



Disability or "this" ability?

Born in 1933, on a small farm in South Leitrim, I was educated at the local national school, that of Corduff. There, when aged 13, my formal schooling ceased, but not without a good understanding of the basics necessary to take me through life, including reading, writing and arithmetic. In addition, I had a good knowledge of the Catholic religion.

The most important thing in my life, I was told, was to be a good strong workman, not a pen-pushing, muscle starved, useless "get". To be a good ploughman, a good turf-cutter, a good haymaker eventually would secure my destiny. I grew up strong. At 20 years, I had mastered most important jobs on our 30-acre farm, only to discover that these back breaking tasks yielded very little financial return.

Money needed for social activities, such as a dance at every weekend, was never available, not that my parents would refuse it if they had it. The money was not there. It was as simple as that, for this was the era of the cow, the sow and the plough.

In 1953, I emigrated to London and became a barman, a change from the plough, loy or turf-spade. Here, my arithmetic came in useful. This was also the era of the halfpenny. A round of drinks would cost about six shillings and sixpence. You'd have to have the amount right, first time. This included making up the price of each drink in halfpennies, pennies and shillings while still pouring, maintaining a conversation with the customer and making sure not to hesitate when asked "How much?"

An Englishman immediately would send for the manager if he were short a halfpenny. Indeed, he would call the manager if he received a halfpenny too much: such was his attitude to the servant. You would want to be a diplomat, an acrobat and a doormat to meet all his requirements.

It was not long before I moved to construction work, to make plenty of money and friends (fair-weather friends). Each year, I would return to help at peak periods on the farm. In 1961, I got married and in 1962, our first child was born, a son. We decided to return to Ireland and bring up our children the Irish way.

In 1964 we returned to Co. Leitrim and, ironically, set up on a small farm. I got a job as a lorry driver, to help subsidise our low income. Later, I bought an excavator, a JCB (with the help of a loan), the first of its kind in the district. Now, I was self-employed, my own boss! But, as I was soon to find out, it is really hard work toiling for oneself. I worked that machine night and day until I nearly fell off it.

One day in 1976, I noticed my right arm was a bit weak. Months later, while extending this arm, I saw one finger dropping, unable to resist the pull of gravity. Not to worry. Were there not nine more to go? In 1977, another finger fell and it was time to act.

I went to my doctor who found nothing wrong though he suspected a nerve problem. He warned me that, whatever about having the condition arrested, there would be no reversing a damaged nerve.

After numerous tests and long periods in a Dublin hospital, finally, in 1978, I was diagnosed as having a terminal illness, known as motor neurone disease. So far, medical research has failed to find a cause or a cure. A simple explanation of what happens is that the message from brain to muscle somehow becomes interrupted, causing the neurones to die, resulting in massive muscle-wasting in the part of the body affected.

The disease does not remain confined to any one part. As the years pass, it attacks other areas, such as neck, throat, speech organs, lungs and breathing equipment, thus resulting in death, usually from respiratory failure. Life expectancy with this disease is between two and five years, according to the experts.

You can well imagine my anxiety and frustration when a neurologist at St. Vincent's Hospital, Dublin,

diagnosed this fatal disease. As a man of 45 years, I was absolutely devastated. Having a wife and six children, aged from 16 to three years, this was not the future I had anticipated. But I continued to work as an excavator driver, though with limited power in one arm.

I had a few contracts secured and was determined to complete this work, which included digging and laying watermains for rural schemes. The reward was a fair standard of living for the family. Looking back, I could say that I was on the first rung of the ladder to success. One advantage of being on the first rung of the ladder is that, when it snaps, you don't have far to fall.

In 1980, my arm somewhat weaker, I decided to go to Lourdes, so important to people with terminal illness. Indeed, as they say up here in this neck of the woods; "Try Lourdes, it's yer only man". I went with the diocesan pilgrimage in June of that year. We stayed in the hospital wing attached to the holy ground and this allowed me to visit the grotto four or five times a day. I prayed at the grotto like I had never prayed before.

I stared at the statue of our Blessed lady straight in the face until I almost thought it moved! I made promises, deals and bargains with the Lady. I looked at the sticks and crutches hanging up, implements now discarded by invalids who had found cures at this holy spot. Thousands of all nationalities passed by, some in wheelchairs, others on stretchers which were their death-beds. But I never gave them a second glance, just continued to pray: "Cure me and let me back to my JCB".

At the end of that 1980 pilgrimage a madame director gave our group a lecture, telling us something of the few miracles that had happened in Lourdes. She pointed out that all who came to Lourdes receive some gift: "It may happen while you are in Lourdes. It may happen when you return home, or in years to come. But, eventually, everyone will receive something". I returned home from that pilgrimage a happy man. I would not have long to wait for my gift. Had I not put in the "twist", as far as prayer and devotion were concerned.

One, two, three years on, and my arm got weaker and weaker. I started using my left arm and hand for every little chore. By four, five or six years later, the disease had spread to my left arm. I became bitter, infuriated and angry, angry with God, angry with the whole religious concept.

"WHY ME?" I shouted. I had kept my end of the bargain and had received nothing. Seven, eight, nine years, and everything that I touched fell to the ground. A straw became my credit card: "Don't leave home without it".

Then one day in May, 1990 two women visited me. They were from CASA (Caring and Sharing Association). It was obvious that they knew all about my disease. They invited me to visit Lourdes with their Association the following July. "Lourdes", I said, trying hard to control my rage and not to offend them. "I've been to Lourdes ten years ago and got nothing!" One of them, a nun, Sister Mary, spoke: "Andy, not many people live 10 years with that disease. What do you mean, you got nothing? Physically, you look great to me".

After some coaxing and persuading, I decided to return to Lourdes. This was a giant step for me. I could hear and inner voice say "Go for it, Andy". This was the first step away from the loving care of my family. My dependence would be exposed. I would have to depend on a total stranger for my little, daily needs. Yet, subconsciously, I knew this would have to happen some day. My two visiting friends assured me that "every disabled person is assigned a carer of the same sex while on pilgrimage with CASA. That carer has responsibility for every need of that sick or disabled person"

They would allocate a good carer to me, they promised. And did.

Some 30,000 feet over the mountains, I was introduced to my carer, a young, energetic, athletic, Cork man 20 years my junior. We hit it off right away. At least, we had one thing in common, the same Christian name, Andrew. Next morning, he had me out of bed, shaved, showered and "shammied" in 15 minutes flat.

That pilgrimage went like a dream. I found myself totally relaxed, not praying for anything in particular, just going with the flow. Then, one night, nearing the end of this great tour, our group visited the grotto at midnight. My carer and I were the last of our group walking around. He rubbed my useless hands against the glazed rock and prayed. The tranquillity, serenity and quietness of this holy place was awesome: just the birds chirping in the ivy over the grotto; the sound of traffic in the distance; hundreds of people of all nationalities moving slowly, as if in a daze. This must surely be heaven on earth: Just let it be.

We lit candles and drank water from the taps, still in prayer. When we had regained our composure, looking

around, we discovered that our group had returned to the hotel. My carer whispered in my ear: "We will have to get a move on".

He took off in strides not recommended for the weak-hearted. I matched him every step of the way, with great effort. As we approached the main road, we could see the emblem of our Association (blue headgear) stepping on to the footpath on the far side of the road. The traffic started moving, leaving us standing on the kerb. I was glad of this for it gave me time to draw my breath. I looked sideways at my carer who had his hand up to his face, trying to control his laughter.

"What are you laughing at"? I asked, quietly. He turned towards me, now a bit more serious, and said: "Ah, sure you're the fittest invalid in Lourdes"

The traffic stopped. We crossed the road and soon were reunited with our group.

That night, I lay awake in bed for some time, thinking about that remark: "You're the fittest invalid in Lourdes". To me it was not funny. Nobody ever before had told me that I was an invalid and probably I had been avoiding this stigmatised term all those years.

Next morning, the final day of that 1990 pilgrimage, we visited the grotto for the last time. As we waited our turn, ironically I found myself kneeling on the very same spot where I had knelt ten years previously. I looked up at the statue of Our Lady of Lourdes. I felt guilt, shame and remorse. How could I have been so stupid, so demanding, so selfish, seeing nobody sick except myself? All those years, torturing myself with the "WHY ME" syndrome. In fact, I had got the greatest gift given to anybody, that of acceptance. For ten long years I had suffered hell, because I had failed to recognise that gift. When it happened it took only a few words from a man I had known for only four days to rock me to the very foundations of reality; "Sure, you're the fittest invalid in Lourdes". I have been back to Lourdes many times since 1990. I pray for the continuation of that gift, acceptance:

"Our Lady of Lourdes, give me the serenity to accept the things I cannot change!".

Today, physically, I'm worse off; but, inside, I'm a happier and more contented person, willing to accept whatever God sends. I have been carrying unnecessary, excess baggage for far too long. My life has completely changed since that 1990 Lourdes pilgrimage. I have learned to confront challenge and pursue other goals. I write this chapter with the aid of a computer and printer, operated by my right foot, something that would have been impossible for me 10 years ago.

The high-tech equipment was supplied to me by The Irish Motor Neurone Disease Association, of which I have been a member since its foundation in 1985. They provide an equipment service for patients with this disease and to a very high standard.

Fourteen years ago, they delivered a computer and printer to my home, showed me how to write my name (Andy), left me three instruction manuals, and said: "Goodbye". Can you imagine a man sitting in front of a computer for the first time, with nothing but his right foot to make it work? However, I persevered, making hundreds of mistakes. But, as the man said, there's only one failure in life, the failure to learn from failure.

Each letter or character demands an individual movement of the toe or heel. Two weeks after receiving the computer I wrote a short letter, far from perfect, to the Association, thanking them for giving me back the art of writing, something I thought I had lost forever. Otherwise, a lot of material would have remained imprisoned in an active, alert brain.

They have transformed a disability into "this" ability by encouraging me to search for the power within.

In the year 1998, I went on local radio to highlight awareness of this disease, MND. At first I was nervous. The interviewer questioned me in detail about the disease. Soon I regained my confidence: I knew more about this illness than he! That interview went splendidly.

"Are you doing anything for the Association?" he asked. I said I intended to climb Croagh Patrick on Sunday, July 13/1998, to raise funds for the Association; and if there was anybody out there who would like to sponsor me, I would be grateful for the support.

When I came off air, the phone started ringing with offers of help, support and funds. The local newspapers, Leitrim Observer and Longford Leader, published articles about my expedition. Encouraging letters and funds arrived from many places. People with whom I had lost touch contacted me after a silence of 40 years.

The roller-coaster had started. There would be no turning back now. On Sunday, July 13, I boarded a bus for Longford town for the journey to Co. Mayo, to be greeted in the car park at the foot of the Reek by Association colleagues, who had a barbecue of sausages and burgers awaiting.

At one o'clock we were ready to start the climb. The mountain looked huge in the distance. A cloud, on occasions, would cover the summit. Committee members approached me: "Don't go up the whole way, Andy," they urged. I had two young men accompanying me. Their mother has the same disease. They would take care of me, they promised, and I had to warn them: "Don't put a hand on me as this will only affect my balance. Just pick me up if I fall down!"

The first stage of the climb was not too bad. We rested; I looked up; the peak was half a mile up; and, stretching before me was a long trail of people clinging to the side of the mountain, like flies on a wall. My God, I thought, what's keeping them from falling off?

My heart sank to the bottom of my shoes. I'll never make it, I said to myself. Then we started climbing again. I searched for the hero inside me. He responded! I plodded on in the footsteps of my young, energetic carer. After that I never looked up, just kept repeating to myself: "You can do it, Andy; you can do it". Some time later I heard a shout: "We're nearly there". I lifted my head and, there it was, a small, flat piece of rough, stony ground, with a little church to one side. There were no triumphant celebrations.

That's the thing about climbing Croagh Patrick. You have achieved nothing until you get down in one piece!. Indeed, my thoughts now were for the people we had met coming down the mountain as we struggled up, some of them sliding on their behinds, their balance totally out of control.

I entered the little church and prayed. I thanked God for giving me the stamina to complete this expedition. I prayed for the people who supported and encouraged me. Then we began the descent, my two caring companions out in front.

"We will catch you, Andy, if you take flight", they said. However, I never slipped once; and carrying a stick or any other balancing equipment was physically impossible for me.

As we entered the car park, we were greeted with spontaneous applause from about 100 of our colleagues who had been awaiting our return. The only man disappointed with my success was the man selling sticks (ash-plants) at the foot of the mountain, for he sells the sticks to those going up the mountain and who, on their way back, throw them away. This man has a gasun (from the Irish, *garsun*, a boy) collecting the discarded implements so that they may be sold again. He was on a winner until he met me, who bought no stick nor threw any away.

In Hotel Westport I drank a glass of Heineken beer through a straw. I never tasted a drink so good as this in all my life. I could feel the blood flowing through my body: the adrenaline was at work. Tears of joy and satisfaction trickled down my cheeks and, for a moment, I even forgot I was disabled. Winning the Lotto would have been an anticlimax in comparison to this exhilaration.

The fund-raising endeavour was an outstanding success but the benefit I received from the expedition and the climb never could be measured in money. "I just did it my way".

The year 1997 was a great one for me. That may seem ironic, coming from one with a terminal disease for the past 20 years. But it is true! The reason: my involvement with various organisations for the disabled; my visits to Lourdes, Knock, Croagh Patrick; and the writing of this book. These activities have occupied me, taken me out of my comfort zone, and from under the umbrella of my loving, caring family.

On occasion, a family may have a negative influence on a disabled person, with discouraging advice, for example "Don't go out.....You'll catch cold.....You might fall.....Take it easy.....What will people think"? All this arrives in good faith but it does little to boost the courage of a handicapped person.

I feel very privileged to have survived more than 33 years with this disease. Most patients are not so lucky. However, the use of my arms and hands has become greatly reduced over the years, thus causing me to abandon little everyday tasks taken for granted and not appreciated by the able-bodied. For example, just writing a note or picking up a biro now has become for me a thing of the past.

Thus, you can well imagine my anxiety and frustration when a staff nurse, Mary Mulligan, and an occupational therapist, Nuala Tierney, at Our Lady of Lourdes Hospital, Dun Laoghaire, suggested that I write

a book. My immediate reply was; "When will pigs fly?"

But they insisted: "You definitely have got the material, if you could get it down on paper."

Well, this pleasant compliment did nothing to boost my ego. Without hands, letter-writing was impossible, as far as I was concerned. However, the Irish MND Association became aware of my problem and came to my assistance with a computer. This enables me to write, using my foot. After months of intensive effort and dedication, finally I have acquired the necessary skill to operate this 'high-tech' equipment with my right foot.

Each day, there is a special place on our farm for which I head. It is a quiet, derelict spot with a bush, a shrub, rock and some fern. It is of no agricultural value whatsoever. Nobody else comes here. The only visitors are from the wild. There I sit for about ten minutes in total solitude, weather permitting, taking in good, fresh, clean, blue air, absorbing the tranquility of this isolated place. I close my eyes and try to cut off everything. The birds singing in the trees nearby; an ass braying far away, a sound fast becoming obsolete. hens cackle at a neighbour's house, and a cock replies to a rival. There goes another beautiful tradition.

Everything here is perfect! If I were to die in this place, nobody would find me for hours, perhaps days. A frightening thought, you might say, but the solace of this timeless place, alone, far outweighs any such fear.

I open my eyes, stand up and assert myself. A fox runs hastily past. He has become aware of my presence, his brush or tail rises as he struggles to control his balance. Then he disappears into the bushes. A rabbit's white 'scut' (from the Irish, *sciot*, 'bobbed tail') disappears down a burrow. The pheasant flies by, cackling continually, and lands in the moors far below. This is heaven, my heaven. This is beauty like I've never seen it before.

In my youth I travelled to many places, my young, eager heart demanding more excitement and adventure. I once was familiar with the sound of the London Underground, the graffiti-stained carriages of the New York subway, the overcrowded Paris Metro and the Dublin Dart, as it rocked its way past Sandymount Strand. Now, in my twilight zone, I am privileged and content to have found my forgotten heritage and to have returned to my native habitat: "Oh, like the hare that hounds the horns pursue, I will pant to the place from whence I first hath flew."

My goals for 1998 are to have this book published, and to < donate all proceeds from the sale of this book to the Irish Motor Neurone Disease Association >, to master the art of operating the Internet, the ultimate in communication, to participate in promoting a newsletter highlighting disability in Co. Leitrim. I hope to climb Croagh Patrick once more and to get involved with other disabled people, to swap laughs, smiles and chats with them. My main wish today is to share myself with other people, now that the gift of acceptance has changed my life forever: "A candle loses nothing when lighting another candle" (and old proverb).

An illness can take the body or one's life. But it will never take the person, the soul, or the spirit. I will continue to live for the moment. I am looking at life from a different angle.

I'm not writing this for praise, credit or personal recognition. I'm writing it for the benefit of other disabled people. If I can get one more disabled person to accept his or her condition, I will have achieved my objective.

To disabled people I recommend: Go out. Get involved, confront a challenge. Join an organisation. Go on holiday. Go to Lourdes, with a total stranger as carer, if possible. These organisations provide carers, capable of handling any situation, regardless of mobility or disability. Write that letter. Make that phone call. Do not hibernate in the bosom of your good family. Eventually, that will make one obsolete. A disability can ignite dormant talents and can actually become the ability to pursue other goals: "No man can discover new oceans unless he has the courage to lose sight of the shores."

A terminal disease can have different interpretations for different people. Life itself is terminal.

"I will live for the moment!!!"

Solo Natural Speaking!

In the year 2000, The Motor Neurone Disease Association: loaned to me a new PC complete with Dragon Solo Natural Speaking, a voice recognition software. This programme is an advanced state of the Art of Assistive Technology, it allows me to write by just speaking into a microphone and on occasion using a foot

mouse.

I can perform any transaction by just simply choosing one of a numerous command available. I can now write with the speed of any typist and indeed, have become the envy of some keyboard users. I would recommend this equipment to anyone with impaired use of their arms and indeed, to able-bodied people who are not familiar with keyboards.

Nevertheless, the working of this programme demands a lot of patients at the start. One must do a training session provided by Dragon. This includes reading a script over and over again until the system recognises your speech and pronunciation, only then will it file your speech into the system. It matters not, where you come from, Dublin, Donegal, New York, London or Cork. Dragon will recognise you as long as you have completed the training programme, and each time after, that you use voice recognition and save your speech file, the performance become easier, simply, because the system has now recognise almost every word of your vocabulary

However, I will admit, there is a lot more I can learn about Dragon. In the words of that famous Microsoft tycoon, Bill Gates, who said: "learning is a process that lasts a lifetime" !!

Computers are of great benefit to disabled people and with this new Assistive Technology we have transformed a disability into "This Ability" and ignited dormant talents that would otherwise be imprisoned in active, alert brains forever!!!

I'm will conclude now by expressing an explanation given to me by my first tutor, Ger Craddock, Andy, he said: "learning to operate the computer is like learning to ride a bicycle, once you get your leg up, your there"! **How true!**

"This Ability" 2004"

"Please understand me. The outlook of a Motor Neurone Patient"

I first titled this short article **"You eat, drink and walk too fast"** but on reflection I realised I was making an unfair judgement. Aren't you as an able-bodied person entitled to eat, drink, walk, run and act in whatever capacity your body and mind allows. You have a right to this freedom.

I once did all the things you do with compatible ease and speed and of course, I too have the right to continue to do these things at my new reduced speed and level of output. It's hard enough! I want you to have patience with me, to understand me when I drink through a straw, when I refused to shake hands, sometimes awkwardly, when I fail to open doors and when I ask for assistance, just to bear with my inadequacies because of my disability.

You see, I want all these things but in reality I need, first of all, too have these same expectations of myself; to have patients with myself, to wait and in my waiting to learn to accept my own new status in life as a disabled person growing in dependency on you my able-bodied friend. That is the hard part?

The title of this article **"This Ability"** is a great inspiration to me as it challenges me to ask what ability? When I attempt to answer it I run out of space. I begin to list my own abilities beginning with I can or I am able to. For example, I can listen to another's story, to music, to bird-song. I can smile to brighten someone's day, I can laugh, I can think, I can write, I can read, I can pray, I can enjoy fun, I can love. My list is endless. I invite all my disabled colleagues to make your own list and give thanks.

We are all very worthwhile just because we live. And my final invitation is to you, my able-bodied friend, to list your own abilities and give thanks too, particularly for all the little things you take for granted as I previously did. All together we can make this world a happier placed for everyone!!!

"If you can break the chains on your mind then you can break the chains on your body too."

In this the year 2014, I thank God that I am now living with MND for 38 years. What an education those years have been for me. I am a different person to the man who existed in 1977

As a person for whom Motor Neurone Disease didn't prove fatal in the prognostic time; three to five years, I have been given the opportunity to look at the disease, and at my life, in a new way. When I was diagnosed with this disease, I was faced with the prospect of severe disability and a life span of just a few short years.

After a pilgrimage to Lourdes with Casa (caring and sharing Association) in 1990, I found great spiritual

strength to accept the disease and learn what I can from the experience. In short, that spiritual serenity empowered me with a power greater than myself. "Our Lady of Lourdes, give me the serenity to accept the things that I cannot change." I seldom take what I'm told seriously especially about this disease. I make up my own mind and follow my own instincts. I will try almost anything to test my remaining abilities, and they are many!

I want to live to watch my grandchildren grow up. This doesn't mean that I've got my head buried in the sand or that I'm wallowing in self-pity or the "why me syndrome." I see myself as a useful and valued member of my family.

I believe that a treatment will be found . It may not arrive in time to save me, but that does not worry me. I've had a good innings. 38 years since diagnosed! And I thank God for that!

I've learned to understand and accept my remaining abilities, I want to reach out to others living with MND/ALS and their families. I want to share myself and the lessons I have learned as I cope by searching for the power within.

I have a good sense of humour and I hope I never lose it. I can laugh with others about my disability and inadequacy. MND has opened new doors in my life. Now rather than dwelling on the door that is closed, I look to the new doors that have opened up for me.

I don't know what the future holds. However, I face my future in the knowledge that God will give me the strength to deal with whatever comes my way. I know that I am lucky to have the support of a loving family....

Abstract From My Book! Against the Odds. Living with MND! At forty three years of age, I was sitting right on top of the world. Married with a wife and six children, they were my joy and greatest treasures. I had my own business and the world was mine. As I busily planned our future, I was not to know that the hand of faith was about to intervene, and change everything. My rollercoaster of life had brought me up in the world. I savored success. But from that very same rollercoaster, I was flung back down to rock bottom. Shattered dreams came down crashing with us. All our many hopes and aspirations lay in shatters at our feet. When, I was diagnosed with a terminal illness, Motor Neuron Disease. The story I now share with you is one of picking up the pieces and of having to rebuild a broken jigsaw. It is a story of digging deep to find the inner hero, and of summoning every ounce of courage and strength that a human being can find. The daily struggles and pain of living with MND during the early years of this disease, the frustration, the anger, and the feeling of helplessness. Then slowly, like the 'Phoenix from the ashes', I immerge. I shake off my mantle of despair. I come to accept my disability. I reclaim my life back, and slowly I find my rainbows end. To my amazement, I can once more reach those dizzy heights of life as the many joys of living I taste again. My greatest desire is that my story will bring inspiration to other disabled people. And that they will have the courage to deal with their circumstances. After the publishing and printing costs of my book – the proceeds from the sale of this book will be donated to the, The Irish Motor Neurone Disease Association. I wish to help this association as they strive to support patients and those who battle to find a cure for this devastating terminal disease. Now that I have reached my 80th birthday, I am conscious of the fact that a cure may not be found in my lifetime, but that does not worry me. I had a good innings. I believe that a cure will be found and if I'm not here to witness that, I will smile from the Heavens above knowing that I have made a slight contribution to this victory. The people, who are then living with MND will benefit greatly! To my many colleagues who are like me. My sole purpose and endeavor is to create a world free of MND. Andy.

"I would like to thank my wife and family for their support over the last 38 years that I have been coping with this debilitating disease, MND. I pay tribute to my wife Bridgie, although having her own health problems, she has never failed to support me .

I would also like to thank my children who have been very encouraging to a father that has been physically disabled during the prime periods in their lives. I am very proud of each of them and how they have made something of their lives. Without their support, I would not be writing this tribute!! When you take the time to honour a disabled person, don't forget to thank the spouse and family as well".

Andy McGovern. Ireland's longest Survivor of MND/ALS!



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