

<sup>3</sup> Latin expression meaning ‘seize the day’.

## **Asanas**

A few years ago, when I started researching the benefits of yoga for Keegan, he already had a

Sutra II.46-48: The posture of yoga is steady and easy. It is realized by relaxing one's effort and resting like the cosmic serpent on the waters of infinity. Then one is unconstrained by opposing dualities.<sup>1</sup>

physiotherapy program, which I had compiled into a book, complete with pictures and which was being carried out by his team of helpers. Like most parents, I was actively looking for alternatives that may further support Keegan towards maintaining and developing his physical condition. Physiotherapy was a great tool but its main focus was physiological; exercises mainly concentrated on stretching and strengthening muscles. *Yogasanas*, like physiotherapy, also focus on stretching and strengthening muscles. Nevertheless, other aspects, like for example body awareness, attracted my curiosity and I soon became convinced that a yogic approach would add value to Keegan's exercise regimen.

### **1. Understanding movement**

At this point, I need to clarify how movements are generated, and how the process of movement affects people with Cerebral Palsy:

"When we signal our brain of the intention to perform a particular activity, the control centre instantaneously computes which joints need to move, in which order and sequence, and by how much, at the same time, of course, making all the other adjustments necessary to maintain our body in balance...

Our muscles work in patterns and the brain responds to our intention by making groups of muscles, not single muscles, work...

Normal postural tone provides the background on which movement is based, high enough to withstand gravity, but low enough for easy movement."<sup>2</sup>

The main characteristic of Cerebral Palsy lies in the damage to the nervous system: communication between parts of the nervous centres and its motor pathways is compromised, affecting postural control and the performance of particular activities.

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<sup>1</sup> Stoler Miller, p56.

<sup>2</sup> Finnie, pp47-50.

Practically this translates to the following challenges:

- ✓ increased muscle tone (spasticity): instead of a particular group of muscles working together to achieve a task, like standing up for example, **all** muscles contract to try to contribute to the task.
- ✓ anti-gravity flexor tone: reactions to master gravity. They can be either lacking or absent.
- ✓ equilibrium reactions: "their function is an automatic response to loss of balance, helping us to both maintain and regain our balance, thus making free and independent movements of the head and limbs possible in all positions."<sup>1</sup> These can be lacking or completely absent.
- ✓ saving reactions: automatic postural reactions to protect ourselves during very sudden or unexpected loss of balance, like thrusting out our arms with straight elbows to place our open hands on a supporting surface. These can either be absent, incomplete or exaggerated.

The unusual forces forming the patterns of spasticity "are applied over some joints and the increased tone of some muscle groups means that those muscles are never stretched or elongated by their antagonists<sup>2</sup> and a state of imbalance is created. Over a period of time, those muscles and their tendons which are hypertonic (spastic) lose their elasticity, as indeed does the tissue surrounding the joint over which they work."<sup>3</sup>

We are now able to understand the importance of stretching the agonist (contracting) muscles and supporting the antagonist muscles in their strengthening task.

As this hypertonic activity is at work twenty-fours a day, in most movements and intentions of movement (thoughts and emotions), counteracting its effects in terms of potential muscle contractures would need to occur for the same length of time, which is practically impossible if Keegan is to have any quality of life.

The yogic management of Keegan's health therefore involves a combination of carefully chosen *asanas* in order to stretch and strengthen specific muscles, applied with the specific goal of creating body awareness at all levels (physical, mental, emotional).

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<sup>1</sup> Ibid. p51.

<sup>2</sup> Antagonist muscles are muscles that oppose movements; agonist muscles are active muscles that contract and shorten.

<sup>3</sup> Ibid. pp257-258.

## 2. Stretching

Stretching can either be passive or active, the active action being more effective than the passive.

Nevertheless, as active stretches are for Keegan very difficult to perform, the first approach of yogic management concentrates on passive stretches. As reduced mobility stiffens muscles and joints, which in turn further reduce movements, a gentle daily stretching program practised first thing in the morning is paramount in order to maintain flexibility in his joints while carefully stretching and relaxing his muscles.

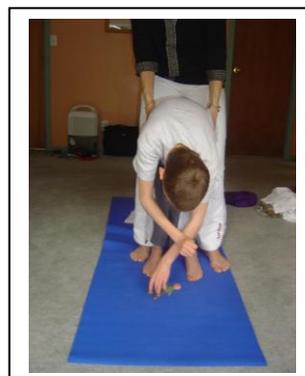
It is through my own practice of the *pawanmuktasana series* as described by Swami Satyananda Saraswati in his book "Asana Pranayama Mudra Bandha"<sup>1</sup> that I realised the potential benefits of such exercises for Keegan. Until then, Keegan's stretching routine mainly focused on his muscles. So it is with Keegan's level of abilities in mind that I designed his personalised program<sup>2</sup>, based on the *pawanmuktasana series*, which focuses on joints as well as muscles. *Pawan* means 'wind' or *prana*; *mukta* means 'release' and *asana* means 'pose'. Therefore *pawanmuktasana* means "a group of *asanas* that remove any blockages which prevent the free flow of energy in the body and mind."<sup>3</sup>

The results showed quite quickly; it only took a couple of weeks of daily practice to notice that his arms and legs had gained more range of movements.

Active stretches are also part of Keegan's daily routine, but they are more subtly included in his program. Every movement that Keegan makes towards his mobility can be used to actively stretch, like for example bending over to pick up a toy will actively stretch his hamstrings (picture 1). Another example is taking the opportunity of coming out of his standing frame to stretch his hip flexors (picture 2).



2



1

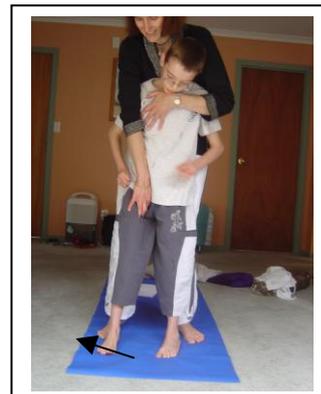
<sup>1</sup> Saraswati, *Asana Pranayama Mudra Bandha*, pp21-73.

<sup>2</sup> See Appendix 3.

<sup>3</sup> Ibid. pp23-24.

### 3. Strengthening

The stretching action of muscles needs to be balanced by some strengthening of different groups of muscles in order for Keegan to be able to hold his posture, build his balance and maintain equilibrium within his body. The muscles in need of strengthening are the muscles antagonist to those which are hypertonic. This means that these muscles help and promote the stretching action of the muscles in need of stretching and relaxing. For example, **side stepping** strengthens the gluteal muscles (gluteus medius and minimus), helping the adductors to stretch (picture 1).



1

Exercises are a combination of *yogasanas*, supported by props if need be, swimming and horse-riding therapy.

Lying prone on a wedge helps strengthen back and shoulders as well as stretch hip flexors (picture 2).



2



The gentle and rhythmic movements of the horse help relax the muscles (picture 3).

3

In the water, Keegan's movements are less affected by gravity, giving him more freedom and ability to independently stretch and strengthen his muscles (picture 4).



4

#### 4. **Body awareness**

The development of body awareness is an integral part of Keegan's independence. We have all heard "move it or lose it". Restriction of movements for Keegan entails limited awareness of the parts of his body that he is not able to move or move with difficulty. Subsequently limited awareness of these body parts engenders less mobility.

According to Michael Reed Gach, body awareness includes "intuition, mental attitudes, **physical** awareness, centering meditation, balancing pain and the emotions through the breath and awareness in daily life."<sup>1</sup>

Bringing awareness into Keegan's life is certainly the most rewarding aspect of my teaching. It requires presence, caring and patience. Physical awareness is, at this stage of his physical growth, a very important part of creating awareness, as posture and correct alignment are paramount for the integrity of his spine and the prevention of deformities. In order to develop this awareness, Keegan is learning his body parts, where they are, their function and how to centre himself.

It may be tempting to move his legs or arms for him while transferring from one place to another but, as Keegan is getting bigger and heavier, it is in fact a disservice. In the quest for his independence, letting him participate in meeting his own needs and initiate his mobility is central and respectful of the autonomous adult he will be one day.

As Keegan is not able to actively perform his daily *pawanmuktasana* routine, I 'practise' them for him, taking him through the movements while trying to create awareness and participation at a **physical** and **mental** level. To achieve this, I combine talking him through the practice and touching the parts of his body that need to move, strategically placing my hands and fingers on acupressure points to encourage deeper awareness and release of tension. Helping Keegan towards body awareness also encompasses teaching him to get in touch with his inner self and to trust his feelings, whether physical, mental or **emotional**. Learning to communicate with his 'teacher within' is a valuable source of constant information and wisdom for knowing himself and for letting go of rigidity and negativity of thoughts.

As Keegan's awareness grows, he is learning to extend and include his awareness into his daily life. He is often seen breathing in deeply in order to achieve mobility, to open his airways when wheezy or to relax.

The next stage of his awareness is to slowly turn some of his passive stretches into active ones.

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<sup>1</sup> Gach, p30.

## **5. Areas of Keegan's body requiring particular attention**

- 1) As the **spine** is the foundation of our body, I pay particular attention to its flexibility. "The nerves that go to all parts of our body and to all our internal organs branch out from the spinal cord. When any vertebra is out of position, it affects the nerves and muscles in the local area, and also the internal organs associated with it through the related nerves and meridians. Muscular tension will collect around the imbalanced area, and can ultimately cause back pain, and more severe back problems."<sup>1</sup>  
Being less mobile than an able-bodied person, Keegan does not get to involuntarily massage his internal organs as we do during the course of the day. So by systematically stretching his spine in all directions, I can help him release tensions and keep it properly aligned.  
As the neck and head are extensions of the spine, neck stretches are vital and form part of Keegan's daily routine. By freeing tight areas, they promote better flexibility, control and balance of his head.
  
- 2) "The **pelvis** connects the upper and lower body. It provides for a great range of body movement, with the overall posture of the body being determined by the position of the pelvis. Therefore, when the pelvis is pulled out of place or stagnated by tension, the whole body is affected. Conversely, if the posture of another part of the body is poor, the pelvis cannot properly do its job of distributing the body weight, and muscle strain and joint tension in the pelvic region can result. Approximately 36 muscles attach to the pelvis; they act together to stabilize the pelvic girdle in relation to the spine."<sup>2</sup>

Within the pelvis lie the hips, which are constantly being put under strain due to the unusual forces mentioned before. The hip joint is a ball-and-socket joint. The socket (acetabulum) lies in the pelvic bone and is flatter in shape during infancy. It only truly becomes a socket as the child begins to take weight through the joint.

At the age of ten, Keegan has already undergone major hip surgery as well as two interventions of Botox<sup>3</sup> injections, in order to protect his hips and prevent dislocation. So, ensuring flexibility of his hips through the prevention and the removal of blockages is vital for his mobility. Developing strong hips is achieved through as much weight bearing as possible (buddy walking as seen on the front cover of this paper, walking frame and standing frame).

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<sup>1</sup> Ibid. p34.

<sup>2</sup> Ibid. p206.

<sup>3</sup> Botox is injected in a muscle as a relaxant; the effect lasts about three months, during which rehabilitation takes place. In children with Cerebral Palsy, it is not cosmetic but a way to stretch some particular muscles and therefore prevent or delay surgery.

At a psychic level, as the sacral *chakra*<sup>1</sup> (*swadhisthana chakra*) dwells within the pelvis, learning to manage the flow of energy around it would enhance the notion of self-acceptance attached to this *chakra* and help him deal with tightness or blockage in that area.

- 3) The more a muscle is involved in movement, the more it contracts and as a result, the more it becomes susceptible to develop contractures. Particularly at risk are: biceps, hamstrings, gastrocnemius, quadriceps and adductors. Keeping these muscles flexible is a never-ending challenge, which is addressed through active and passive stretching, strengthening of antagonist muscles and correct positioning in equipment.



Sitting on a bolster enables Keegan to play while stretching his adductors and strengthening his upper body.

His muscles get further attention as Keegan treats himself, about once a week, to a deep-tissue massage (touch adapted to his needs), performed by a qualified massage therapist. It provides a precious opportunity to address physiological blockages and ensure that permanent misalignment and pain do not settle.

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<sup>1</sup> "In yogic context, *chakras* are vortices of *pranic* energy at specific areas in the body which control the circulation of *prana* permeating the entire human structure. Each *chakra* is a switch which turns on or opens up specific areas of the brain." (Saraswati, p513).  
 "Chakras are connected to the functions of the physical body primarily through the endocrine glands and the spinal system. They mediate the energy within and without the body through the various spinal contacts. Distribution (of energy) occurs throughout the body by means of the nerve pathways and the circulatory system. In this way all of the organs, tissues and cells receive the energy for their various uses." (Andrews, p37)

## **Pranayama**

### **1. Understanding the role of the breath in our development<sup>1</sup>**

Respiratory development is fundamental to the development of structure, function and cerebral metabolism in children.

After birth the internal pressures from the baby's breathing begins a lifelong process of muscle strengthening and the establishment and maintenance of neurological connections between the brain and the body's tissues. Increasing respiratory strength develops the muscular skeletal infrastructure of our trunk, which in turn supports each stage of functional ability. The strength of the respiratory muscles creates increasingly strong pressures on the pre-capillary sphincter muscles. This increases capillary blood flow, strengthening muscle tissue and improving their electrical connection in the brain. Respiratory muscle pressure during breathing develops and supports blood flow to trunkal and connective tissues between the bones.

Before and after birth and throughout infancy individual muscles and co-ordinating groups of muscles are stimulated in stages by gentle pressures from the external forces that surround them. This external stimulation enhances blood flow to the muscles. Increased blood flow creates an enhanced electrical current like a louder voice that can be picked up by the brain. Only when the brain can identify the muscle's existence and whereabouts can a command signal be sent from the brain and received by the muscle.

### **2. Keegan's breathing pattern**

Children with neurological impairments do not learn to breathe normally and this affects the complex metabolic feedback systems between the body tissues, the bones, the respiratory system and the brain.

Keegan's breathing is superficial and shallow, located in the upper lobes of his lungs, as if the tightness around the abdominal area<sup>2</sup> is squeezing the air out of his lungs, exaggerating the overall tightness of his body. This is called paradoxical breathing; the abdominal wall moves in rather than out during inhalation and moves back out during exhalation.

Some people breathe like this all the time, unaware that its purpose is to prepare for fight or flight. For example, we may suck our stomach in if we hop in a cold shower expecting the water to be warm. Paradoxical breathing gives us an immediate jolt of adrenaline. Breathing like this keeps our sympathetic system continuously activated. It puts undue stress on the supportive systems of our body (digestion, circulation, endocrine, immune...) and creates anxiety. Thoughts and emotions aggravate this pattern, as well as illnesses, which interestingly mostly seem to settle in Keegan's lungs.

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<sup>1</sup> Information collected on the website of the Institute for Advanced Neuromotor Rehabilitation. [www.advancecentre.org.uk/index](http://www.advancecentre.org.uk/index).

<sup>2</sup> Due to unusual forces of the numerous pelvic muscles.

### 3. Yogic management

Establishing healthy complete (full) breathing is fundamental and complementary to Keegan's physical program. Expanding his breathing to the central and lower lobes of his lungs initiates the development of stronger respiratory muscles. Stronger respiratory muscles strengthen the connective tissues between the spinal vertebrae and the shoulder and pelvic girdles which then respond increasingly to signals from the central nervous system.

Fortunately, apart from the most basic reflexive breathing, breathing is a learnt behaviour.

The first step is for Keegan to become aware of the muscle tone affecting his mouth muscles, tightening and protracting his upper lip, rendering full lip closure tricky. This process is being helped through massaging, positive reinforcement while eating and games (blowing or playing the recorder).

The second step is to create awareness of his breath in his abdomen in order to develop a good habit of the complete yoga breath. This is achieved by teaching him to observe my own breathing, listen to my explanations and by the touch of my hand on his abdomen and his hand on my abdomen. This way, Keegan is learning to feel the movements of his breath up and down his lungs.

Being able to direct his breath where tensions are empowers Keegan to have more control over his muscles. He can relax them either to facilitate his mobility or to induce pure relaxation in response to physical, mental or emotional tension build-ups.

Thanks to abdominal breathing, Keegan is learning to increase his lungs' capacity. This in turn has a positive effect on the movements of the various *pranas* within his body (for example: it relieves constipation).

Regulating the breath also increases oxygenation of the brain cells, which strengthens the central nervous system and builds up his immune system, making him more resilient to illnesses.

Keegan is currently learning *kapalbhati* and *bhastrika pranayama*<sup>1</sup>. They are both highly energising and strengthen the abdomen. *Kapalbhati* clears and energises the mind and prepares it for meditation. It cleanses the lungs (useful in the treatment of asthma and bronchitis) and balances and strengthens the nervous system. It tones the digestive organs. *Bhastrika* also cleanses the lungs by alleviating inflammation in the throat and accumulation of phlegm, but its main action is to stimulate the metabolic rate through increased oxygenation, producing heat and flushing out wastes and toxins. It saturates the lungs and blood with fresh oxygenated air, strengthens the diaphragm and increases circulation.

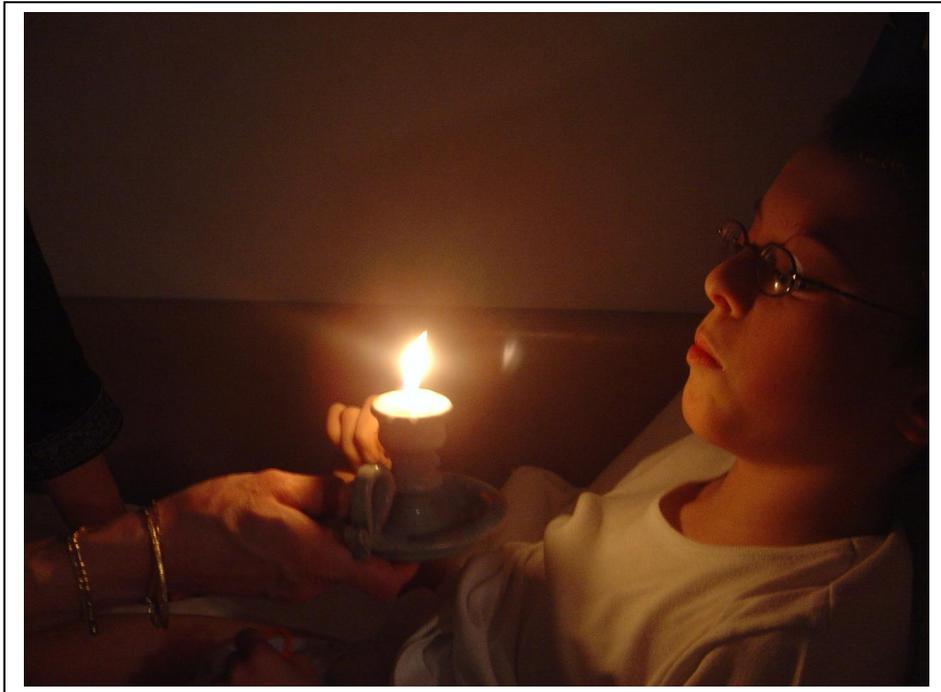
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<sup>1</sup> For more information on these practices, read Saraswati, *Asana Pranayama Mudra Bandha*, pp394-400.

I am also progressively introducing him to *viloma pranayama*<sup>1</sup>. This practice cultivates greater lung capacity and elasticity and promotes extension of the breath. This is achieved through the interruption of the flow of the inhalation and/or the exhalation.

I have tried to teach him *ujjayi pranayama*<sup>2</sup> for its calming effect but it seems too challenging at this stage. As for most teaching, repetition is the key. I have no doubt that Keegan will manage to learn this breath if he feels the need for it.

When sick, Keegan often gets asthma. To help him calm down and regulate his breathing, he blows on a candle with the aim of not blowing it out, as seen in the picture below. This has the effect of lengthening his exhalation, which helps the expelling of carbon dioxide out of his lungs (as well as mucus), therefore also easing his inhalation.



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<sup>1</sup> For more information on *viloma pranayama*, read Somerville, p52.

<sup>2</sup> For more information on *ujjayi pranayama*, read Saraswati, *Asana Pranayama Mudra Bandha*, pp392-393.

## **Pratyahara**

"Some old Yoga texts refer to the mind as a 'cage full of excited monkeys'. The conscious regulation of the mind-stuff, as illumined by the soul, is the real 'work' of Yoga."<sup>1</sup>

Keegan has come a long way in learning to cope with the over-stimulation of his senses. He used to hyper-extend when going out in the brightness of the sun or cry when listening to classical music. High-pitched voices or sudden sounds would make him jump, frighten and unsettle him.

This sensibility is still apparent through the expression of his emotions, which bears a considerable impact on his management of external stimuli. Interestingly, David Coulter mentions the existence of the **enteric** nervous system and the possibility of connections between this system and our emotions.<sup>2</sup>

So, strengthening his nervous system through a daily yoga practice has a definite and positive influence on reducing the sensibility of his sensory receptors, building a strong base for him to learn to detach himself from his senses when needed. It is a challenge that he is progressively overcoming, thanks to his increased body awareness.

In order to help him experience sense withdrawal, or when over-stimulated and excited, Keegan is encouraged to use his breath to relax body, mind and emotions. As he experiences spasticity in all his movements as well as in his intentions of movement (thought) and expression of his emotions, relaxation plays an essentially regulatory role in restoring homeostasis in his body. Touching the parts of his body holding tension gives signal to his brain (through the muscle) to let go and relax. Thanks to receiving numerous 'Touch for Health'<sup>3</sup> massages, I have learned to instinctively identify or feel these tensions and apply my 'hands of light'<sup>4</sup> where necessary.

Whenever possible, and sometimes once a day, Keegan is taken through a twenty-minute relaxation practice just before going to sleep.

As Keegan's mental agitation is continuous, he needs his focus to be channelled to more peaceful and calming places. I find music to be the most effective tool to achieve complete relaxation.

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<sup>1</sup> Dye, p37.

<sup>2</sup> "The enteric system, part of the autonomous nervous system at the same level as the sympathetic and parasympathetic system, is comprised of the vast system of nerve cells that resides in the wall of the gut (by definition, the entire digestive tube from the oral cavity to the anus). Neuroscientists nowadays know that it is capable of supervising the digestion of food, the propulsion of food through the bowel and the management of all other bowel functions, even when all nerve connections from the brain and spinal cord have been experimentally severed." (Excerpt from Coulter, pp560-561)

<sup>3</sup> Type of deep tissue massage promoting lymphatic drainage.

<sup>4</sup> For more information on 'hands of light', read Brennan.

Taking him through a relaxation session involves a combination of 'Touch for Health' massage<sup>1</sup> and soft and transcending music (his favourite is listening to a compilation of three Ave Marias<sup>2</sup>). He usually rests in *advāsana*, as seen in the picture below, with a pillow under his chest. Lying prone is highly beneficial for Keegan as it inhibits spasticity, promotes opening of his chest and relieves stiffness in his neck.



Regular touch relaxation sessions, besides creating muscle awareness and promoting the release of tensions, also have the benefits of alleviating cramps and stimulating the flow of blood throughout the body.

It is so relaxing that he sometimes falls asleep...

When preparing himself to go to sleep, Keegan always listens to his relaxation compact discs, specifically designed for children<sup>3</sup>.

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<sup>1</sup> See Appendix 4 for an example of Touch Relaxation.

<sup>2</sup> See bibliography for reference.

<sup>3</sup> See bibliography for references.

## **Dharana**

"Concentration is the fixing of the mind-stuff upon a particular object."<sup>1</sup>

Stilling the mind is the goal that is attainable through concentration. Concentration exercises are known for relaxing the skeletal muscles and for letting the autonomous nervous system manage the internal organs and tissues of the body without the necessity of conscious input<sup>2</sup>.

Concentration is a recognised issue amongst ex-preterm babies, probably due to the hypersensitivity mentioned in the previous section (*pratyahara*) and the challenge of being aware of the different parts of the body. Keegan can be extremely focused on some matters that are of high interest to him but he can be obsessed with them, to the exclusion of anything else. After repetitive efforts from his entourage, he almost reluctantly lets go and then tries hard to disconnect from the obsessive thought.

To teach him concentration, I use the ABC technique created by my friend Trish Dye: A for alignment, B for breath and C for concentration. It involves regularly reminding Keegan of his ABC: standing up straight in his standing frame, breathing patterns while doing *asanas*, focusing on what he can do to help his helpers with transfers between pieces of equipment (like grounding his legs, correcting his balance...), paying attention to the colour and texture of the food he is eating...

On the mental and emotional levels, increased concentration manifests itself in the ability to control his thoughts and emotions through detaching himself from worrying consequences and to transmute negativity into creative activity. Affirmations and *mantras* are a great way to break through his circles of negativity.<sup>3</sup>



According to Yogananda, concentration of human thought and will acts on the cells of the body: "Concentrated human thought touches Divine Thought; it is that which can heal, not unfocused fanciful thought or imagination."<sup>4</sup>

5

<sup>1</sup> Bailey, A. Cited in Dye, p38.

<sup>2</sup> For more information, read Coulter, p562.

<sup>3</sup> For more on affirmations, read Hay, L.

<sup>4</sup> Yogananda, p334.

<sup>5</sup> Photo from: [www.flickr.com/photos/untitlism](http://www.flickr.com/photos/untitlism).

## **Dhyana**

"Sustained concentration (*dharana*) is meditation (*dhyana*)".<sup>1</sup>

"The ultimate aim of the meditator is to be able to hold steady focus and mental poise under every kind of condition in daily life."<sup>2</sup>

This is a challenge in itself, but I find that music therapy is actually promoting a prolonged state of concentration in Keegan.

On a more practical level of his everyday life, I am trying to introduce the practice of *sati*<sup>3</sup>. This helps him deal with negative thoughts and emotions through observing an upsetting situation without reacting to it. It teaches him to accept and welcome life experiences for what they are, to appreciate the present moment and to 'be in the now'.

## **Samadhi**

Besides the fact that Keegan's

"Pure contemplation is achieved when the meditative subject is so absorbed in the object of meditation that the distinction between subject and object disappears."<sup>4</sup>

impairment makes him stand out in a crowd, his whole persona attracts people like a magnet. His soul radiates with beauty, originality and authenticity. "He has been here before" some kindred spirits say. He is an old soul and brings to the world experiences from his past lives with him.

According to Acharya Ram Sivan, the term *samadhi* can either refer to a state of being or to the practice that leads to it. Technically speaking, *pratyahara* and *dharana* are 'practices', while *dhyana* and *samadhi* 'happen'.<sup>5</sup>

Keegan's little steps toward self-realisation can truly be seen when he listens to music. As an indigo child<sup>6</sup>, he lives and feels music. He seems to 'disappear' in another world, entirely absorbed in the melody and merged with the music, synaesthetically<sup>7</sup> experiencing it. His sensitivity to music is so intense that he even senses disturbing sounds before they occur (e.g. a scratch on a record) and startles to them as they happen.

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<sup>1</sup> Bailey, A. Cited in Dye, p41.

<sup>2</sup> Dye, p41.

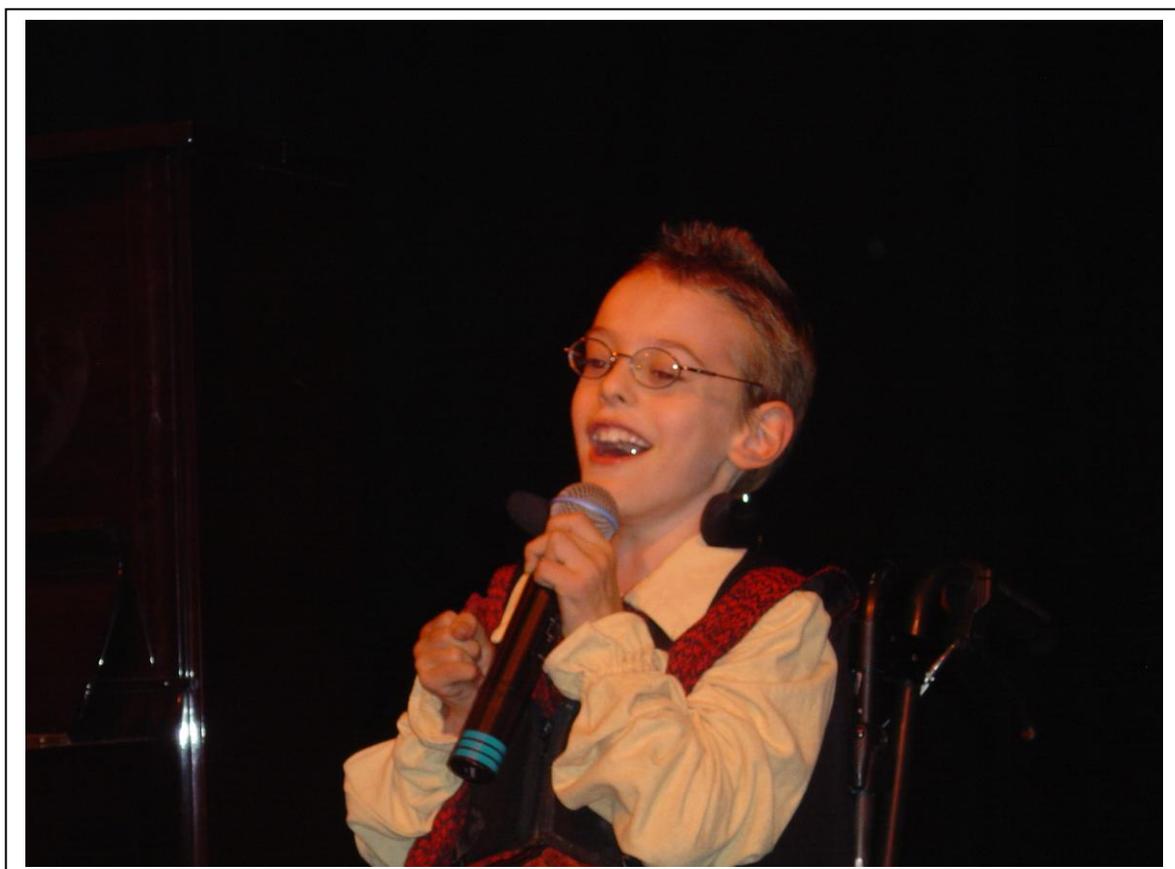
<sup>3</sup> *Sati* consists in the bare noticing of the object of attention, whatever it may be. It is pure Awareness.

<sup>4</sup> Stoler Miller, p61.

<sup>5</sup> Sivan, p4.

<sup>6</sup> Newly evolved child. For more information, read Lee C.

<sup>7</sup> Visualising music as it is being played.



Keegan performing on stage in a concert organised by his singing teacher Lisa Lorrell - December 2004

## **YOGA** **AN APPROACH FOR PARENTS**

Physical well being is inseparable from emotional well being. Happy people are healthy people. The wisdom traditions of the world tell us that happiness does not depend on what you have, but on who you are.<sup>1</sup>

As research about parental stress seems to indicate<sup>2</sup>, raising a child with a disability can generate a lot of stress. It certainly did for me (hyperventilation, depression...), until I felt myself spiralling out of control. Being the buffer between the outside world and Keegan's world was very painful and isolating as I felt that no one understood our needs and who we had become. Finding equilibrium under these circumstances was almost impossible...

Nevertheless, my re-acquaintance<sup>3</sup> with yoga a few years ago clearly made me understand that the source of my stress was not Keegan's impairment but rather the pressure from the outside to conform to a society that ruthlessly caters for the fittest and the strongest.

Through understanding the yogic principle of Oneness, I find the courage and strength to let go of the struggle; living with a disability does not need to be a battle. All these years of grieving and unhappiness made me overlook the fact that Keegan is my child before being disabled and that he deserves the right to be seen as such. I continuously seek and discover in myself the refreshing and renewed energies of caring, love, wisdom and compassion. I finally find a way to accept the reality of our situation and even more, I am now grateful for the richness and beauty of our experience. I would not want my life to be any different.

However, I still 'hold on to' physical pain, which I create in the process of physically helping Keegan. I deal with it thanks to my regular *yogasana* practice and with the support of deep relaxation and meditation techniques. These involve the process of first acknowledging the pain and recognising which thoughts or emotions are attached to it. Then comes acceptance: being with the pain, feeling it and smiling interiorly at it before ultimately letting go of the physical tightness at the same time as all mental and emotional tensions attached to it.

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<sup>1</sup> Chopra D. Cited in [www.images.meadigital.com/users/chopra/namaste\\_August2006](http://www.images.meadigital.com/users/chopra/namaste_August2006).

<sup>2</sup> See Appendix 2.

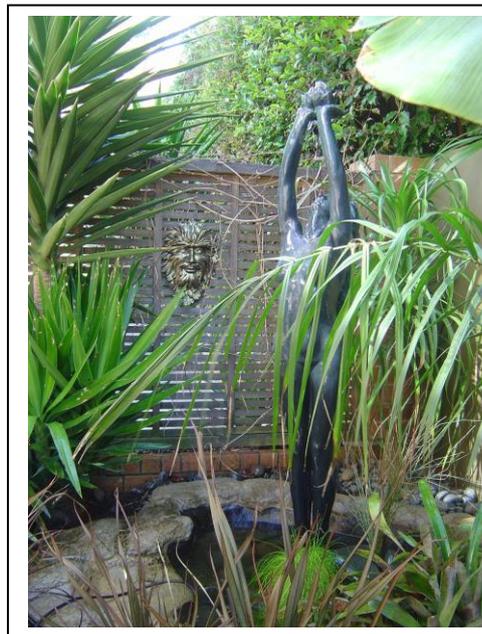
<sup>3</sup> My parents started teaching me yogic principles when I was a toddler. My yogic awareness became dormant during my younger adult years, despite numerous synchronistic events like meeting Swami Satchidananda in 1991, and the same year receiving for my birthday a life-size original picture of Gandhi while I was working in Baghdad, Iraq.

For me, yoga has opened the door to my dormant potential. My daily yoga practice of Patanjali's eight limbs is purifying my body, mind and soul. It is continuously activating my *chakras* and is now an integral part of me. Nourishing myself with ancient texts like the Bhagavad Gita makes walking on the path of selfless service an easier matter.

I also keep in mind the teachings of the now famous American movie "What the Bleep Do we Know"<sup>1</sup>: reality is a question of personal perception. I relate to Keegan according to my perceived reality, which may not be in full accordance to his. I learn everyday to become more perceptive of his vision of life and ask him for forgiveness for any misunderstanding or hurt from my part.

As a testimony and encouragement for the future, Keegan has been seizure free for ten months, since I started to act from my heart rather than my head<sup>2</sup>.

Help carries more healing when it comes from the heart, as it is the place from which love and compassion freely flow.



Garden Inspiration<sup>3</sup>

"Learn now that sacrifice of any kind is nothing but a limitation imposed on giving. And by this limitation you have limited acceptance of the gift I offer you."<sup>4</sup>

<sup>1</sup> What The Bleep Do We Know. [www.whatthebleep.com](http://www.whatthebleep.com).

<sup>2</sup> According to L. Hay, the probable cause for epilepsy is: rejection of life; running away from the family or the self, a feeling of great struggle. (Hay, pp 167 and 197).

<sup>3</sup> Author's garden.

<sup>4</sup> Et. al., p324.

## **CONCLUSION**

The main goal of my teaching with Keegan is to help him find a place of stillness where he can gain more control over his physical, mental and emotional states, therefore encouraging his independence. This teaching involves patience, discipline and perseverance. It is very subtle and has become an integral part of his daily life. It is my gift to him.

A combination of conventional and holistic therapies like yoga, acupuncture, massages and swimming are approaches that I have found very helpful and successful in dealing with the challenges of his impairments (Cerebral Palsy, epilepsy, Asperger's Syndrome).

More specifically, the application of yoga through Patanjali's Eight Limbs is playing a major role in establishing a strong developmental foundation, providing me with the tools that I need to support Keegan towards achieving independence. Instead of the traditional medical approach of each symptom and impairment, yoga enables me to synthesise my previous teachings to him into a sturdy reference base, which I am continuously building on as I explore and discover new ways of promoting his independence.

As Keegan is learning to integrate these ideas (adapted to his age), he is developing a sense of discrimination as well as creative ways of independently finding solutions to his personal challenges.

Working on removing blockages with the help of *asanas* and *pranayama* techniques, Keegan has been able to maintain range of movements in his muscles as well as improve his mobility. Relaxation, better control of his breath and the use of affirmations have strengthened his immune system (he is not sick as often as he used to be and has been seizure free for almost a year). The development of his concentration skills is making him more aware of his body, mind and emotions, helping him to acquire the necessary life skills to become more independent.

Integrating the *yamas* and *niyamas* into our daily life is now bringing a sense a security, self-confidence and equilibrium in our family where stress had previously ruled our lives. We are learning to observe and highlight what really matters: awakening Keegan to his potential in the most loving and compassionate way. Along with Patanjali's other limbs, they contribute to peace and unity within our family, and more importantly they proactively support Keegan's journey towards independence.

## GLOSSARY OF SANSKRIT WORDS

advasana	reversed corpse pose
ahimsa	non-violence
aparigraha	non-possessiveness
asana	posture
asteya	non-stealing
Atman	essence, god in us
bhastrika pranayama	bellows breath
brahmacharya	continence, non-gratification
Brahman	God in the universe (encompassing <i>Atman</i> )
chakra	wheel
dharana	concentration
dhyana	meditation or pure contemplation
ishwara pranidhana	self-surrender
kapalbhati pranayama	cleansing breath
karma	effects of past actions, from this or previous lifetimes
kosha	body
mantra	divine sacred word or sound
maya	Illusion of separation
nadi	energy channel
niyama	observance
prana	vital energy, life force
pranayama	control of the life force
pratyahara	withdrawal from the senses
samadhi	meditative state of union with the Absolute which we attain when we completely surrender to <i>Brahman</i>
samadhi	self-realisation
santosha	contentment
sati	bare attention
satya	truthfulness
saucha	purity
sutra	aphorism
swadhyana	self-study
tapas	austerity, ascetic practice
ujjayi pranayama	psychic breath
viloma pranayama	breath that goes against the flow
yama	abstinence
yoga	to yoke

## **Appendix 1: Hyaluronan Accumulates in Demyelinated Lesions and Inhibits Oligodendrocyte Progenitor Maturation**

### **NEW RESEARCH OFFERS CLUES TO PREVENT BRAIN DAMAGE IN PREMATURE BABIES**

#### *Factors inhibiting the brain's natural self-healing process identified*

Factors that inhibit the brain's natural self-healing process and that may offer new insights into how to prevent brain damage in premature babies have been identified by a team of researchers supported in part by the March of Dimes. The research is published online today in Nature Medicine.

Stephen A. Back, M.D., Ph.D., an Associate Professor of Pediatrics and Neurology at the Oregon Health & Science University School of Medicine, Portland, and colleagues identified some of the key factors that prevent brain damage repair in premature babies and patients with multiple sclerosis (MS) or certain other neurological diseases. Their findings offer important clues about why the nervous systems fails to repair itself and suggest that some forms of brain damage could be reversed.

Dr. Back, who studies developmental brain injury in premature infants, previously found a link between damage to white matter in the brain associated with premature birth, and damage to immature cells in the brain and spinal cord, called oligodendrocyte progenitors. These cells normally mature to become oligodendrocytes that make myelin (the insulating sheath surrounding nerve fibers in the brain and spinal cord) throughout life. In some cases, these cells fail to mature and cannot repair damage to the white matter of the brain.

The white matter is made up of long nerve fibers wrapped in myelin. Different kinds of white matter injury cause cerebral palsy and learning problems in children born prematurely, and MS in older children and adults. Dr. Back and his colleagues found that hyaluronic acid (HA) prevent immature oligodendrocytes from maturing and coating nerve fibers with new myelin. Astrocytes, the first-responders to nerve damage in the brain, produce HA, which accumulates on nerve fibers where myelin is missing.

**"Preterm birth can interrupt the normal myelination process. Therefore, this report may help to explain the brain damage seen in premature babies, some of whom have cerebral palsy,"** said Michael Katz, M.D., Senior Vice President for Research and Global Programs at the March of Dimes, which is supporting Dr. Back. "Until we find the answers to preventing prematurity, research such as this may lead us to new ways to prevent brain damage and has the potential to improve the lives of thousands of infants."

Prematurity is the leading killer of America's newborns and has increased 29 percent since 1981. More than 470,000 babies are born prematurely each year in the United States. Premature babies often die or suffer lifelong consequences,

including cerebral palsy, mental retardation, chronic lung disease, blindness, and hearing loss.

**According to research conducted by the National Institute of Child Health and Human Development, 25 percent of extremely premature babies have neurological problems at 18 to 22 months, and 17 percent will develop cerebral palsy.**

"Hyaluronan Accumulates in Demyelinated Lesions and Inhibits Oligodendrocyte Progenitor Maturation," published in the September 2005 issue of Nature Medicine, volume 11, number 9, was a collaborative effort of Dr. Back, senior researcher Larry Sherman, Ph.D., an Adjunct Associate Professor of Cell and Developmental Biology, OHSU School of Medicine, and other colleagues at OHSU, the National Institutes of Health, and the Cleveland Clinic Foundation.

08/07/05

(Neonatology and Rights of Families, TEMP NAROF Mailing List  
[rcrother@bigpond.net.au](mailto:rcrother@bigpond.net.au), Tue June 6)

## **Appendix 2: "Stress for parents of premature babies"**

NEW YORK (Reuters Health) - An early-intervention program can significantly reduce parents' stress after the birth of a preterm infant, according to a study conducted by researchers in Norway.

**"Mothers and fathers of preterm infants experience a sustained increase in parenting stress"**, Dr. Per Ivar Kaaresen from the University of Tromso told Reuters Health.

Kaaresen and colleagues evaluated the impact of an intervention program by randomly assigning 146 parents of preterm infants to the program or to a comparison 'control' group.

The program consists of several sessions. The first is designed to allow the parents to "vent experiences from the hospital stay and possibly their feelings of grief."

Thereafter, the sessions aim to "enable the parents to appreciate their infant's unique characteristics, temperament, and developmental potential." The parents are taught to recognize their infant's signs of distress or stimulus overload or readiness for interaction, and to respond appropriately.

The preterm intervention group had significantly better stress scores at 6 and 12 months compared with the preterm control group -- regardless of the prematurity of the baby, mothers' and fathers' education or income, or number of older siblings -- the team reports in the journal *Pediatrics*.

"Because some studies have shown that parenting stress is a risk factor for later behavioral problems in both preterm and other children, the reduction in parenting stress during the infant's first year of life may potentially be an important factor in reducing long-term behavioral problems in these infants," the investigators conclude.

"We think that reduced parenting stress is a benefit for the parents by itself, although the effects on childhood development are still not clear," Kaaresen said. "We plan to examine the role of early parenting stress on later potential behavioral problems and the effects of reduced parenting stress on later development."

SOURCE: *Pediatrics*, July 2006.

(Neonatology and Rights of Families, TEMP NAROF Mailing List  
[rcrother@bigpond.net.au](mailto:rcrother@bigpond.net.au), Thu Jul 13)

### Appendix 3: Keegan's daily routine

A close-up photograph showing a person's foot being held by two hands. One hand is positioned at the base of the foot, while the other hand is at the toes, pulling them towards the heel to demonstrate toe bending.	A photograph showing a person's ankle being held by two hands. One hand is on the heel, and the other is on the front of the foot, pulling it towards the knee to demonstrate ankle bending.	A photograph showing a person's ankle being held by two hands. One hand is on the heel, and the other is on the side of the foot, rotating it to demonstrate ankle rotation.
Toe bending (Padanguli Naman)	Ankle bending (Goolf Naman)	Ankle rotation (Goolf Chakra)

A photograph showing a person's knee being held by two hands. One hand is on the knee, and the other is on the lower leg, pulling it towards the chest to demonstrate knee bending.	A photograph showing a person's knee being held by two hands. One hand is on the knee, and the other is on the lower leg, rotating it to demonstrate knee rotation.
Knee bending (Janu Naman)	Knee rotation (Janu Chakra)

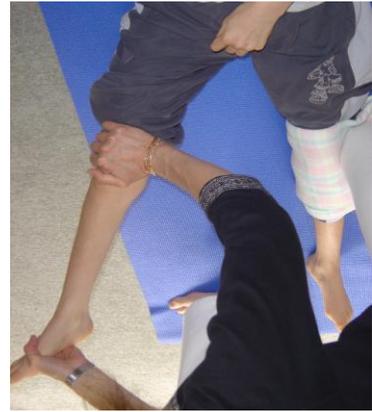
A photograph showing a person in a cycling pose (Pada Sanchalanasana). The person is lying on their back with their legs raised and bent at the knees, held by two hands.	A photograph showing a person in a raised legs pose (Utthanpadasana). The person is lying on their back with their legs raised and bent at the knees, held by two hands.
Cycling (Pada Sanchalanasana)	Raised legs pose (Utthanpadasana)



Half butterfly  
(Ardha Titali Asana)



Hip rotation  
(Shroni Chakra)



Leg rotation  
(Chakra Padasana)



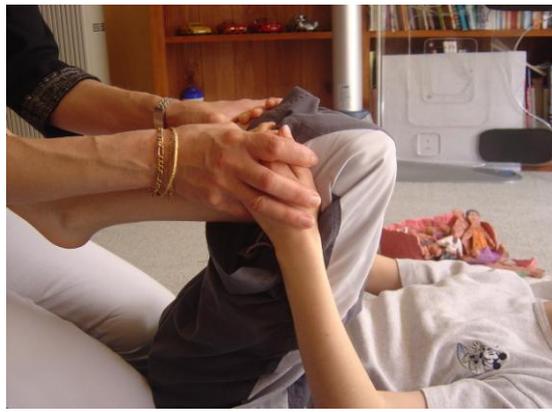
Full butterfly  
(Poorna Titali Asana)



Leg lock pose  
(Supta Pawanmuktasana)



Rocking and rolling  
(Jhulana Lurhakasana)



Sacral massage



Dynamic spinal twist  
(Supta Udarakarshanasana)



Universal (static) spinal twist  
(Shava Udarakarshanasana)



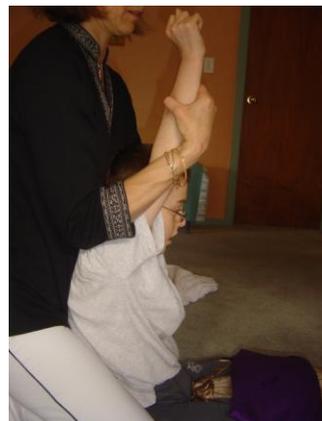
Spine stretch



Lateral stretch



Seated forward fold  
(Paschimottanasana)



Spine extension



Wrist rotation  
(Manibandha Chakra)



Wrist bending  
(Manibandha Naman)



Elbow rotation  
(Kehuni Chakra)



Elbow bending  
(Kehuni Naman)



Shoulder rotation  
(Skandha Chakra)



Neck movements  
(Greeva Sanchalana)  
Stage 1  
Back and forward



Neck movements  
Stage 2  
Chin right to left



Neck movements  
Stage 3  
Ear touching shoulder



Eye movements



Tadasana and side stretching



Sphinx asana



Cat stretch pose  
(Marjari asana)



Camel pose  
(Ushtrasana)



Child's pose

## **Appendix 4: Touch Relaxation**

To promote energy flow and relaxation.

Excellent for joint problems such as arthritis or broken bones, after being seated for long periods and general stress.

Can be done with client in chair or lying on floor with shoes (and socks) off.

1. Start behind client and gently brush their brow from centre to outside x3
2. With client's eyes closed lightly brush across eyes x3.
3. Place hands on top of head and brush down, around the ears and lightly tug the ear lobes x3.
4. Starting at the chin brush the jaw and up behind the ears.x3
5. Move to client's left (if they are seated support their arm). Brush from shoulder to inside client's elbow x3.
6. Brush from elbow to the palm of the hand. X3.
7. Massage palms and fingers – massage each joint and pull the energy off by Grasping each finger with own fingers and sliding your fingers off the end of client's finger
8. Remove energy from suprasternal notch by a grasping movement with hand.
9. Lightly brush down the sternum to the waist and over to the left side you are working on (lifting their arm out the way if necessary) x 3
10. Brush from the hip joint to the back of the knee. X 3
11. Brush from the outer knee to the inner arch of the foot. X 3
12. Massage toes and foot.
13. Grasp each toe with fingers and lightly tug to remove excess energy.
14. Move to the right side and repeat steps 5 to 13.
15. Using the side of the hands, use a light chopping motion to break up the energy on the shoulders and brush off .
16. Ask client to sit up, if sitting lean forward. Lightly brush back beginning at the coccyx and on either side of the spine. Continue to the neck, and then brush across the shoulders.

*Rosemary Weaver*

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*"A most useful paper for yogis, yoga teachers and anyone coming into daily contact with disabled people. It is a reflection of two yoga journeys, Franky's in accepting and working with what is and seeing the potential for more; and Keegan's journey of developing awareness and strength. Thank you Franky. You are an awesome yogi!"*

Jenny Fellows, research paper tutor for the IYTA (N.Z.) Inc.

*"Franky, this is a beautifully presented paper. It is well thought out, with a logical development of your theme. You have included a lovely programme, with photographs, which will be very useful to many people I am sure."*

Anne Scott, course tutor for the IYTA (N.Z.) Inc.

*"I read your paper, which I really enjoyed. It was beautifully written and described yoga in relation to you and Keegan very nicely. It was very touching really. Not just words and facts but lots of soulful emotion as well. I certainly understand now how much more yoga offers you and Keegan than just physical components like stretching and strengthening solely. Great job, it is an excellent resource and confirms the many benefits of yoga practice."*

Colleen Remus-Bodle, physiotherapist.

*"You are such a gifted writer! ... Expressing your views and feelings so exquisitely. How lucky is your son!"*

Louise Wiggins, AUA, Dip T, IYTA Dip, SAIYT Dip.

*"You are a tower of inspiration...people will see it ...some just not now ...much love to you..."*

Pat Armitstead, Joyologist.

*"Beautifully said Franky. It's a quality that bursts forth from you."*

Adrian Daly, teacher and national president for the IYTA (N.Z.) Inc.