CHAPTER 1

Unanswered questions

> *One day Leonie, thinking no doubt that she was too big to play with dolls, brought us a basket filled with clothes, pretty pieces of stuff, and other trifles on which her doll was laid: "Here, dears," she said, "choose whatever you like." Celine looked at it, and took a woollen ball. After thinking about it for a minute, I put out my hand saying: "I choose everything," and I carried off both doll and basket without more ado.*
>
> THÉRÈSE OF LISIEUX[1]

In less than twenty years, Thérèse Martin had acute and agonizing tuberculosis. She suffered terribly, coughing blood from her lungs, experiencing breathlessness and suffocation. Eventually, her vital functions began to fail. No painkillers, such as morphine, were administered to relieve the agony. She died on 30 September 1897 in a convent in Northern France. She was only twenty-four. When her sister, Agnes, who was a nun, visiting her a week before her death, remarked, "What a terrible sickness and how much you suffered!", she replied, "Yes! What a grace it is to have faith! If I had not any faith, I would have committed suicide without an instant's hesitation."(Last Conversation, 22.9.6)

This is not a book about Thérèse of Lisieux, as she quite soon became known. But it *is* about choosing, and living, and

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[1] *The Story of a Soul*, Chapter 1, trans. Thomas Taylor, Project Gutenberg Ebook, 2009.

dying. And it *is* about faith and the difference faith makes when you are facing illness, especially "incurable" illness. Particularly, it is about *choice*. It is often thought, or implied, that the world is divided into those who are "pro-life" and those who are "pro-choice". My observation is that this is a false antithesis. Thérèse Martin went on to write: "This childish incident was a forecast, so to speak, of my whole life… then also, as in the days of my childhood, I cried out: 'My God, I choose everything, I will not be a saint by halves, I am not afraid of suffering for Thee, I only fear one thing, and that is to do my own will. Accept the offering of my will, for I choose all that Thou willest.' "[2] This is not a passive acceptance of whatever life throws at us; it is a positive choice to embrace the whole of life, whether we like it or not. It is a position of faith – for many, faith in God, but for many others faith in the value of life itself.

I have Primary Lateral Sclerosis, a relatively slow form of Motor Neurone Disease, about which I have written in *My Donkeybody – living with a body that no longer obeys you*.[3] (Motor Neurone Disease is also known as Lou Gehrig's Disease or Amyotrophic Lateral Sclerosis, but will be referred to as Motor Neurone Disease or MND here.) There, I primarily tried to paint a picture of what it's like to be diagnosed with a terminal condition and to live with the diagnosis. I wanted to get across the way the reality crept up on me, to the point where there was no doubting that the consultant's verdict was right: I had a fatal illness. And I wanted to get across the relentless progress (if you can call it progress) of the disease and its invasion of my body, emotions, and my whole existence. So I told my story. I told it for myself, of course, but I mainly told it for anyone who cared to read it, especially those facing the multitude of "terminal" degenerative conditions, and for the carers of those

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[2] Thérèse of Lisieux, *ibid*.

[3] Monarch Books, Oxford, 2008.

with these diseases. I was writing for people with faith or with no religious convictions, but I did not attempt to conceal my own faith.

However, for a Christian, of course, and indeed for anyone who is vaguely thoughtful, illnesses such as mine raise some profound questions which could not be avoided. So, in a few chapters of *My Donkeybody*, I have addressed them in a somewhat summary fashion. They were questions to do with the use of stem cells in research and treatment, assisted suicide, miraculous healing, and the consolation of an afterlife.

But there were some big unanswered issues I was aware of by-passing. One was the question "Why?", "Why is this happening to me?", or, more fundamentally, "Why does a good God, if there is one, allow all this pain in his world?" Another was, "How does a Christian steer his or her way through the experience of suffering?"

I am not sure whether this book is going to provide theological (or, as a friend recently wryly observed, what this usually means: theoretical) answers. Since beginning this journey of illness, I have met several fellow-travellers and from them I have gained wonderful insights. One of them I have met only via the Internet. She is Jozanne Moss, who lives in George, near Cape Town in South Africa. We were "introduced" by Dr Peter Saunders in June 2009. We both have Motor Neurone Disease, but Jozanne's is of a more aggressive form than mine. That, and our shared faith, forged an immediate bond between us. Jozannne, who has two young children, seems to me someone who has chosen everything with inspiring faith. This book is largely inspired by our correspondence, of which the greater part was hers, and forms the chapters here entitled "Jozanne's Story".

We hope that this is not seen as a book about our particular condition. We hope that you read it as two twenty-first-century Christians struggling with the age-old questions raised by sickness and faith. It could equally have been written by those experiencing the panoply of other "incurable" diseases. God has just chosen to bring us together with the same illness and the same goal: to encourage and inspire others with the life God has purposed for us all.

Of course, if one looks in the pages of the Bible, there too one meets people of faith wrestling with the human condition. And, as the beginning of this chapter reminds us, saints throughout the ages have walked similar and harder roads.

This book is addressed specifically to those saints' successors. Not in the sense of "a bundle of bones which fools adore when life is o'er"[4], as Newman's chorus of demons mocked, but all those who have known "amazing grace". In other words, it is for Christians of all sorts, all ages, and all complexions, and perhaps in particular for those for whom the words of the old carol hold an aching resonance:

O ye beneath life's crushing load,
Whose forms are bending low,
Who toil along the climbing way
With painful steps and slow...[5]

We want to assert that the promises of God are not extinguished by our darkest experiences. "The light shines in the darkness, and the darkness has not overcome it" (John 1:5) – or, "has not put it out" – because it cannot. It did its damnedest to stamp out the light, but it could not. "For the Son of God, Jesus Christ... was not Yes and No, but in him it is always Yes. For all the promises of God find their Yes in him." (2 Corinthians 1:19, 20)

We want to sing the resurrection psalm:

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[4] John Henry Newman, *The Dream of Gerontius*

[5] Edmund H. Sears, "It came upon a midnight clear".

> *Even though I walk through the valley of the shadow of death,*
> *I will fear no evil, for you are with me...*
>
> Psalm 23:40

As one modern song puts it, "for my God is with me. If my God is with me, whom then shall I fear?"[6] Or, indeed what shall I fear?

We hope you will come on the journey with us.

Michael Wenham

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[6] Matt and Beth Redman, "You never let go" © 2005 Thankyou Music (Adm. by worshiptogether.com songs excl. UK & Europe, adm. by kingswaysongs.com tym@kingsway.co.uk www.kingsway.co.uk) with permission.

CHAPTER 2

I wish...

Jozanne's Story

I wish I could take a long walk on the beach at sunset and feel the sand between my toes and the waves against my legs.

I wish I could jump from rock to rock with Luke and Nicole, catching rock fish with nets in the tidal pools on a beautiful sunny day.

I wish I could hike up the Outeniqua Mountain with Dave and the kids, and stop halfway up for a scenic picnic.

I wish I could bake cookies with Nicole, and giggle with joy as we decorate them with chocolate sprinkles and glazed cherries.

I wish I could tap my feet to the rhythm of Luke's guitar as he practises so diligently and enthusiastically for the Young Musicians' auditions.

I wish I could shoot goals with Nicole outside in the net. She loves to play netball, especially when she can be the goal shooter.

I wish I could stand and give Luke a big hug… I'm sure he is almost as tall as me, or at least up to my chin.

I wish I could run my fingers through Nicole's beautiful blonde hair and help her tie her ponytails in the morning before school.

I wish I could straighten Luke's tie and collar every morning, and help him flatten that piece of hair he always seems to miss at the back of his head.

I wish I could get up in the middle of the night when the kids are sick and feverish, and when all they need is a cool facecloth and a comforting touch. I know Dave is there for them... but I wish I could be.

I wish I could wake Dave in the morning with a hot cup of coffee and a soft kiss on the cheek. He brings me my tea every morning.

I wish I could cook him his favourite dinner, set the table beautifully and eat by candlelight like two lovebirds, while the kids visit ouma (grandma).

I wish I could play Nicole's karaoke game "Sing Star" with her. She has a beautiful voice and loves to perform. I am sure I could give her a go.

I wish I could be a cricket and hockey mom. I would love to sit by the sports field for hours, just to give Luke a big smile and a cheer when he looks my way "unintentionally" after he scores a goal or bats a big shot.

I wish I could paint Nicole's nails and give her a facial, do real girly things together like shopping at the mall, and having milkshakes, just the two of us.

I wish I could bake pancakes on a rainy day, or flapjacks and waffles for breakfast, just for the fun of it. The kids would say I am "the best mom in the whole wide world".

I wish I could help Luke when he puts gel in his hair before he goes to a friend's party, and "It's not because there are girls coming to this party, Mom."

I wish I could play "chopsticks" on the piano with Nicole, but I am sure she would play faster than me.

I wish I could dance with Luke, and show him how to hold a girl gently as you sweep her across the floor… "Agh Mom, we don't dance like that!" he would say.

I wish I could wipe away Nicole's tears when her little heart is broken by an insensitive friend after a whole day of playing together.

I wish, I wish...

Jozanne Moss, May 2009

CHAPTER 3

Jozanne's diary

> *You never really understand a person until you consider things from his point of view – until you climb into his skin and walk around in it.*
>
> Harper Lee [7]

Jozanne's Story

I was diagnosed with Motor Neurone Disease on Wednesday, 16 November 2005.

Saturday, 19 November 2005

I have decided to start writing down the things I feel in the hope that it will help me cope, but also so that one day, when this is all over, Dave, Luke, and Nicole can read it to remember me by, and also really to understand what I went through. Today, I feel great and at peace – but on Thursday my whole life seemed to tumble in.

I will start at the beginning – at least the beginning for me. In about June 2005, I started noticing that I couldn't run anymore. Now, I am not a runner by nature (built for comfort, not for speed – as my dad would say). We were having a school concert and, believe it or not, on all four nights of the performance, I forgot the same silly sashes the children wore and had to run back to the classroom to fetch

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[7] *To Kill a Mockingbird*, © Harper Lee 1960; Penguin Books, Harmondsworth, 1963.

them, literally moments before my kids went on the stage. It was during this running that I started to notice that my left leg didn't do what it was supposed to. It felt like it wanted to drag and I had to work extra hard just to get my one leg before the other. But with me being such a couch potato, I was convinced that it was because I was so out of shape and unfit. I was sure that a few sessions in the gym would change things. In any case, it wasn't affecting anything else. I didn't really tell anybody.

I don't know how much later, but I started to notice that, even when I walked, my left leg felt like it wanted to drag. I had to focus to pick it up, but yet again I was convinced that, if I had been more of a gym girl, this would not be happening. Remember, I am closer to forty than to thirty. I felt too embarrassed to really tell anybody, especially Dave, my husband. He was already on my case for not doing anything active. Well, time passed and I could feel that things were getting worse, slowly but surely. It was when I started noticing that my left hand seemed weaker (it couldn't do little things that I used to be able to do) that I told my mom. I have always been a mommy's girl! I was still convinced that a little bit of regular exercise would do the trick. It was my mom who eventually pleaded with me to go and see a doctor. Even then, I really wasn't urgent about it.

One day, both the kids were sick and I took them to the doctor. He examined them both and joked about whether there was anyone else in the Moss family that needed attention. I just happened to think that maybe I could mention to him what was going on. He examined me, watched me walk, and that is how it all started. He made me realize that maybe this was not nothing, especially when he suggested that I go to a neurologist. He could only get an appointment with the neurologist a month later. This made me feel more at ease. If this was serious the doctor would have squeezed me in sooner.

It took a whole month before I could see Dr Freda, the neurologist. On 20 September 2005 she examined me and immediately booked me for a brain scan (MRI) the very next day. I was thrown. What could it be? A brain tumour? The next day's MRI, thankfully, showed a perfectly healthy brain. It must be something else. Within a week I went for a spinal scan and a batch of blood tests. These too only showed how healthy I was.

By this time, I realized that the doctor was looking for signs of Multiple Sclerosis. I started to read up on the condition and it sounded terrible. The doctor seemed confused because the MRI was supposed to show lesions on the brain if indeed the diagnosis was MS. Next the doctor booked me for a spinal puncture to test the spinal fluid for early signs of MS. I was convinced it was MS. All the signs pointed to it, and I was starting to prepare myself mentally for this new turn that my life was going to take. When the results finally returned negative, I was still convinced I had MS and I had information from the Internet to prove that the spinal fluid test was a sensitive test and needed to be performed meticulously to get an accurate result. I didn't trust the outcome of the test.

Dr Freda decided that the next step was to do a MRI of my neck. I knew she wouldn't find anything, but I guess she had to cover all the bases. "A beautiful neck" were her words. At this stage I started feeling the anxiety that comes from uncertainty. Any diagnosis would do, I just needed something to be confirmed. I was also getting used to the idea of having MS. It seemed bad but I could live with that. In any case, someone in my family had it and they were still alive and kicking. Although their life had now changed, it was still a life of some sorts. Eventually, Dr Freda decided to send me to Cape Town for further tests. An appointment was made for me with a professor from the University of Cape Town.

On Wednesday, 16 November 2005, Dave and I left for Cape Town at about 10 a.m. I was quite excited, hoping that at last someone would be able to tell me what was going on. I just wanted to know, so that I could educate myself, make the necessary adjustments to my life and carry on. (It all seemed so simple!) I was also looking forward to the five-hour drive, time I could spend with Dave in the car, real focused time. Time to talk about everything. Just the two of us. We hadn't had time for us lately, and hadn't discussed what was really going on. It looked to me as though Dave was in denial about everything. He still felt that, if I would just get some exercise, eat healthy foods, and get more rest, all this would go away.

The trip to Cape Town was nice and quiet. We couldn't really talk about IT. We just made idle chatter, but even that was fine. It felt like we were on holiday. We made good time on the road and arrived in Cape Town early. We decided to go to the Prof early and make sure we got all the paperwork done. After some searching we finally found the University of Cape Town Private Hospital at 3.55 p.m. It all seemed very unassuming, like a real academic hospital. We were sent down the passage to room no. 2 and on the way there passed an odd-looking little man, probably a hospital orderly or something. I was feeling excited and anxious at the same time (a very weird feeling), but we arrived at room 2 and sat down to wait.

The odd little man we had passed in the passage came back and introduced himself as the Professor. Surprise! He definitely did not look the part, but I am sure he had lots of brains and experience. He asked all the usual questions, did the same examination as Dr Freda without the same professionalism, and after approximately 35 minutes let us sit down at his desk again. At this stage it did not look like he really had anything new to tell us. "Well," he said, "I have good news and bad news. The good news is that you don't have MS." I was overjoyed by the news, something solid. Dave and I looked at each other. We were so pleased; and I could see that look in Dave's eyes that said, "See, I told you so".

"Great, Professor! What is the bad news then?"

"Well, it could be blocks in the muscles. These cause the impulses from the brain to get blocked in the muscle and not to pass through, thus leading to weakness and spasticity. But my favoured diagnosis would be Motor Neurone Disease. I think it could be MND. There is just one more test we need to do called an EMG. This would confirm whether it is MND or not." We didn't know what he was talking about. He asked us whether we wanted him to be totally honest with us, even if it was bad news. "Of course!" we said.

The Professor explained that the neurones in my brain and spinal cord, that carry the messages from the brain to the muscles, were dying, and that slowly but surely I would lose the use of my muscles (and so limbs, etc). He assured me that my brain would not be affected, and when I expressed relief, he commented that maybe it is not such a good thing. This comment I did not quite understand at the time, but it now makes perfect sense to me. I asked the professor whether my breathing would be affected. He commented, "Not really so much," in a very uncommitted way. The Professor said we could listen to him dictating the report he was sending to Dr Freda, and that maybe we would have more questions afterwards. The report sounded mostly like Greek to us, except where he spoke about how he "favours" the diagnosis of MND. That word "favour" amused me at the time. It just seemed an unusual word to use under the circumstances, but I guess that was just his way of speaking.

Dave and I walked back to the car in a bit of a shock. What do you say? I guess we had some sort of diagnosis now, but what did it all really mean? Could the EMG test maybe prove that it was not MND? I broke down in tears, not because I really knew what was going on, but because so much emotion had built up to this one moment. I wanted certainty, and what I had now was still a measure of uncertainty. Dave held me for a while, and within moments I pulled myself together, and we headed for the traffic of Cape Town. We decided to go to the Strand and to get out of the rush of the city. We were able to get the last room at the Pavilion Hotel, overhanging the sea. It was all so beautiful.

God was there; and from that moment on I could feel God's arms (his everlasting arms) around me.

Dave went to the shops and came home with sparkling wine and some snacks. In the meantime, I telephoned people close to me to tell them the news. When Dave got back we sat on the patio and watched the sunset as we drank a toast to something – I don't really remember what, but I know we wanted to celebrate something. It was wonderful and beautiful and moving. It was here that I realized I would not be alone and that I did not have to be scared. The evening was perfect. The next day we headed home.

I was eager to have that test (EMG – electromyogram) done as soon as possible because waiting was not something that I could do anymore. I telephoned my doctor to try to set it up for Friday, but was disappointed to hear that I could only have it done the next Thursday. So we were back to waiting!

I was eager to get home to see the kids, but also to jump onto the Internet for more information on this unknown disease that I might have. We arrived in George and went straight to my mom's house. It was when we stopped there and my parents came out the door that I realized something was terribly wrong. They looked in shock, as though someone had died. They had read the information on the Internet. We went in, and I asked my mom for the information they had read. I went into the study by myself and read. The shock was indescribable. This was not a disease: it was a death sentence. Everywhere, I read the life expectancy was between two and five years. That could not be: the kids are too young. How could I die now? Who would love them as much as I do or take care of them as well as I could? What would become of them? What now?!

I wasn't afraid for myself, or even Dave; we were OK. I am not afraid to die – how could I be? I knew and understood God's love for me and the grace that he has poured out in my life. Life with God is so much better than life here on earth. But my children! How do children so small grow up happily without a mother? This can't possibly be God's plan for them. How could it be? I know God wasn't looking away when I got this disease, but he has allowed it to happen; and I know that God does everything for the good of those who love him. Therefore, I do believe that there is a good reason why I have MND. I know that God does not give us anything that we cannot handle; so God must know that I can handle this. I just need to know and believe that. I believe that many people's lives can and will be impacted by this disease. My prayer is that I will be a beacon of light that shines God's love.

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