

## Laryngectomy Dhamma.

Hello again! First an update: I'm living in my own home again – just came back last week. Many thanks to all my friends and family for helping me get this far, and especial thanks to Margaret and Pat with whom I have been staying since I left hospital in September. For their friendship, tireless care, encouragement and quiet, unfussy kindness, I am truly grateful.

What follows is another reflection on life since my laryngectomy (removal of the vocal chords) last July.. This time I'm going to explore my experience of living without my natural voice. I'm only scraping the surface of this teaching. In fact this essay is my first attempt to reflect on the experience. But for what it's worth ... here goes.

At many levels its easier than I could have imagined. Like the way shopkeepers hardly bat an eye when I write on the whiteboard instead of asking them verbally for what I want. Texts and emails still work fine. And among friends, when discussions get deep, the slow pace of writing can be OK. It gives time for relaxation and reflection by contrast to the fast pace of speech. And at times it can be great to be able to take a back-seat and listen to conversations without any pressure to contribute. Once, when someone came to dinner and I was exhausted by the effort before we even sat down at the table, I felt so relieved to be able to stall the pace, writing slowly, giving myself time to take a few breaths and recover some good humour.

I'm still using the whiteboard for many interactions – only beginning to attempt the electro-larynx in public though using it more and more among friends and family. The electro-larynx I is basically a buzzer. If you press it against the throat the buzz penetrates to the vocal cavity where it can be modulated into speech sounds by moving your jaw and tongue and lips just as you would when speaking normally. A wonderful device really ... but ... do you remember the Dalecs in Dr.Who? That's what to expect when we meet! The first thing Bhante asked me to say was "*Exterminate them!*"

Children love it – I'm a great novelty for them. And sometimes it gives me a laugh too. Those are the good days. But it's hard work by comparison to natural speech. My tongue and other muscles round my neck have been damaged by the surgery, so I can only speak quite slowly and have to make a big effort to articulate. It feels like I'm shouting. And often I have to repeat words again and again or throw in a bit of mime in order to be understood. So it gets tiring. Writing on the whiteboard is more calming for me, but quite cumbersome for any level of detail. I've experimented a bit with some speech synthesis software, and found an Irish female voice which I was able to install on my computer. It has been useful for telephone calls where I can prepare my questions in advance, but so far I haven't got much use out of it for face-to-face conversations, mainly because of my slow pace of typing.

So a lot of things get left unsaid. Sometimes it's because I don't have my whiteboard or whatever to hand when I think of something I would like to say. And many things that I would ordinarily have mentioned to others now just don't seem worth the bother of writing down, or 'shouting' with the electro-larynx. So I noticed myself more often 'doing my own thing' without reference to others. This is uncharacteristic and could cause misunderstandings or hurt, and again I have to thank Pat and Margaret

for their patience and understanding here. I do have good fun in conversations on occasion but lots of opportunities for light-hearted interaction get lost.

During the initial recovery period and the radio / chemo treatments, I hardly thought about losing my voice at all. I had plenty of fear, anxiety and other forms of aversion, but they weren't connected to coherent thoughts of having lost my voice. The only thoughts that came up were mildly consoling ones. For example, I often thought "I don't need to talk right now" or "You don't *need* to talk a lot of the time". But the down-side of my situation was literally unthinkable.

Then a friend gave me Colm Toibin's book 'The Testament of Mary'. This opened Pandora's box and the snakes came sliding through! I wondered why the book was making me so happy (it's a powerful but not at all a happy story). I found I was buzzing with the delightful thought of Jesus's miracles! I had never reflected much on that aspect of the Christian story before. But now ... the possibility of a miracle .. and maybe for *me* ... a glimmer of hope was born! At one level, of course, I could laugh at myself. But a moment later I was sucked in again. Miracles happened then – why not now? I could go to Lourdes, Knock, Medjugorje! Or why not a Buddhist healing – that would be more appropriate! Bhante's Bodycare. The Medicine Buddha. And sure, while he was curing my throat, couldn't he give me back my strength and mobility in my arms and neck and shoulders as well? How about the body of a thirty-year-old? That would be grand. Smiling happily, heart soaring, I just knew the healing was coming my way soon. Then a wave of rationality would wash over: 'Come on Noirin, get a grip!'

The daydreams didn't come up in formal meditation but for days or even weeks they flared up again and again in daily life. This was my first emotional reaction to the laryngectomy – getting high on the thought of reversing it all! The high certainly lifted my spirits, but the effort of continually reigning in the delusion was exhausting. Eventually I got fed up with the daydreaming mind and really wanted to stop buying into the delusion. But ... how to do this without suppressing the hope, and the desire for well-being? I noticed it only happened when I was in good humour. The mind would catch on to the good humour and build a great future of health and strength. Why couldn't I just enjoy the good humour instead? I tried the note '*dreaming of now, dreaming of now*' to help bring me back to the present moment. I could feel the happiness, and on the edge of this, my painful flickering attempts to grasp at it, to make it mine, to project it into a wonderful future. As I focused on these feelings, the other aspects of 'now' sank in: no miracle, no voice box, no speech. Happiness turned to sorrow, but I preferred it to delusion, and my heart began to open, grateful for the Dhamma lesson, glad to be touching at last on the grief of losing my voice.

With that the heady daydreams disappeared and I was able to start thinking rationally about the reality of my situation. I had been wondering when it would hit me. Now that I could recognize the grief I could also see it had been lurking, unrecognised, in my earlier fear and anxiety. I had been turning away from the obvious reality in terror, having no idea how to live without a voice. I was reminded of the opening words of C. Day Lewis's "A Grief Observed": *No one ever told me that grief that was so like fear*. It was a relief to be able to name it as grief. With that, compassion arose and I could acknowledge the loss. It was as simple as saying: *Yes Noirin, this is tough*. But that simple recognition meant everything. I felt more able and willing to care for a being who lives with laryngectomy.

Sometimes, when I want to talk but cannot, I feel tremendous shame. For those moments I am a failure, a lesser being. Remember the last link the Wheel of Dependant Origination: *Conditioned by birth, there follows ageing, death, sorrow, lamentation, pain, grief and despair.* I have 'taken birth' in the notion of myself as someone who can talk. Someone who can say hello, contribute to a conversation, make a point, ask questions, laugh, chant and sing (probably out of tune but still!), lead meditations, talk about the Dhamma. I liked the sound of my own voice. Now it's time to learn from the results of this birth. The desire *not to be* manifests again and again. Not to be someone who sounds like a dalek. Not to be someone who brings a whiteboard and marker to the shops. Not to be someone who's rasping cough makes heads turn all around.

When I have the time and space for deeper meditation, I am always reassured that I haven't lost anything of real value. The beauty of the Dhamma is still open to me. That's all that matters ultimately. But then, in daily life, this wisdom can desert me. Occasionally when people see I can't speak they assume I'm deaf too, or intellectually impaired. Sometimes they join me in writing on the white-board, or 'mouth' their words silently. If I'm in good humour, this can be amusing. But if I'm not, it can trigger rage. One time, when I was in a sulk, a nursing attendant assumed my incommunicative state meant that I didn't understand what he was saying (in fairness to him I wasn't even nodding to acknowledge his message, just glaring at him - so you could say I got what I deserved! Such is the cost of expressing anger angrily. His response was just a reflection of what I was putting out into the world). He started speaking loudly, one word at a time, miming and gesticulating in his efforts to communicate. I wanted to shout: "I'm not stupid, I'm not deaf, I'm just furious can't you see!" But of course I couldn't (just as well or I would have had plenty of 'wrong speech' to regret!), and scrawling it on the whiteboard didn't seem like an option. When he left I paced the room, dragging my drip-stand with me, livid with rage and frustration. Later, I remembered the Buddha's words: *What the world finds ugly, I find beautiful.* Everything around me and within me seemed despicable and horribly ugly. And yet the Buddha would find this beautiful? Tears of rage and self-pity flowed into the incomprehensible consolation of his vision.

Then again, there is the temptation to find fault. Someone must be to blame for all this. Myself? For not taking the warning signs seriously enough? My doctors? My kamma? The Buddha taught that misfortune can occur for many reasons - e.g. heredity or environment as well as resulting from past misdeeds. So I cannot assume that this is a fruit of 'bad kamma'. Intellectually I accept this, and am very glad that I don't have to see this as punishment. But when a neighbour called and, probably troubled by my condition, said: "*I don't know what you did in your previous life but I hope you enjoyed it at the time!*" I saw how little I understood the teaching at depth. I reacted with deep anger at her judgement but once again I was saved by the slow pace of the whiteboard and her visit passed off cordially. Good thing too, as it was Christmas eve! But later as I reflected on her remark and my reaction, I saw my deeper fear: this speechless condition was a sign to all that I was being punished for my misdeeds. With that my resentment toward the neighbour diminished. I saw that what was troubling me was not her judgement but my own confusion, at the heart level, regarding the law of kamma.

I was shocked and depressed by that glimpse of my judgemental mind's reaction to having a disability. Another deep layer of dukkha needing exploration. What could give me heart for the journey? I

remembered my initial bravado in thinking I could greet this Devadutta gladly! That seemed like such wishful thinking now. And yet I'd gone and written an essay on it, so I was going to have to *try* to live up to the ideal! I tried to dredge back some enthusiasm for the path. I remembered my initial excitement at hearing that it was possible for a human being to understand the workings of the universe. All the hours of meditation I'd put in since, trusting that I too could come to know and understand the truth of how things are. And now a messenger (in the form of a laryngectomy) had been sent to show me the way. With a rueful smile I let my guilty, shameful self be coaxed into feeling chuffed, singled out, not for punishment, but for very rapid progress through the rounds of samsara! Ok Devadutta, I sighed, lead on!

The Devadutta has graced me with other teachings besides loss of speech, such as difficulty swallowing and loss of flexibility and power in my upper body. In time, I'd like to reflect on these and write some more. But for now I'll sign off with good wishes for your own rapid progress through the rounds of samsara. Or, as a Dalek with a yen for Nibbana might say: *Exterminate those hindrances! Exterminate! Exterminate!*

**Noirin Sheahan**

## Laryngectomy Dhamma.

Hello again! First an update: I'm living in my own home again – just came back last week. Many thanks to all my friends and family for helping me get this far, and especial thanks to Margaret and Pat with whom I have been staying since I left hospital in September. For their friendship, tireless care, encouragement and quiet, unfussy kindness, I am truly grateful.

What follows is another reflection on life since my laryngectomy (removal of the vocal chords) last July.. This time I'm going to explore my experience of living without my natural voice. I'm only scraping the surface of this teaching. In fact this essay is my first attempt to reflect on the experience. But for what it's worth ... here goes.

At many levels its easier than I could have imagined. Like the way shopkeepers hardly bat an eye when I write on the whiteboard instead of asking them verbally for what I want. Texts and emails still work fine. And among friends, when discussions get deep, the slow pace of writing can be OK. It gives time for relaxation and reflection by contrast to the fast pace of speech. And at times it can be great to be able to take a back-seat and listen to conversations without any pressure to contribute. Once, when someone came to dinner and I was exhausted by the effort before we even sat down at the table, I felt so relieved to be able to stall the pace, writing slowly, giving myself time to take a few breaths and recover some good humour.

I'm still using the whiteboard for many interactions – only beginning to attempt the electro-larynx in public though using it more and more among friends and family. The electro-larynx I is basically a buzzer. If you press it against the throat the buzz penetrates to the vocal cavity where it can be modulated into speech sounds by moving your jaw and tongue and lips just as you would when speaking normally. A wonderful device really ... but ... do you remember the Dalecs in Dr.Who? That's what to expect when we meet! The first thing Bhante asked me to say was "*Exterminate them!*"

Children love it – I'm a great novelty for them. And sometimes it gives me a laugh too. Those are the good days. But it's hard work by comparison to natural speech. My tongue and other muscles round my neck have been damaged by the surgery, so I can only speak quite slowly and have to make a big effort to articulate. It feels like I'm shouting. And often I have to repeat words again and again or throw in a bit of mime in order to be understood. So it gets tiring. Writing on the whiteboard is more calming for me, but quite cumbersome for any level of detail. I've experimented a bit with some

speech synthesis software, and found an Irish female voice which I was able to install on my computer. It has been useful for telephone calls where I can prepare my questions in advance, but so far I haven't got much use out of it for face-to-face conversations, mainly because of my slow pace of typing.

So a lot of things get left unsaid. Sometimes it's because I don't have my whiteboard or whatever to hand when I think of something I would like to say. And many things that I would ordinarily have mentioned to others now just don't seem worth the bother of writing down, or 'shouting' with the electro-larynx. So I noticed myself more often 'doing my own thing' without reference to others. This is uncharacteristic and could cause misunderstandings or hurt, and again I have to thank Pat and Margaret for their patience and understanding here. I do have good fun in conversations on occasion but lots of opportunities for light-hearted interaction get lost.

During the initial recovery period and the radio / chemo treatments, I hardly thought about losing my voice at all. I had plenty of fear, anxiety and other forms of aversion, but they weren't connected to coherent thoughts of having lost my voice. The only thoughts that came up were mildly consoling ones. For example, I often thought "I don't need to talk right now" or "You don't *need* to talk a lot of the time". But the down-side of my situation was literally unthinkable.

Then a friend gave me Colm Toibin's book 'The Testament of Mary'. This opened Pandora's box and the snakes came sliding through! I wondered why the book was making me so happy (it's a powerful but not at all a happy story). I found I was buzzing with the delightful thought of Jesus's miracles! I had never reflected much on that aspect of the Christian story before. But now ... the possibility of a miracle .. and maybe for *me* ... a glimmer of hope was born! At one level, of course, I could laugh at myself. But a moment later I was sucked in again. Miracles happened then – why not now? I could go to Lourdes, Knock, Medjugorje! Or why not a Buddhist healing – that would be more appropriate! Bhante's Bodycare. The Medicine Buddha. And sure, while he was curing my throat, couldn't he give me back my strength and mobility in my arms and neck and shoulders as well? How about the body of a thirty-year-old? That would be grand. Smiling happily, heart soaring, I just knew the healing was coming my way soon. Then a wave of rationality would wash over: 'Come on Noirin, get a grip!'

The daydreams didn't come up in formal meditation but for days or even weeks they flared up again and again in daily life. This was my first

emotional reaction to the laryngectomy – getting high on the thought of reversing it all! The high certainly lifted my spirits, but the effort of continually reigning in the delusion was exhausting. Eventually I got fed up with the daydreaming mind and really wanted to stop buying into the delusion. But ... how to do this without suppressing the hope, and the desire for well-being? I noticed it only happened when I was in good humour. The mind would catch on to the good humour and build a great future of health and strength. Why couldn't I just enjoy the good humour instead? I tried the note '*dreaming of now, dreaming of now*' to help bring me back to the present moment. I could feel the happiness, and on the edge of this, my painful flickering attempts to grasp at it, to make it mine, to project it into a wonderful future. As I focused on these feelings, the other aspects of 'now' sank in: no miracle, no voice box, no speech. Happiness turned to sorrow, but I preferred it to delusion, and my heart began to open, grateful for the Dhamma lesson, glad to be touching at last on the grief of losing my voice.

With that the heady daydreams disappeared and I was able to start thinking rationally about the reality of my situation. I had been wondering when it would hit me. Now that I could recognize the grief I could also see it had been lurking, unrecognised, in my earlier fear and anxiety. I had been turning away from the obvious reality in terror, having no idea how to live without a voice. I was reminded of the opening words of C. Day Lewis's "A Grief Observed": *No one ever told me that grief that was so like fear*. It was a relief to be able to name it as grief. With that, compassion arose and I could acknowledge the loss. It was as simple as saying: *Yes Noirin, this is tough*. But that simple recognition meant everything. I felt more able and willing to care for a being who lives with laryngectomy.

Sometimes, when I want to talk but cannot, I feel tremendous shame. For those moments I am a failure, a lesser being. Remember the last link the Wheel of Dependant Origination: *Conditioned by birth, there follows ageing, death, sorrow, lamentation, pain, grief and despair*. I have 'taken birth' in the notion of myself as someone who can talk. Someone who can say hello, contribute to a conversation, make a point, ask questions, laugh, chant and sing (probably out of tune but still!), lead meditations, talk about the Dhamma. I liked the sound of my own voice. Now it's time to learn from the results of this birth. The desire *not to be* manifests again and again. Not to be someone who sounds like a dalek. Not to be someone who brings a whiteboard and marker to the shops. Not to be someone who's rasping cough makes heads turn all around.

When I have the time and space for deeper meditation, I am always reassured that I haven't lost anything of real value. The beauty of the

Dhamma is still open to me. That's all that matters ultimately. But then, in daily life, this wisdom can desert me. Occasionally when people see I can't speak they assume I'm deaf too, or intellectually impaired. Sometimes they join me in writing on the white-board, or 'mouth' their words silently. If I'm in good humour, this can be amusing. But if I'm not, it can trigger rage. One time, when I was in a sulk, a nursing attendant assumed my incommunicative state meant that I didn't understand what he was saying (in fairness to him I wasn't even nodding to acknowledge his message, just glaring at him - so you could say I got what I deserved! Such is the cost of expressing anger angrily. His response was just a reflection of what I was putting out into the world). He started speaking loudly, one word at a time, miming and gesticulating in his efforts to communicate. I wanted to shout: "I'm not stupid, I'm not deaf, I'm just furious can't you see!" But of course I couldn't (just as well or I would have had plenty of 'wrong speech' to regret!), and scrawling it on the whiteboard didn't seem like an option. When he left I paced the room, dragging my drip-stand with me, livid with rage and frustration. Later, I remembered the Buddha's words: *What the world finds ugly, I find beautiful*. Everything around me and within me seemed despicable and horribly ugly. And yet the Buddha would find this beautiful? Tears of rage and self-pity flowed into the incomprehensible consolation of his vision.

Then again, there is the temptation to find fault. Someone must be to blame for all this. Myself? For not taking the warning signs seriously enough? My doctors? My kamma? The Buddha taught that misfortune can occur for many reasons – e.g. heredity or environment as well as resulting from past misdeeds. So I cannot assume that this is a fruit of 'bad kamma'. Intellectually I accept this, and am very glad that I don't have to see this as punishment. But when a neighbour called and, probably troubled by my condition, said: "*I don't know what you did in your previous life but I hope you enjoyed it at the time!*" I saw how little I understood the teaching at depth. I reacted with deep anger at her judgement but once again I was saved by the slow pace of the whiteboard and her visit passed off cordially. Good thing too, as it was Christmas eve! But later as I reflected on her remark and my reaction, I saw my deeper fear: this speechless condition was a sign to all that I was being punished for my misdeeds. With that my resentment toward the neighbour diminished. I saw that what was troubling me was not her judgement but my own confusion, at the heart level, regarding the law of kamma.

I was shocked and depressed by that glimpse of my judgemental mind's reaction to having a disability. Another deep layer of dukkha needing exploration. What could give me heart for the journey? I remembered my



initial bravado in thinking I could greet this Devadutta gladly! That seemed like such wishful thinking now. And yet I'd gone and written an essay on it, so I was going to have to *try* to live up to the ideal! I tried to dredge back some enthusiasm for the path. I remembered my initial excitement at hearing that it was possible for a human being to understand the workings of the universe. All the hours of meditation I'd put in since, trusting that I too could come to know and understand the truth of how things are. And now a messenger (in the form of a laryngectomy) had been sent to show me the way. With a rueful smile I let my guilty, shameful self be coaxed into feeling chuffed, singled out, not for punishment, but for very rapid progress through the rounds of samsara! Ok Devadutta, I sighed, lead on!

The Devadutta has graced me with other teachings besides loss of speech, such as difficulty swallowing and loss of flexibility and power in my upper body. In time, I'd like to reflect on these and write some more. But for now I'll sign off with good wishes for your own rapid progress through the rounds of samsara. Or, as a Dalek with a yen for Nibbana might say: *Exterminate those hindrances! Exterminate! Exterminate!*

Noirin Sheahan