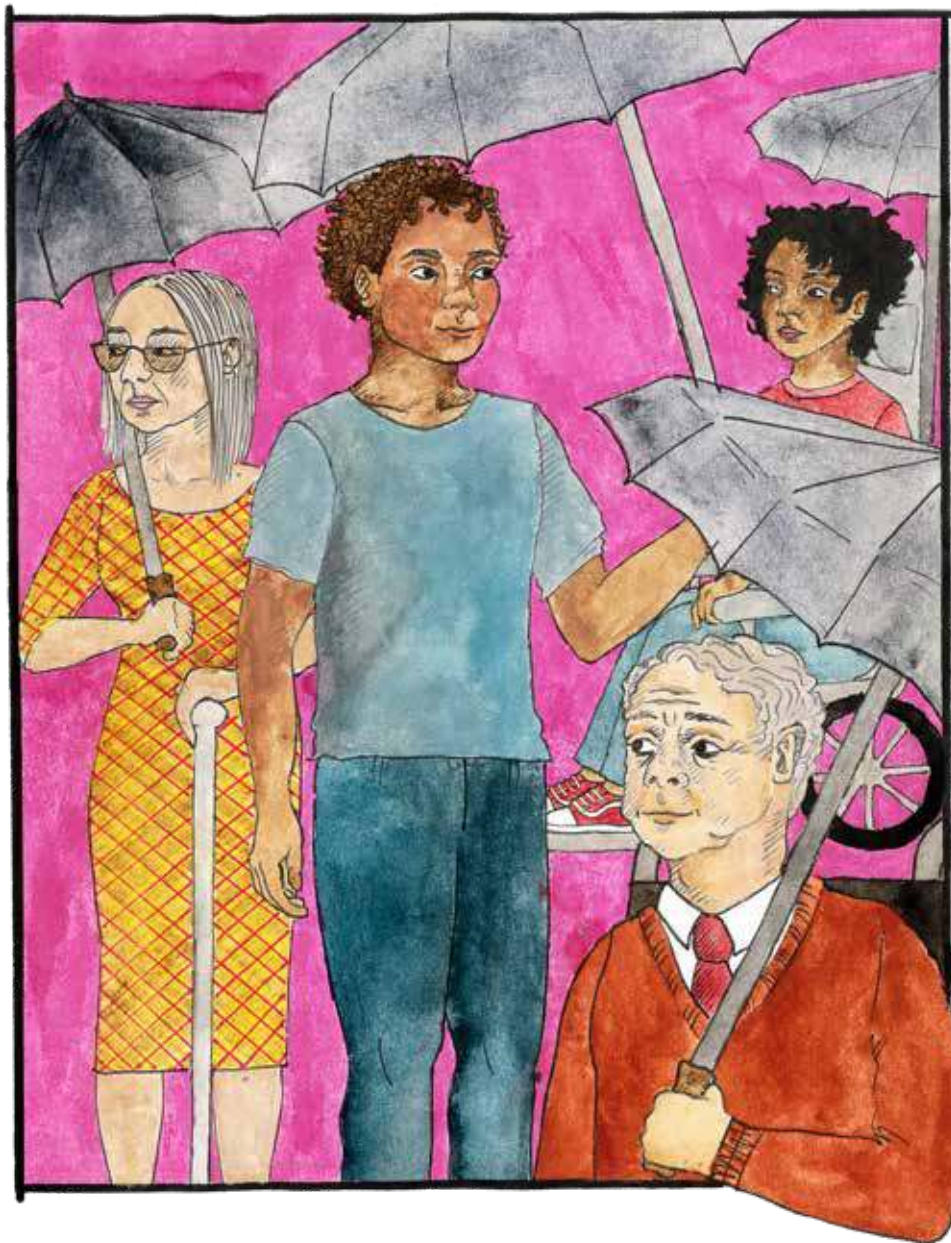


# Collected Stories:

## Living with Multiple Sclerosis



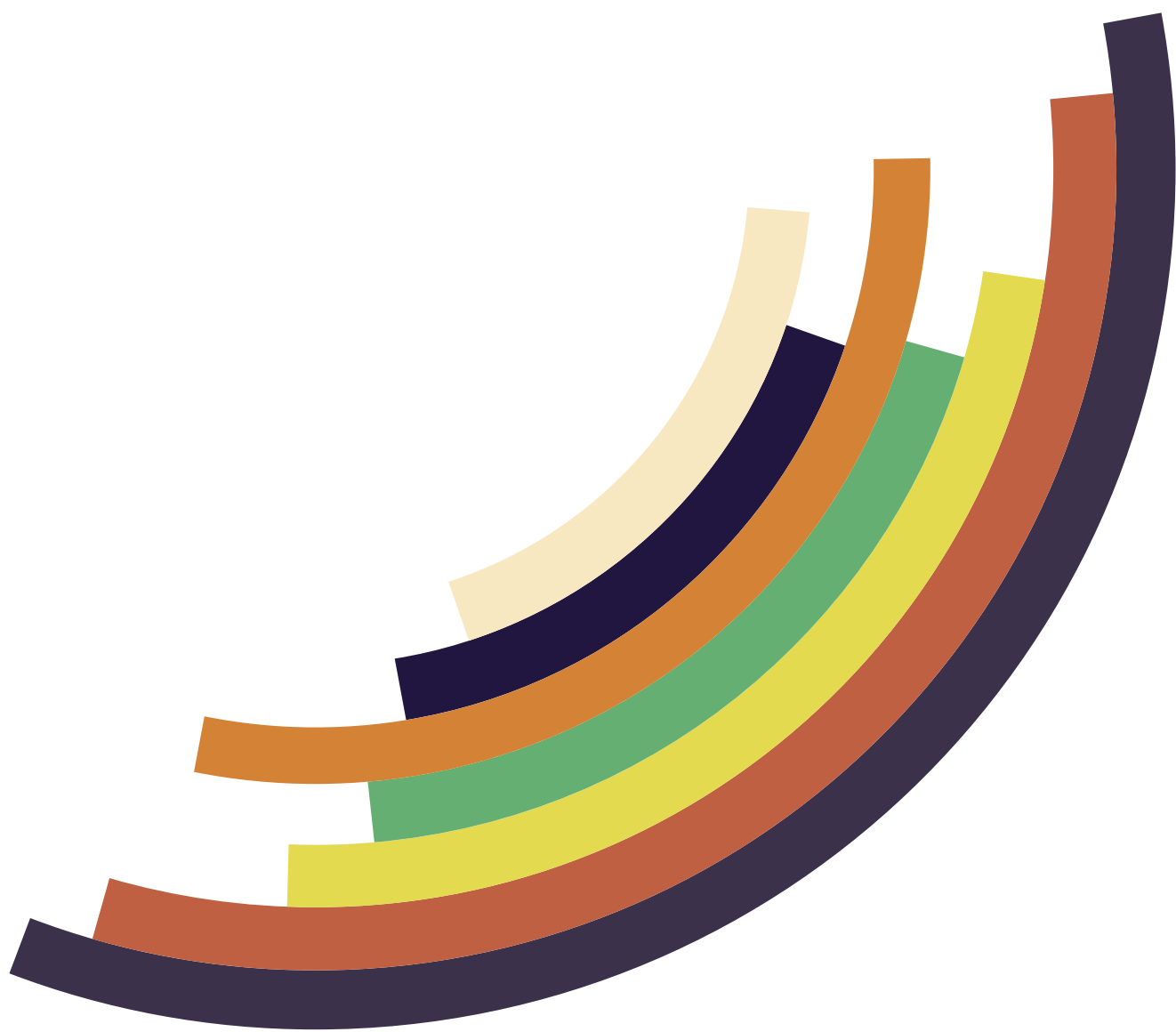
**It's your life, and that's what matters.**



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This book is dedicated to  
Tez and Sue.  
Remembered with love, laughter and  
many happy memories.



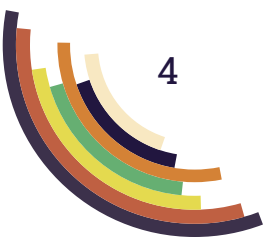


## **Foreword**

**Emeritus Professor Carl Chinn MBE, Ph.D.**

For far too long our people, the common people, were mostly hidden from history. Having to labour for day after day, year in and year out just to survive, they had neither the time nor the energy to write down their stories or compile diaries. That absence of written testimonies from working people means that their appearances on the historical stage are restricted to rare mentions in official annals or relate to events when they had committed an offence according to the laws imposed for their own benefit by the ruling class. Sadly so much of our knowledge of the past is gleaned through these official reports that lack the verve of personal testimony and that relate to working people in an arrogant and insensitive manner; or else our understanding of the past comes via historians who interpret what they have researched according to their own background, upbringing, beliefs and attitudes.

Of course, the voices of the past are the concern of every historian; yet some historians speak louder than those whom they study. They muffle the voices of the past, making them difficult to understand and to appreciate. Oral history is a valuable way through which we can overcome this problem and speak with the past more directly and so too is life story history. When writing down their story, or part of their story, the writer sets down what they themselves want to in the manner they want to. As such an oral history, life stories are vital and vivid first-hand sources allowing use to engage with the past in a more democratic, egalitarian and emotional way.



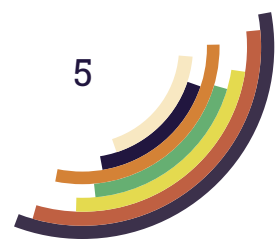
Every person has made their mark upon history and each and every person has a story to tell – but even now too few actually tell it. There is a real need for us to pass on our lives before our memories are lost forever; and there is as great a need for those who know something about those who have now gone to ensure that these stories are also handed down. Such stories can be told in many ways – whether it be in letters, poems, life stories, creative writing, photographs, paintings, drawings, recordings or videos.

Yet for all the importance of passing on the past, too many of us put off the capturing of that story until it is too late and the opportunity is lost.

Therein lies the importance of *Collected Stories: Living with Multiple Sclerosis*. Its stories are told by those who live with MS and through their testimony they bring to the fore their own thoughts and feelings in their own words. But these stories are invaluable in another way.

Over the last 50 years, many social historians have striven to tell history from the bottom up and in so doing have drawn attention to the stories of the poor, women and ethnic minorities. Yet many people still remain hidden from view, amongst them the disabled and those affected by chronic illnesses and diseases. It is vital that they too tell their stories in their ways and ensure that they are not forgotten. Therein is the added importance of *Collected Stories: Living with Multiple Sclerosis*. In giving a voice to those with MS it serves as an exemplar for others affected by illness and disease to speak out and also make clear their vitality and value to themselves, their families and society.

As one contributor states, ‘MS is a cruel disease’ and as another stresses, ‘this thing that demobilises me’ is hateful. Yet what exudes from these and other stories is not despair, depression and negativity but hope, resilience and positivity. As a child and teenager, I recognised those qualities in my Granddad Arthur Perry, whose life was drastically affected by MS from the early 1950s but who was one of the most influential people in my life. Though I did not record my Granddad’s memories, his story is with me yet and it resonates with the stories of those in this powerful and moving book. They are stories that show that whilst MS is life-changing physically it can also change perceptions of life and as one person emphasises, as much as it is debilitating it is not the end. The spirit of these storytellers cannot be doubted and their message is simple: carry on and never give up.

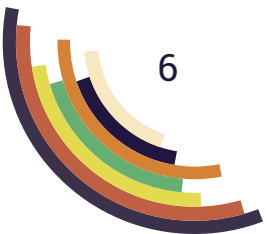


“

**I was reading it in Woman magazine, and I thought, hang on, hang on that looks very familiar to me. The waterworks problems, and this sort of thing, and hummm, I wonder. So I sort of worked it out for myself that that's what it might be.**

”

(Person diagnosed 40 years ago)





## Foreword: Granddad Perry

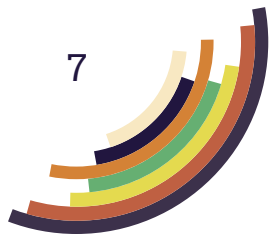
### Carl Chinn

I never knew Our Granddad (Arthur) Perry to walk. Multiple sclerosis had took hold of him before I was born, when he was in his forties, and quickly changed his life. It started off with Granddad swaying and losing his balance when he was walking but quickly it got worse. Back then in the 1950s, very little was known about MS but Granddad spent time in the Queen Elizabeth Hospital, where he had an operation to try and help him walk. It didn't work. Mom, Sylvie Perry, was fifteen or sixteen and living in Aston, but of a Saturday after she knocked off at the factory, she would visit Granddad. It was a trek for her as she didn't know anything about Edgbaston, where the QE was, and how to get there was but she was very close to her Dad and was determined to see him. The two of them loved fairs and each September, he would take her to the Onion Fair on the Serpentine by Villa Park. They also went to other nearby fairs and I have a poor quality but precious photo of them on one of those occasions. Granddad was wearing a flat cap, which he always did in the summer, whilst he wore a trilby in the winter.

Mom married Dad in 1954 and Granddad just about walked her down the aisle but thereafter, he lost the use of his legs and right arm and was in a wheelchair. One of my earliest memories of him was in about 1961 when I was five and we went to see Granddad in convalescence at Summerfield Hospital. He had been operated on in the adjacent Dudley Road Hospital because the MS had forced his legs to cross over so that they could not be uncrossed. That made things really difficult when Our Nan and Mom and Dad were lifting Granddad in and out of his wheelchair. So the doctors took the guides out his legs, which allowed them to be moved more easily.



That visit was on a Sunday afternoon. Over dinnertime we had listened to 'Two Way Family Favourites' on the Light Programme, as we always did, with its fascinating and seemingly exotic BFPO locations. Then we headed off to the hospital. It was a sunny day. 'Beyond Our Ken', with Kenneth Horne and Kenneth Williams, was on the wireless in Dad's car as we went down the Stoney Lane, along the Stratford Road, over Camp Hill and up past the Bull Ring and into New Street.



Then we went across Victoria Square, past Chamberlain's Fountain, around which young people were gathered, into Congreve Street and from there down to the Sandpits, Summer Hill and the Dudley Road to Western Road. Dad parked the car and we went in to Summerfield. When we got to Granddad's ward he was distressed and I remember him saying to Mom, 'You've got to get me out of here Our Sylvie, they've put me in the workhouse'.

As a child I was unable to grasp the significance of why Granddad was so disturbed, all I knew was that he was really upset. Years later I came to understand. Summerfield Hospital had been the Birmingham Workhouse – and as such it had been a hated and feared institution in which the desperately poor were punished for their hardships. Like many working-class people, Granddad still thought of the building in negative terms. Sometime after that, Mom and Dad took Granddad to a big meeting that I always thought was one of Billy Graham's evangelical crusades, but he never came to Birmingham. However, it must have been something similar and it included healing. I was only young, perhaps seven or eight, but I vividly remember sitting on the stairs praying and praying that when Granddad came home with Mom and Dad that he would walk through the door. Sadly he didn't.

Yet though Our Granddad's body was limited to a wheelchair his mind and spirit were never confined and that's something that Mom instilled in me. I recall once when we were out and Mom was pushing Granddad that she stopped to speak to someone. This person looked at he and asked him how Granddad was and she retorted, 'Ask him your bleedin self, he can speak for himself'. Mom always taught me to talk to the person and not the wheelchair and that's one of the important things I learned through Granddad. There was much more that I learned from him directly, and his stories were crucial in inspiring me to become a social historian.





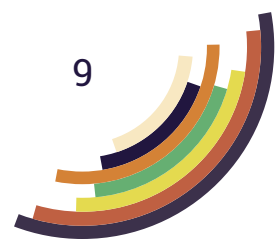
Through them, I went with him and did the things I dreamed of doing with Granddad, like going down the match with him. He was a big Blues fan but used to take Mom to the Brummagem one week and the Villa the next and he reckoned that the finest half back line he had ever seen was Gibson, Talbot and Tate of the Villa. I went for a drink with Granddad to the 'Prince Rupert' in Nechells, because that was the nearest pub that sold his favourite mild brewed by Butler's of Wolverhampton. I was by his side when he bumped into the feared Brummie hard nut, the Tyseley Terror, in Hick Street, Highgate – the street Our Granddad come out of. And I queued with him in Kyrwicks Lane when he had his big touch on the horses, waiting to get his money off the local illegal bookie, Big Horace Foster.

Our Granddad had it rough all his life. His Mom had died in childbirth when he was young and his dad was cruel, locking him in the attic with no food and throwing him out when he was just fourteen in 1920. Granddad had to go and stay the night in the Rowton House – then regarded as a doss house. Fortunately, the next day his best pal's dad, Mr Field the local copper, fetched Granddad out and took him home to live with his family. That's where he stayed until he married Our Nan and moved to Whitehouse Street, Aston. Yet for all his hard upbringing and the onset of MS, Granddad never bemoaned his lot and I looked up to him for his courage and good humour.

Although he could not use his right arm, for some reason his left arm was very strong and he was deft with it, somehow always managing to hide a card when we were playing pontoon or Newmarket at Christmas. Then he'd reveal it with a wonderful sparkle in his eyes and such a loving smile that it will always be embedded in my mind and soul.

Along with Nan, my great aunts and uncles and Mom and Dad, Granddad filled me with a love of the old Brummie speech. On a Sunday everyone in the family seemed to meet at Our Mom's and after a couple of tots of whiskey, Granddad would go 'Well, blige me' when something happened that he wasn't too keen on or which impressed him. Despite what he had gone through and was going through we never heard him say anything stronger. We always admired his fortitude and were amazed at his lack of bitterness and his good heartedness in the face of real adversity.

Then towards the end of the afternoon Granddad would look at Mom and beckon her over. 'Come ere ma wench.' 'What's that, Our Dad', Mom would reply. 'Gie us a piece, ma wench, I'm clammed.' And off Mom would go to cut Granddad a piece of bread and feed his hunger. And before Mom and Dad helped Granddad to bed, he would raise the one arm he could move and beckon me to him. Looking back, I must have been ten when his words began to make a mark. 'Don't you ever forget', he'd urge, 'Don't you ever forget, you're related to the Tipton Slasher'.



Just before Granddad's last Christmas with us in 1973, my brother, Darryl, and myself went up town and into Hudson's bookshop. It was a magical place, like an Aladdin's Cave with little rooms above and below ground, filled with shelves stacked with the treasure of books of all kinds. Suddenly it was as if one of them jumped out to us and leaped into our hands. It was called The Tipton Slasher and was by Tom Langley. We couldn't catch our breath. There was a Tipton Slasher. It wasn't just a story made up by Granddad and this relation was important enough to have been written about.

We grabbed hold of the book and bought it without looking at it. When we got home we couldn't wait to tell Mom. We all sat down and as fast as we could we rushed through it to find out about the Tipton Slasher, one of the greatest of all bare-fisted boxing champions of England. He got his name because he came from Tipton and he slashed with his right hook, but his real name was William Perry. Excited, we thought 'he's got the same surname as Our Granddad'. Delightedly we gave him the book. He wasn't able to hold it because the MS was getting worse but we read it to him. Granddad got a lot of pleasure from that book and I will always be grateful for that because he died soon after.

Before his death we asked Granddad to tell us what he knew of his family but unfortunately it was not a lot. His own father, Thomas Perry, had come from the Black Country and had been a drummer boy in the South Staffordshire Regiment; whilst his grandfather, William Perry, had been supposedly named after his uncle, Bill Perry the famed Tipton Slasher. That was about it, but after researching the family history it doesn't seem that we are – at least not closely. Instead it looks as if the success of the Tipton Slasher encouraged lots of Perry fathers in the Black Country to call their first sons William after the famed boxer who shared their name. My great, great grandfather was one of them. Yet if Granddad was not a descendant of the Tipton Slasher he had a fighting spirit, perhaps not physically but mentally and emotionally.

My Granddad Arthur Perry was a courageous man. His fortitude and humour in the face of adversity, his compelling words and sayings, his entrancing stories, his vivid recollections of the great players of the Blues and the Villa – all imprinted themselves upon my mind. They are with me still as is my Granddad Perry. He always will be.

# Introduction

## Professor Sue Read

Emerita Professor, Keele University, Staffordshire.

We are all storytellers (Gallo, 2016) in one form or another, whether we talk about stories; write stories; draw stories or enact stories. Hardy writes that ‘we dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticise, construct, gossip, learn, hate and love by narrative’ (1986: 5-14) and grieve in narrative. We also experience illness and death in narrative, therefore we cannot discount narratives or stories in healthcare.

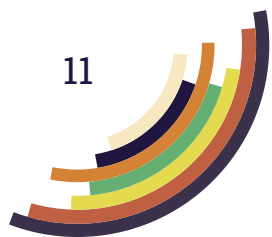
People experience ill health within a particular context (narrative or story) that shapes and gives meaning to their emotions and experiences from one hour to the next; or one day to the next (Donald, 1998). Such experiences may help them to cope with similar experiences in the future, or may suggest simply how best to avoid them.

Stories in healthcare can be powerful (Guntaratnam & Oliviere, 2009), therapeutic (Crawford et al, 2004) and bring reality and meaningful messages to all who read them. Writing promotes healing (Bolton, 1998), and can be a powerful communication tool to a range of different readers (Bolton, 1998). Stories can also be an activator for change.

This project started off as a small idea in a busy, dynamic hospice in the West Midlands - St. Giles’s Hospice, Lichfield, Staffordshire, UK. The CEO of the hospice, one of the authors, wanted to understand how people accessing the hospice who didn’t have cancer, found their lived experiences.

The book incorporates a wonderful, unique collection of 14 stories that provide powerful insights into the impact that Multiple Sclerosis has on the individual, their associated families and professional carers.

We did not intend to pull together this collection of stories from the beginning of the research project, it simply evolved as stories often do in life. Little did we know the work that it would entail, or the impact that these stories would have on those people involved and those listening to the stories. Little did we know what we would learn from the stories and indeed from each other. Little did we know what fun we would share along the way!



## Our Story

Hospice environments have historically and traditionally cared for people with cancer and are often associated with end of life care and dying. More recently, hospices are widening access to other patient groups with non-cancer diseases (such as coronary heart disease and dementia) which may impact on the services they provide, accesses to specialist care provision, and the knowledge and skills required by hospice staff.

A group of people with MS accessed the hospice not as people with MS but as members of an exercise class who stayed for lunch and built a strong reciprocal support network. Eventually this group organically evolved into three groups. The hospice CEO was curious as to what members of this group felt about meeting at the hospice and about how any outcomes might inform the overarching work of the hospice, and contacted colleagues of Keele University, Staffordshire, UK, to conduct a small qualitative study around this topic area. Following University ethical approval, a convenience sample of participants (N=32) was recruited through the facilitator of the exercise classes held at the hospice across two different sites. Information regarding the study was circulated to group participants, participation was totally voluntary, and attendance at a focus group and/or interview was mutually agreed regarding date, time and venue. Of all the members of the three classes, interest was good and 32 participants were subsequently recruited.

People share their ill health stories with others in order for family and friends to fully appreciate and understand a little of what they have survived (or are not surviving) and such stories 'bind us socially with others...' (Donald, 1998: 21).

A writing workshop was organised at the hospice, and while participants with MS were initially sceptical about being able to write about their experiences, their biggest fear appeared to be around who would want to read them.

The book incorporates a wonderful, unique collection of 14 stories that provide powerful insights into the impact that MS has on the individual, their associated families and professional carers.



## **Acknowledgements**

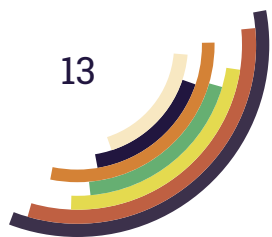
This collection of stories would not have been possible without the support and involvement of a number of people. To all of those people with MS, who shared their stories so selflessly, we thank you for your rich words of wisdom and lived experiences. To all those involved in the exercise groups at St Giles hospice we thank you for tolerating our disruptions and for supporting our curiosities. To those kind readers with an interest in this book, thank you for showing an interest and learning from the experts, the people with MS.

**Dr Emma Hodges, Group Chief Executive, St Giles Hospice**

**Emerita Professor Sue Read, Keele University, Staffordshire**

**Dr Sotirios Santatzoglou, School of Law, Keele University, Staffordshire**

The stories are illustrated by Laura Green, a student undertaking her BSC (Hons) Illustration with Animation at Manchester Metropolitan University, and the book has been designed by Patsy Corcoran, Advocacy Manager, ASIST, Stoke on Trent.





## The dreaded MS

I was first diagnosed with this illness about fifteen years ago. My chiroprapist first noticed the way I was walking and as he felt there may be a neurological problem he suggested I see my GP. Eventually convincing my GP he referred me to a neurological consultant who at first said it was not MS. Seeing as my father suffered with MS for forty years the consultant reassured me this disease was not hereditary. I was worried for myself as I had seen the problems my father had encountered during his life and I did not want the same!

I was still working when diagnosed and the illness progressed. I was becoming aware of the dangers I was causing myself and people around me. One of the problems was keeping my balance working in a toolroom doing manual work on machines. I found that the time it took to perform an operation was taking longer and longer and I was unable to reach parts of the machine that needed attention. When the opportunity to take early retirement became available it was the right time to leave.



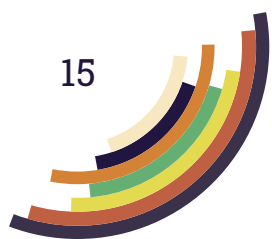
Now having all this free time available to me it lets me take stock of the situation and plan for the future. Unfortunately, all the hopes and plans for the future fail to materialise and as the condition gets worse and confidence in what I could do diminishes leaving me to become more and more frustrated. As I get older I fear what the future will hold. There are so many things you want to do and are unable to do. Simple things around the house become a tremendous task and at times impossible. You are forever relying on people to achieve things. Your independence is tested time after time. One of the main things I miss is playing with the great grandchildren. They want you to kick a ball with them or just go for a walk or even pick them up for a cuddle. This becomes very difficult as I am afraid of losing my balance and falling and as they are too young to understand it becomes very frustrating.

Losing my independence for me would be the killer blow. There are things out there to help and assist you but at times you do not realise what could be achieved with just a little help and advice. I would not wish this or any other illness on anyone on this planet. Hopefully one day there will be a cure for MS but sadly other people will be affected by other diseases.

Attending exercise classes helps take away some of the aches and pain. It also helps by meeting people in the same position as you talk about the illness and their own situation. From this you hear of ideas which you had not thought about. As much as MS is debilitating it is not the end. There is a future as long as you try to achieve things and never give up.

**Reflect on The dreaded MS.**

What losses are highlighted in the story and what future losses can you envisage for this person with MS?



## From an instructor's point of view

I started as Technical Instructor at St Giles in September 2016 and quickly became involved with the MS groups as exercise instructors training on the job in the October. Everyone was very welcoming, offering advice and giving support along the way. After our training we took over the two, one hour groups which enabled us to develop our own styles, which benefitted the groups as it gave each week a different, fresh approach.

As a team we periodically look at the format of the groups to provide equal access to all services on offer and will always be looking at how we can best support everyone involved in the MS groups.

Being involved in the groups has always been a two-way experience. We have continued to learn from the unique individual's perspective which has enabled us to develop our own knowledge base allowing us to improve our own practice. It has been an honour and a privilege to be involved with these groups and see the enjoyment and determination they have. They come together to support each other, sharing knowledge and experiences whether it be about MS or just life in general. They appreciate the friendships and community they have formed just as much as the exercise itself.

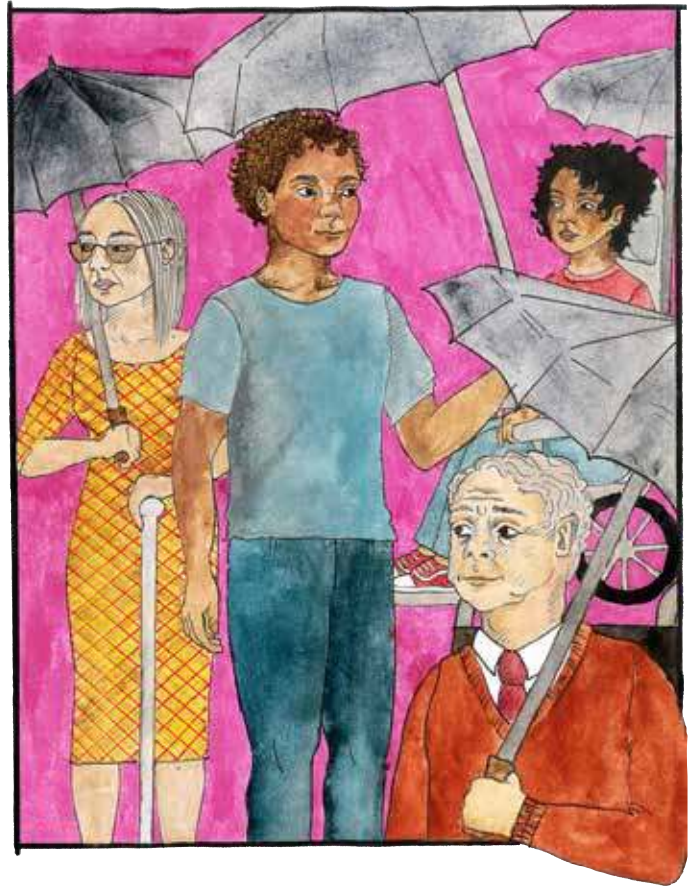
As clinicians we are very aware of the differing levels of ability, not only for the individual in general but for how they are week to week depending how they are feeling that day. With this in mind, providing exercise in a group situation whilst being mindful of an individual's ability has at times proved challenging.

Concerned for meeting needs and expectations we recently asked a few clients that have very limited or no lower limb movement if they would prefer to have a class mainly focused on upper body exercises, however all of them said no for different reasons. Most said they like to work through the movements in their head even if their bodies don't respond, another person said they enjoyed watching others do the leg exercises and another comment was that they prefer to stay in the groups they were already in as they enjoy the friendships they had made in the group.

This represents the importance of not only the social aspects, alongside the support they get from other group members, but also their determination to continue exercising all areas of their body, through actual movement or visualisation.

We are very aware of the need for everyone to keep active and the MS groups provide a safe, encouraging, motivating, supportive environment to do this.

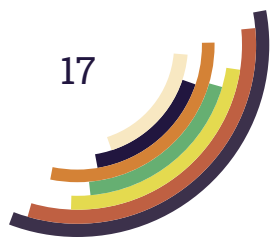
Many have said that if they cannot attend a group for a week or two they really notice the difference on their ability to function, which in turn encourages them to continue to attend the exercise classes. One lady expressed how stiff her joints often feel in the mornings which made caring for her personal needs very difficult. However after she had attended a class her joints are able to move more freely which in turn reduces the time she takes to do activities. In speaking to one lady she expressed that in the many years she had been coming to the groups it had been a “constant” through the progression of her MS. It had become her life line, encouraging her to leave her house each week not only for the exercise but to meet up with friends she has made along the way. Though she knows how beneficial the exercise is she is not motivated to do it when at home on her own, so sees the group as a necessary part of her week.



We have been privileged to hear many different experiences from living with MS and the journeys they are going through. One theme that has seemed to have come from their experiences is that when they were diagnosed they feared the future, be it life expectancy or the level of disability they may experience, however as time has passed they have managed to overcome many difficulties they experience and adapt their lives accordingly. Multiple Sclerosis has a massive umbrella of symptoms. Not everyone will experience every possible symptom, making each person’s journey unique and individual. It is an honour and a privilege to be part of it all. Thank you.

**Reflect on From an instructor’s point of view.**

What did you learn from this story and what will you do differently as a result?





## Fifty years on

In 1968 I had my first child. When he was 6 months old I began to have problems with my left eye. I went to my doctor who referred me to the eye hospital in Edwards Road Birmingham. They told me I had too many white cells and not enough red ones. And to go home and to come back if the drops didn't help, what a waste of time that was. Three years later I had my second child. When she was about nine months old I began to have numbness down the lower part of my body, I began to fall over and drop things. At night I could not sleep, my legs were heavy and ached. I was so tired. After a time I took myself down to the doctors he did various tests on me. He then sent me for physio and that I had a tilted womb, he also gave me a course of vitamin B12 injections, which were a waste of time. The years went by, I think the doctors were treating me as though I was a hypochondriac. I coped the best way I could bring up my two children, working to fit around them and my husband's work. In 1981 they diagnosed me with Multiple Sclerosis, in a way I was relieved. It was not all in the mind I wasn't a hypochondriac. But I did go into denial I only told the families and close friends. I went to work for a few weeks before I told the gaffer and close work colleagues. I made them promise not to tell anyone just yet.



After a couple of years, they had to cut down on staff and guess what I was one of the ones to be asked to go. I couldn't blame them as I had lost quite a bit of time. When I left Highcroft Hospital I applied for a few jobs. I got them until I told them I had MS. Many times I sat in my house and cried, what can I do, I had so many ambitions especially now my children were growing up. But it wasn't to be and life goes on. I walk with a stick, I also use a disability scooter which my three grandchildren loved when they were younger. There was a time when we went to Menorca all three of them were on it with me. So you see life still does go on. Take care...

### Reflect on Fifty years on.

Can you imagine how it must feel to not have a health diagnosis when you know that something is not right with your body?

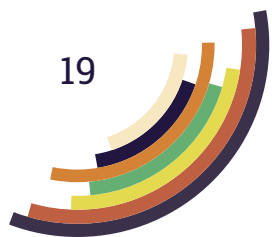


## MS and me

My 'journey' began just before my twenty-fifth birthday in 1980. Following a visit to my local optician and then a letter to my GP, I was sent to Birmingham Eye Hospital in town. I had several appointments and a battery of tests. On that occasion I had been waiting for more than one and a half hours and had just finished reading my book. Inadvisably, I read my patient notes: Optic Neuritis – probable MS. It was like a slap on the face! Knowing very little about the illness I headed straight for the Central Library just up the road. BAD IDEA! My GP was excellent. He did his best to calm down my husband and I by saying that it wasn't definite yet, but even if it was, it was likely to be 'relapsing-remitting'; the best type. In addition, I wasn't obliged to tell my employers anything at all. So I didn't. I remained relatively symptom free for several years relapsing every few years or so but able to return to work after a course of injections.

Nobody wants to be defined by an illness, so I spent the first twenty years after diagnosis in denial (publicly), I told my parents, then my husband's parents but not colleagues or friends. I was lucky enough to be able to concentrate on my career with very little time off work for relapses. My secrecy was my saving grace. It enabled me to 'think normal', and get on with life seeing lots of live music, friends and very supportive family. But denial is very lonely. For decades I knew no-one else with the condition, so was unable to talk about the problem. Multiple Sclerosis is a cruel condition. The only way to cope is to remain as optimistic as possible but the multiplicity of symptoms makes this very difficult. It is degenerative which makes you only too well aware of limitations as they happen to your body. Mobility – or rather the loss of it, is a huge issue. I am very fortunate that thirty-seven and a half years after diagnosis I am still walking – albeit with the aid of a rollator or two sticks. Well, that is on the days that I can get out of bed! Cognitive problems, especially memory, are exacerbated by drugs prescribed for a variety of symptoms such as pain, fatigue, night cramps, bladder and bowel problems etc. Personally one of the worst hurdles has been the loss of independence. I had to stop driving for a number of reasons – blurred and double vision, speed of response issues, fatigue and difficulty in concentration not helped by chronic insomnia.

I am very lucky because, so far, I have only been wheelchair-bound for a few months or so after a prolonged spell of sciatica. I have had a slipped disc and crushed vertebra (at the same time) which my neurologist told me was probably the result of numerous falls. Ditto the fractured toe! Ditto the ribs! I have problems with spasticity when walking and have become very clumsy. Fine motor skills are affected too. My handwriting is now appalling and my spelling has become problematic – both really annoying when your degree is in English and neither was ever an issue before. Truly frustrating!! Most of the above sounds very negative, but I am an optimist.



When fifty I was able to take early retirement on medical grounds – I had no energy and kept falling over and forgetting things. Two months after finishing work I began attending an ‘Extend’ class with my neighbour. It was careful exercise designed for osteoporosis sufferers, but ideal for me as a means of staying active. Two or three years later Julie Robinson replaced the teacher. Eventually she asked me if I would be interested in attending a class at St Giles that she was about to begin for MS sufferers. This was about seven or eight years ago and I am so very glad that I did.

Julie is a truly inspirational teacher. Her exercise classes are hard work but friendly, relaxed, fun and therapeutic all at the same time. The staff and especially the volunteers are always really cheerful, friendly and helpful. Perhaps the most important element of St Giles classes every Thursday is the MS people with MS themselves. It is wonderful to be in a position where you can talk freely about anything and know that your listeners understand exactly what you mean. The exercise classes work on so many different levels. Physically, the tasks set aid flexibility, co-ordination and strength. Intellectually we are constantly challenged e.g. exercises where one part of the body is required to do the opposite from normal or ball games with a partner when counting backwards from 100 in 3's. Most tasks are set to a variety of different kinds of music. The positive atmosphere leads to lots of laughter and fun which has an excellent effect on everyone emotionally. But probably the most important aspect is the social interaction. We are truly among friends. We share ideas, strategies and tips. We have become a community. I wish this facility had been available when I was first diagnosed.



### **Reflect on MS and me.**

This is a very powerful account of a long journey with MS. What did you learn from this story and what has it made you think about in relating to people with MS?

## A feel good anecdote

Train to London on my own to meet a friend for the day. I had a couple of hours on my own so decided to go to the Wellcome Foundation. It is just opposite to Euston, a stone's throw away, but too difficult for me to get across the road in my manual wheelchair. Taxi-driver loaded me into the taxi and asked me where I wanted to go. Very embarrassed, I apologetically told him, he didn't bat an eyelid just said he was not too sure whether he should turn left or right, ha ha!

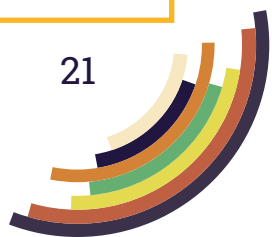
Couple of minutes later he parked at the disabled entrance, unloaded me, wheeled me to the door; opened the door. "Are you OK here?" "Perfect" I answered turning around to thank him and pay him only to see him walking back to the taxi.

"Your money" I called but he just put his hands into the air and with his back to me waved! Wow a free trip but did he ever realise how important this was to me, not the fare but for the confidence he gave me. Always find London Taxi drivers very helpful but this was the ultimate!



**Reflect on A feel good anecdote.**

What did this short story tell you about MS and human nature?

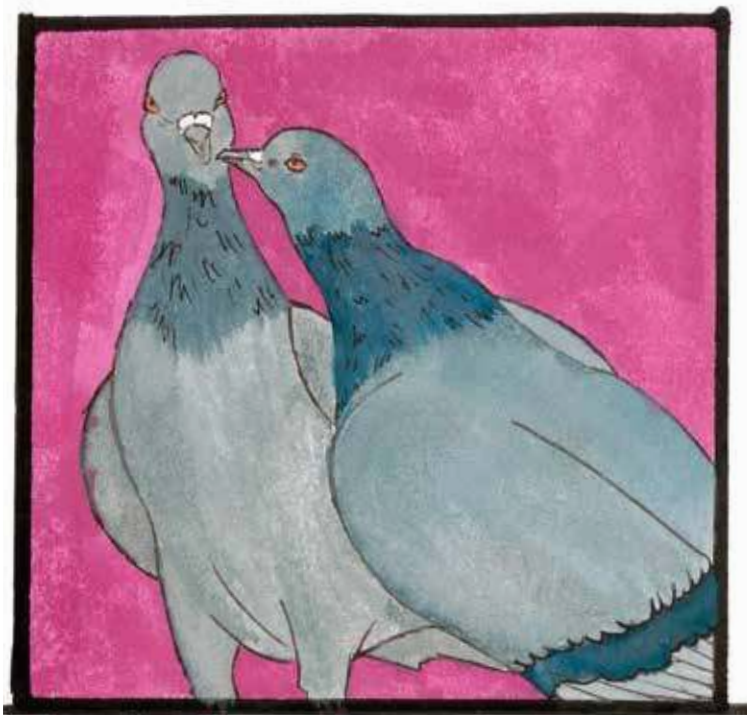




## My elastic's gawn!!!

**The days are long , the nights are too. My shoes don't fit , and I need the loo!**

Brain to feet come in please. Messages have to be sent with purpose. It used to be on automatic pilot, not anymore. In fact it takes several tries to stand from seated. I say it's like being drunk without the euphoria. I Could write about my diagnosis, I could write about the journey from health to broken but life is normal after years of coping with my MS [mad socks] I call it. After all everyone goes to bed, gets up in the morning, brushes their teeth, combs their hair. It's unique for everyone. I hate this thing that demobilizes me but it has changed my perception of life. I have time to watch, time to wait, time to think. I even care about things a lot more, people, animals, plants. I say think, because that's what I can do. Thinking positive, trailblazing high roads, mountaineering, flying in a hang glider. People watching is a good pastime; You know her at number 23, well she shouldn't wear that coat with those shoes. Number 54 parked where he shouldn't have. The newbies, the youngsters just moved in at 18, went to fetch shopping holding hands and laughing. I remember that, young, in love, happy.



Pigeons, have you watched them? A pair coo cooing to each other, then necking then [well that's quite enough of that]. Do birds feet get cold? Mine do, absolutely freezing. Hot's not good either, they swell. Got support socks for that. But if you squeeze it from one place, it moves to another. So it could be the cause of my big bum. Morning sees the struggle to put them on then even more of a struggle to get them off at bedtime. I've tried moon walking like Michael Jackson, that's fun with a zimmer frame.

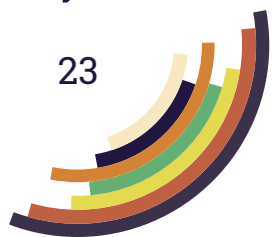
Showering is fun. Got a shower stool. Think baby elephant. Use the shower head like a trunk. Wet myself down, lather up, rinse. That's ok Nelly but hair washing with useless hands, very tricky. Awughaaaaa,, Awughaaaaaa. [elephant noises] and move over wrap in towels and drip dry. So now I'm knackered so back to bed. I can either go back to bed clean or go out smelly. Perhaps that's why I don't have many close friends.

New Game. Bought myself an electric powered carpet sweeper. Fantastic buy. It beats, as it sweeps, as it cleans. [heard that before]. Use it whilst tazzing around in my powered chair. It's like grass cutting really. Down the length of the room, turn, back up again. Got lines in it too. Just like the lawn. Putting 'shake and vac' down, just like 'weed and feed'. then vac up. You know, this predicament has stopped me doing such a lot but it does have bonuses too. Theatre visits are buy a wheelchair ticket and carer goes free. So if you can get a pusher who wants to chip in then jobs a good un. Also because I move in circles that I would never have had, I have contact with some amazing, lovely, people. Went to meet a group, my first MSers (people with MS) meeting. It was like an AA meeting. Hello my name is Sue, I have mad socks, £2.50 for a radar key and I'm in. These new friends changed my life. I found out I wasn't the first to have thoughts of what will happen when my feet don't work, or hands don't respond. Where do I go now? These lovely people gave me help, friendship, pointed me in the way to get up, dust myself off and start all over again.

Went to an MS national meeting one time and was talking to an amazing older lady. She had been a Nun in Australia. She had been poorly for years but was just a poorly lady. Gave up at the Nunnery, came to England, got diagnosed with MS. Numbers shown for MS afflicted head of population smaller in hot, sunny countries. I've met Asian people with MS. South African lady with MS so I wonder that if you were to live in a place without a doctors surgery round the corner with a hospital referral then numbers here may be smaller also.

I do get to see a Neurologist or MS Nurse once a year. My first question always 'got a miracle cure yet'? The Neurologist looks for any changes the MS Nurse is the project manager. She knows how to get help organised. Best of all are people who have had the problem before you've had it. So fellow MSers are invaluable. They're very forgiving too, they understand when you dribble a drink down your chin to your chest. Or throw a cup across the table, drop food on the floor. Best of all 'where's the loo' mid conversation. The OT's [occupational therapists] come and suggest items to assist but MSers have usually been there, tried that so can advise in advance of the OT's visit. Exercise is good for us they say. It's good for all I know but it's so hard. It's a battle to get up and get cracking with body parts that don't do as they were intended to do. I'm a definite useless lump of lard. [mother's expression]. But I enjoy singing. It releases endorphins or summat I just know it gives a feel-good factor. I'm fortunate enough to belong to a choir, yes it's for MSers. I go home on a high travelling the high roads home on my scoot. Singing away, no one to hear, cars speeding by don't notice, so with the wind in my hair, sun on my face and a song what else could this 'lump of lard' want. Better than the telly.

I do a fair few miles on my scoot. The first one I acquired was from a friend. Pauline, could no longer transfer from wheel chair to scooter so I was able to enjoy the last miles with 'Commander 1' as I called it. Wonderful lady, battled MS for over 30 years and is remembered for her lovely smile.





Naming scooters is another good pass time. So first scooter was 'Commander 1' after Pauline. I'm now the proud owner of 'Commander 4'. A friend has 'Razzle' so when she's out and about, she's out on 'the Razzle'. Now look if it's got wheels I've got it. Pavement scooter. Small scooter that dismantles for car boot or bus travel. Powered wheel chair even the zimmer's got wheels. No pretence, I'm wheelie Sue. I use the small scooter to travel on buses. After a couple of excursions a bus driver asked had I got a pass to travel. Hadn't a clue as to what he was asking. So he said that because the bus had brought me to town, then I was allowed to get aboard to get home but check with the Bus Company what I needed to do. I tried, emailed, letters, phone calls but not getting anywhere with my enquiries. So I carried on using buses.

Nobody was saying anything about boarding the bus until one driver said I couldn't board his bus. I wasted time and went for a later bus. So this made my mind up, something had to be done. Kept trying until one day an email came up trumps. Details I needed and an attachment for information. I opened the attached document and it was info for becoming a Bus Driver. Always fancied that but couldn't do it now. However, I managed to sort through tangle and had to go for a scooter boarding bus driving test. Now this test was only held in certain bus depots. Not one was Birmingham. I chose my nearest but if I can't use the bus, how do I get there? Needless to say, thanks to a friend I kept the appointment and am a proud owner of a license. Never been asked for it since but I make sure it's seen by each driver. Proud we are!

Off into town to hit the shops, bit of retail therapy. Favourite shops are charity. It's true what's rubbish to one, is treasure to another. They must have got so many donations they had added extra clothing rails. It was getting difficult to circuit the shop. Forward, backwards then a thirty two point turn. The rails are on wheels, getting hooked with a coat I made for the door. At the door, just noticed the arm rests had collected hangers sporting a swimming costume, a pair of shorts all I needed was the sun hat. Behind a whole host of assorted garments in tow. Whoops! Sorry lady I said 'I wasn't really shoplifting'. The staff were pleased when I left. I was pleased I'd left. Time to calm down, you've got the bus to cope with now.

I wish I could walk again. But if this is what life has in store then I must make the most of it. One life, less than a hundred years. So a few left for me to reek havoc. Let me out.

### **Reflect on My elastic's gawn!!!**

People cope with ill health in many different ways. This powerful and humorous story has lots of hidden meanings - what did you take from this story?

## MS - be positive - my mantra

Imagine –

A physical education teacher being told at 31 that she has MS.

COMPLETE DEVASTATION!

At the beginning it took a long time to get round this. Eventually, after a great deal of reading about MS, I decided to do and carry on with my life in a positive way. I was lucky in that at first it only affected only my left ankle. I had relapsing/remitting MS which meant it only affected me at different times – e.g. no set pattern, a relapse e.g. every 2 months, lasting around a week a month.

The left side of my body was weak especially my legs. Extremely difficult when you are a PE teacher. The trick was to cope as best you can, without having time off. It wasn't easy but you have to learn to live. It was hard as before MS I had represented my country at cricket in the first World Cup in 1973 and played for my county West Midlands.

MS is a difficult condition to explain, but with time and experience you are able to cope. As I said before I was lucky as every individual has different experiences of MS e.g. some can be straight into a wheelchair.

It is all about your mindset plus having the right people around you. Friends are a life line.

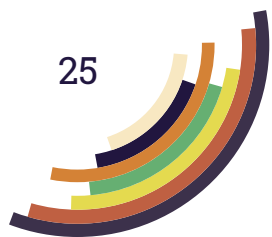
I am particularly grateful to Julie Robinson ([moveitorloseit.com](http://moveitorloseit.com)) which is an exercise class that instructs you to move your body as much as you can; in an hour every week.

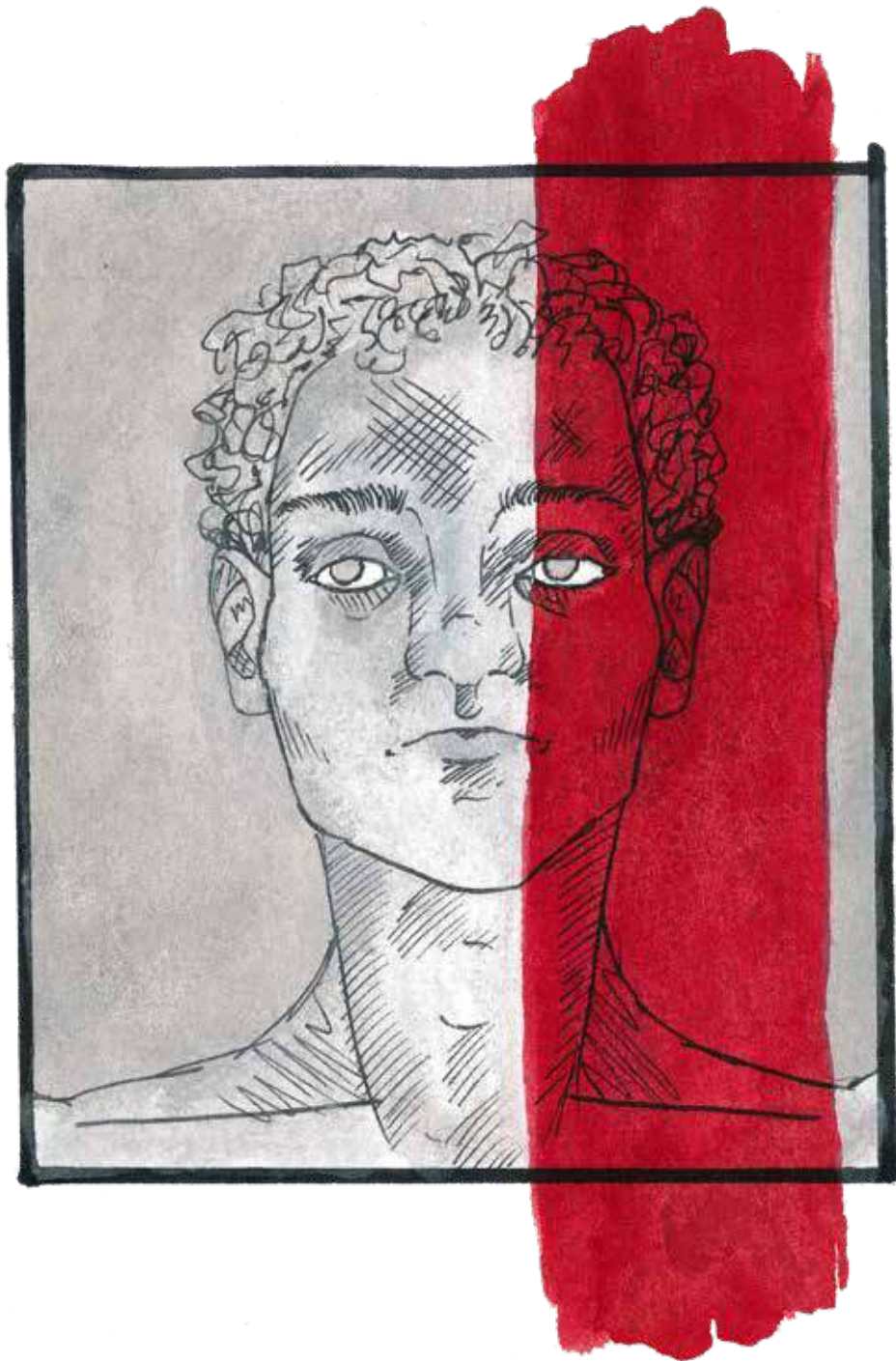
I must mention St Giles who provide the facility for the exercise class. This has kept me going when I am going through bad times. EXERCISE does help! Every person can find something to help.

I have had MS for 35 years and obviously I have deteriorated, but have only been in a wheelchair for about 5 years.

So, don't despair. There is life out there!

Just remember BE POSITIVE.





**Reflect on MS - be positive - my mantra.**

Coping with MS is often difficult, but resilience and determination can make such a difference. What did you learn from the story and what might you do differently as a result?

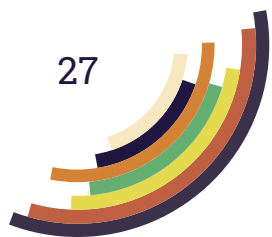
## Reflections of a member of staff

It is about seven years that I have worked (in an organisational capacity mostly) with the clients who have also written stories here. I have learned an enormous amount. I never thought I was in any way discriminatory towards people with a disability, however I realise that actually I knew very little - and perhaps inadvertently I was!

I am now more confident and at ease with all sorts of disabilities. I am OK with asking people "Do you want me to help?" or "Would you rather do it yourself?" Now when I see someone walking down the street with a disability I don't jump to conclusions about what might be their difficulty, as I realize I actually have no idea. All that matters is that if they want to continue on their own without attention that is fine, but if they want support from those around them it should be available. I also feel passionately that they should have all the opportunities that someone who is not disabled has, whether that is access to buildings, use of public transport or career and wellbeing choices.

I have also been humbled and amazed at how resilient people are with the challenges they face. One experience I should share from this work in organising and supporting sessions for clients with MS is how hard it can be for all of us to accept the next stage of disease progression. It is really tough to witness and share with people a deterioration in their symptoms, an acceptance that they might need an extra walking stick, aid, wheelchair, perhaps the need to stop driving. There is also a need for the staff and volunteers involved to occasionally challenge someone who is refusing to accept they are needing a change in their coping strategies. We do not have nurses or clinical staff on site so if people fall and can't safely get up on their own we have to call for the emergency services. It also might be necessary to discuss the need for a relative or carer to now accompany them if there are personal needs that the exercise instructor or volunteers cannot help with. This can be a block for people who enjoy the independence of coming to the hospice sites on their own.

I also think it has helped extend the reach of hospice care - partly because those that attend managed to get over the barrier of us being associated with a hospice and as a result now have a much better understanding of what hospices are, and what they can offer. They realise that hospices might not all be about people dying with cancer, but that in fact a hospice will provide care for people with many types of incurable illnesses. Also that the skills that hospices have to share can be useful in someone living well with their condition. Just as clients themselves are constantly needing to adjust to a changing set of symptoms, we are a service that needs to always be open and mindful for the need to change. Over the last seven years, new people have joined and sadly some have died. Many have had to cope with advancing symptoms and the difficulties that these bring.



The sessions have continued to have a strong focus on exercise, but as time has progressed have also incorporated complementary therapies, mindfulness, singing, information sharing and talks. We are keen to add even more variety if we can so that we can offer something for everyone. I have met such great people and personalities as a result of my involvement in the hospice's work with people with an MS diagnosis. It has been a learning curve. Most of the time they are so positive and determined to make the best of everything. The fight and resilience which many of the participants show is incredible.

We have talked about developing a new programme of "information sharing" - ranging from clinical information from an MS nurse/expert, to ways to enhance one's social life by maybe using a wheelchair/going on holiday with MS. Also political awareness and being proactive about educating others re. MS, and sexual relationships, finances, arts and crafts, Lasting Power of Attorney's, gardening, and many others. It is great when we are able to introduce additional activities. For some years now a famous local guitarist (Gordon Giltrap) has come along to the hospice sites and played for us. It adds to the general buzz on site, as do the other activities that are happening in the centres. It is also great when the volunteer gardeners chat and mix with the MS clients - they have a very fond relationship and hopefully will be working together on planting some raised beds!

Every year for several years now those that enjoy singing have met two times a month to exercise their lungs- and also carol sing at Christmas in the local shopping centre! It has been a privilege to be involved in this fund raising activity, and very enjoyable for all. Food always makes for good bonding! We used to be able to include the cost of cake or lunch in with the exercise - but as time has gone on and we need the service to be as self-funding as possible, food is available but paid for separately. Nevertheless - it is a good time for everyone to sit and chat together - whether they are eating or not, and 'chew the cud'.

The group is extremely supportive of one another - including all the volunteers and staff. I never forget one occasion when one of the long-term clients noticed I was a bit down and had a lovely chat with me about how to approach things I was worried about. It is a mutually supportive environment for anyone involved and many strong solid friendships have been formed. Clients REALLY appreciate that the volunteers are involved the group purely because they want to be! That they enjoy spending time with them and want to help with the exercise, making the teas and coffees, helping people in all sorts of ways.

To quote a cliché - life is one big journey, and to be able to support clients diagnosed with MS on their particular path is without doubt a privilege. It is great that over the last 12 months we have been able to complement our service with the opportunity for those who are no longer driving and for whom taxi rides or lifts are not possible.



We have a “paid for transport service” where volunteers collect and return clients home in a donated bus. The volunteer drivers are much loved by everyone who comes on the bus and they add to the camaraderie of the day.

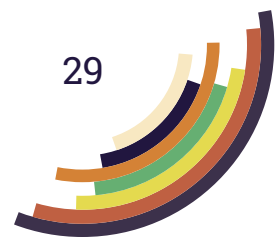
Over the years more and more people have come along to the groups and one of the overriding comments has been about how much support is gained from sharing stories and chatting to one another. I also think that one of the most valued elements is that we provide a place where someone can talk about their MS diagnosis and the effect it has if they choose to, but not if they don't. There is no pressure to be their best, or justify, or explain. I think that space is liberating and allows those who come some time to accept and adapt to the changes forced upon them by their MS.



Without wanting to sound too “cheesy”, I have learned so much from my involvement with this exceptional group of people. Not only the need to constantly re-visit and evaluate the service, determine whether it is coping with changing needs, but also the resilience of this particular set of clients. MS is such a long term but unpredictable and debilitating diagnosis, with many ups and downs, many challenges to be faced. Society still has such a long way to go in increasing opportunities and improving the quality of life for clients with an MS diagnosis and all those diagnosed with an incurable condition. I have known some of the group members of our MS services for many years now and consider them friends.

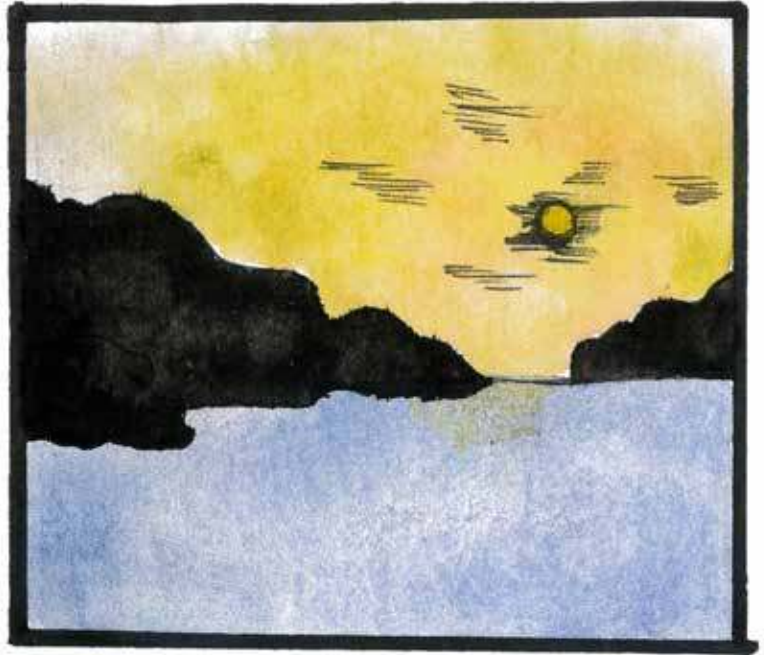
**Reflect on Reflections of a member of staff.**

What did you learn from the story and what will you do differently as a result?



## August 2018

I have just been swimming in the Gulf of the great St Lawrence river on the east coast of Canada. I am looking out to North Atlantic Sea, not far away, the Titanic hit an iceberg and went down on 15th April 1912. Close by is the countryside and fictional home of “Ann of Green Gables”, Prince Edward Island, Nova Scotia. Author Lucy Maud Montgomery wrote of “the wonderful red rich earth” that grows the King Edward potatoes. “Smart and shabby painted wooden houses set on grasslands with no fences and abandoned rusty tractors



in the fields”. Her saying “Big little world” resonates in my head. I am on an adventure, not much of a traveller or an explorer but suddenly grateful to be here in my advancing years and acceptance of those who are struggling.

I think of those at home, it is a Thursday. My thoughts run on to those people, who for no fault of their own, are confined to a “little world” and how some of them may have liked to be in my shoes. It reminded me of how one lady had spoken when a group of people with Multiple Sclerosis sat around tables together thinking about stories. Her life had once had been easy and straightforward. That life is now spent planning and working out how to complete even the most simple of tasks.

Restricted by lack of movement and power, almost fully wheelchair dependent, life confined to a “little world”, but still striving to get out. Mix with people and make all possible effort to hang on to the normal things about keeping independence and being “just human”. I thought of the lifeline that we offer to those with long term conditions by providing facilities that they can access, peer support and inclusive activities, where we can encourage fun and enjoyment and a sense of normality.

### Reflect on August 2018.

What did you learn from the story and what will you do differently as a result?

## An unexpected journey

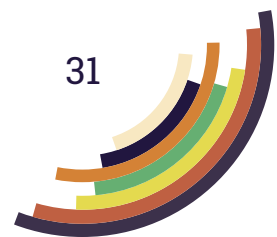
This is the story of an unexpected and unwanted journey which has taken me from being a healthy, fit person with an active, energetic life to one where I can barely walk without a stick and feeling old long before my time. It is a journey that encompasses many feelings and emotions from fear and anger, anxiety and frustration but eventually to acceptance and accommodation.

My first encounter with multiple sclerosis ('MS') was in 1982 at the age of 27. During a holiday in the Lake District I woke one morning with a mild problem with the vision in my right eye with some blurring and a small blind spot. A few months of inconclusive tests culminated in a lumbar puncture (which gave me the most excruciating continuous two-week headaches of my life). The diagnosis was that it was an attack of optic neuritis – nobody mentioned MS. It seemed to largely resolve itself over the next year and so for the following 23 years I gradually forgot all about it. My life was pretty average – I exercised – playing football, swimming, cycling and skiing in particular. I got married and had a daughter; got divorced; drank; smoked; ate badly; worked too hard; suffered from stress and anxiety – all the usual things but generally I was physically quite fit and healthy.

23 years later in 2005, aged 50, I developed a pain on one side of my lower back. It didn't seem terribly serious or sinister but it wouldn't go away and over the next couple of years I saw a variety of physiotherapists and chiropractors to little effect. By mid-2007 it began to affect my walking; my right leg felt heavy and weak and mobility became increasingly laboured.

I saw a neurosurgeon and then a neurologist and went through a battery of MRIs, X-rays and blood tests, courtesy of private medical insurance, but nothing of significance was found. I gradually became anxious and depressed as my condition was inexorably getting worse and nobody had any idea what was causing it. I tried all sorts of therapies, mainstream and complementary, all without any lasting benefits.

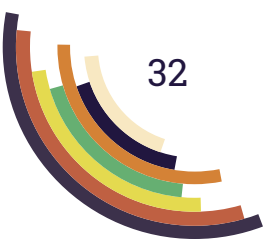
My journey seemed to have lost its way at this stage but eventually, in 2010 – five years after the initial presentation, I was given a diagnosis, of sorts - a rare condition called Hereditary Spastic Paraparesis ('HSP') which is entirely genetic, poorly understood and untreatable. Worse still, my daughter would have a 50% probability of inheriting it. HSP wasn't positively identified but was diagnosed on the basis that the symptoms fitted and everything more obvious had been ruled out. I recall asking the neurologist if it could be MS and was told there was no indication of the usual signs on the MRI scans and that the gradual accumulation of symptoms was not typical of MS.





Despite a second opinion from another neurologist, this turned out to be a wrong turning or a dead end, whichever you prefer. Unhappy with the accuracy of this diagnosis I located an HSP specialist in London and with some persistence on my part, he performed a(nother) lumbar puncture, this time without the awful side effects. This confirmed there was something abnormal in my spinal fluid which was inconsistent with HSP. Many other possible conditions were ruled out by further tests and MS then became the most likely candidate. In 2012 further more powerful MRIs confirmed the diagnosis of progressive MS. It had been a long and unhappy journey and my initial reaction was partly some relief that it was over, with the comfort that my daughter's chance of contracting the condition, although above those of the 'normal' population, were still only around 1-2%.

I don't believe in fate or that everything 'happens for a reason' or in any cosmic guiding hand. I don't know if everything is either pre-determined or probabilistic but I feel that things just happen the way they do without reason. My path may have been influenced by a combination of my genetic structure, over which I had no influence, or the experiences during my life, which I had some control over, but ultimately any connections are far too complex to identify and so I don't feel particularly responsible in any meaningful way for my condition.



I don't know if the specialists I saw in 1982 even considered that my optic neuritis was an early presentation of MS (what would now be called Clinically Isolated Syndrome). There was no drug therapy available in those days anyway, so even if they did consider it, they may have considered it better for my mental state to say nothing. Nowadays, when disease modifying drug therapies and lifestyle recommendations abound, I should like to think it would be different and that such an early episode would have triggered some sort of intervention and advice which could have prevented the later development of full scale and unstoppable MS.

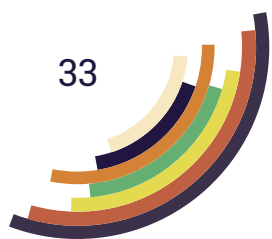
But now I have it and the damage is done – and is continuing to be done at its slow but unrelenting pace. There is still no treatment for this type of MS despite many years of research and, frankly, the NHS in my area is too stretched and under-resourced to provide more than a cursory level of monitoring and little or nothing of a proactive nature. Even if something were to be developed in the next few years (which is highly unlikely) the best I could hope for would be that future damage could be slowed or even halted. It is probably already far too late for any meaningful recovery as my nervous system is already damaged beyond repair. Consequently, and probably rightly, scarce research resources are focused on helping people at the earlier stages of the disease and with the much more common relapsing/remitting variant.

At times it feels that many of us who are 60+ years old and have lived with the gradual damage of MS for, in some cases, decades, are overlooked as being beyond more than minor symptomatic relief.

Although I try not to dwell on the past or contemplate the future more than I have to, sometimes I cannot avoid wondering how different my life would have been if my journey had taken me down a different and happier path.

**Reflect on An unexpected journey.**

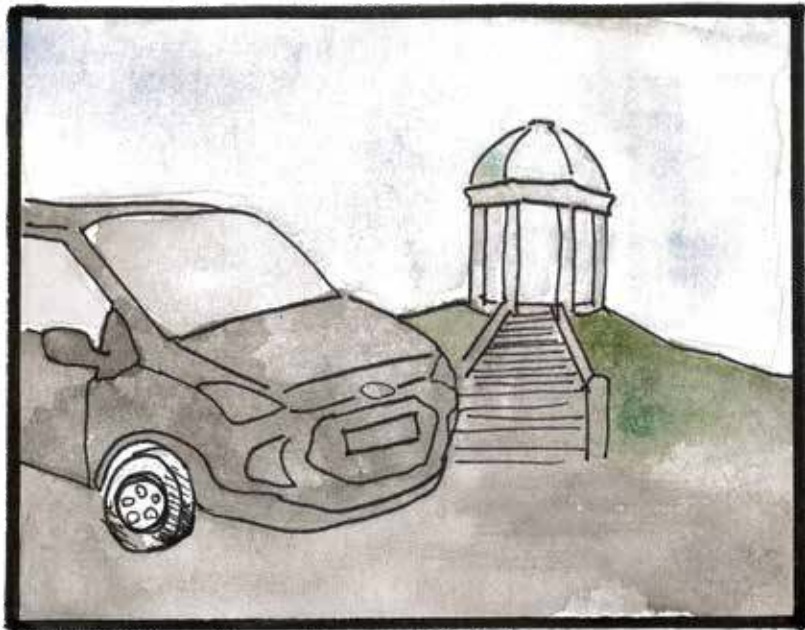
What can you personally take away from this story and how might this influence what you can do differently in the future?





## Dawn's story

I was diagnosed with MS in April 2007. For years I'd been having these instances where it could happen in the morning and I'd be walking down the street and I'd fall flat on my face. People would just look at me to say 'She's drunk' and that early in the morning. Walking became very painful, my legs got tired and that's what made me go to the doctor. It was the paranoia. The GP referred me to the QE where I had an MRI and a number of tests and then when I went back to my GP he confirmed I'd got Multiple Sclerosis. I knew a little bit about it. I remember when he told us, me and my husband drove up to the top of Barr Beacon and sat in the car and sat in silence for about half an hour. But it was more him that was shocked and was upset than me because I knew, I knew, at least I knew what the problem was. At least I could find out ways to deal with it. It was a relief to be told. It wasn't upsetting, it was more of a relief. I had points that before that I thought 'You are really unfit, you're only 27' and it wasn't that, I've got this disease.



It doesn't really affect me day to day. I have my good days and I have my bad days but I've learnt how to cope with them. We're fortunate we've got amazing MS nurses, they are fantastic and I think that's what helps as well and helps me deal with it, because they are so good. And I've got the group at St Giles to come to. I know that if I do have instances where I am going out walking and I have pains I know I need to sit down somewhere and give my legs a bit of a massage and then I can get back up and carry on. Good days I can do a walk that I have to make to walk to my daughter to school and I have to go through a gully by the houses and that on a good day takes me eight minutes. On a bad day it can take me twenty plus minutes. I know when I wake up what type of day it is.

It's good to come to a group to speak to people, We're all different, everybody has different symptoms and deal with it differently. We can't be branded as the same and it annoys me when people that don't really understand about MS, just put you in the same bracket as everyone. We've all got our different phases. My mum for instance will say 'You can't do this and you can't do that' and can't is a word I hate. I can and I will. I might go about it the hardest way but I'll do it. It's not going to beat me. It's not going to define me. Multiple Sclerosis is not what defines me. I like to be individual, I don't like being the same as everyone else – I never have, even as a child I didn't want to be the same as every other child. I had to have something different, a quirk about me. Cheeky sometimes probably, I could be cheeky. Being diagnosed is not the end of the world. When I was diagnosed I said there's people out there, there's younger children that have had far worse, it is not the end of the world. There are ways and means of getting about it and there is help. Don't be afraid to ask.

My older sister, she looked up MS when I got diagnosed we looked at a lot of things on the computer and we printed off some information and my mum didn't even read the information. I think it's like a denial, she's your child, you can't look at it. I might be the same if it was my daughter, my child. You don't know do you? I think having my daughter was, well people say that you can't have children when you have MS, but you can. And having her as well, it pushed me and it keeps me going, it really does and it is the best thing we've done. She's 7 now. They used to think that MS affected pregnancy but it didn't for me, it never affected mine. Some people, yes, they can have relapses but I continued my treatment because there was more of a chance of me not having a relapse. I didn't have any falls with her or any trip ups. Maybe there's something in the back of your mind that tells you that you've got a little one growing inside, so you can't fall. It was hard getting pregnant. I had four miscarriages before I had her and when I fell pregnant I didn't believe it. It wasn't until I did three pregnancy tests at home and two at the doctors and the doctors took me upstairs and got me to listen to her heartbeat and said 'Do you believe it now?'

But it's when people say to you 'Are you going to have more? Are you not going to have more because of your MS?' No, that's not the reason. The reason is because of the emotion that I went through when I had all the miscarriages and now we are happy as a three, a little family. I've said it to my mum at times when my mum said you are not having more. At first my mum couldn't, she wasn't happy like lots of mums would be because all she could think about was me and my MS. And that really upset me. I understand now I have my daughter that all she wants to do it protect me.

**Reflect on Dawn's story.**

What key messages do you take from Dawn's story?

## John's story

I was in my early 20s and I was staying at my girlfriend's house (now my wife) when I woke up and I couldn't move my legs. They were totally numb, shockingly numb, just like I'd trapped a nerve. There was nothing unusual that day, I hadn't had an accident that day so I went to the doctors. They said it could be a trapped nerve when I was riding my mountain bike around campus or it could have been caused by banging my head when I played rugby. There was a big long analysis and I went to see a consultant at Leicester Royal Hospital and there was a lengthy process and they said we'd have to wait and see. Eventually I needed a lumbar puncture which is taking fluid off the spine, which didn't go brilliantly because they lost the fluid sample, then had to do it again, which wasn't too pleasant. Then they said 'Well, we've got enough information and we know it's MS.' And that was just 'Oh my god what is this?' I had no idea what MS was. The only thing I had seen was a series of posters from the MS Society of people with their spine taken out, which were quite shocking.



So then they put me on steroids and they needed to put me on a large amount. That was shocking treatment in itself, because they are small pills with big side effects. Five little pills that affect you quite a lot – mood swings and you don't sleep when you are on them. They knock your mind out too. You take them in short bursts in a large dose. I'd got the lapse and remitting MS, which is the first type. You take them when you have a lapse. It's a general shock to the system mentally and physically because it's a chronic disease and it's not something you think about when you are an undergraduate and enjoying yourself and being young and immortal. No one else around me really had experience of MS – lots of family were researching and finding things out.

A friend of my mum's has MS and that was really difficult, because it can vary. You can be like me and live longer with the relapsing and remitting for a while or it can be really significant. I've had more than I was entitled to in a way, I was relapsing and remitting for 15 years. There is a mixture of impact – there's the uncertainty of 'When will it take me?' which was psychological and the physical side of it, when you think 'Oh my god it's coming back' then it would go again. There is the physical side, but the mental side of it is there too, 'What's this disease going to do to me?' and 'Will I die quickly or will I have a few years?'

Initially the information is out there and you turn away from it because you don't want to deal with it. You are in denial and you don't want to face the MS. And you shy away from people with disabilities because you are blanking it. It's too scary to try and forecast the future, too uncertain and it leads to a train of thought that's never good. My diagnosis changed from lapsing/remitting and became secondary progressive later than usual really, I can't say I was lucky but it was more delayed. I was getting worse and not having an attack so I queried it with the doctor and they said this will be your secondary progressive. So there's a plus side as the attacks were horrible, vicious and quick, but the secondary gets worse over time and is less treatable in a way. I joined the MS Group 18 months ago and until then I didn't know anyone with MS, or talked to anyone who was a fellow MS person. It's quite a thing because you see lots of people in wheelchairs but we don't talk about MS as a group. We do mention it of course, but it's not all let's talk about our condition. We talk as people who know each other as friends and form groups and talk about this and that. Lots of things to do with MS we know, we're already aware of that. So someone saying 'Let's sit down and talk about MS' isn't important. I wanted to do some exercise and some activity so I went once and that was OK, then went twice and got into going. I found myself enjoying it – they are nice people there and nice staff. They aren't tilty head, tilt your head and ahhhh. No one wants to advise each other because we know enough to know you can't advise each other and give out advice because it's an incurable disease so you can't say 'Oh it will be fine' or 'Cheer up' unless someone is just being a miserable git. You aren't embarrassed that your foot is playing up or that your hands aren't working. Sometimes I'll have to drink my coffee through a straw, and it's not something that people normally do, so elsewhere people might look or comment, but it doesn't happen in the group.

I've lived most of my adult life with MS so I don't know what life's like if I'd never had it in the first place. I've gone through denial, anger and eventually acceptance. I basically shoved it away at the start and then went through being very resentful and angry and very scared. And then trying to accept it, that it's here and I can't change it. That's kind of where I am now. Trying to accept it is very personal, the worst thing is 'Let's do a leaflet about this'. It's too personal to do a flyer. Sometimes you scream in your head it'll be OK but that's not true, it might not be OK, it might be awful and you might die quickly. The hardest part is the not knowing. But you don't know anyway. You could be hit by a bus next week. My wife and I dance around the future. We know it's there but we don't say 'Right you've got MS so you've got to plan around that', we don't want MS to be such a factor in the plan, although we do know it's there. In recent times we know it's happening and it's staying and it's permanent and changing lifestyle is more relevant than before. MS was a series of incidents, now it's a longer game.

**Reflect on John's story.**

What did you learn from the story and what will you do differently as a result?



## Me and my MS – or to be told or not to be told

It was 1972, I was 24, married, no children. Began to feel numb over much of my body, very strange. Unable to hold onto things tightly, getting on and off the bus was worst, could not tell whether I was gripping the rail or my hand had just let go. Would I fall off but no I survived! With much concern I went to see my GP who sent me to hospital. I was admitted to hospital, horror of horrors, I had never been to hospital before! I was there for a few days and had a lumbar puncture and various tests. The result was that I was told it was polyneuritis or something like that, I have forgotten exactly what! It would just fade away, yes, it did fade away until a year later when I was left with just tingly fingers. Soon learned how to tell if the washing was dry by using the base of my thumb which always remained quite sensitive. Cured.

In 1973 my first child was born, no problems.

Fine then until 1976 when I began to have slight numbness on my arms. Would not have noticed if I had not had similar before. Visit to the doctors revealed it was nothing, just hard work looking after a child, 'Take it easy'.

In 1977 the birth of my second child, again no problems.

1981. My mother died, I had a severe migraine, something I had never had before or since. I lost the sight in my left eye and had some lesser problems with the right. Urgent visit to the hospital where after tests I was asked what I was told when I had the problems with numbness previously. Polyneuritis was my reply. Just more of the same thing he added. Sight gradually returned, after 5 weeks was almost back to normal, no treatment required.

1986. Studying full time planning to move to Wales, husband's job move, children changing schools. All very stressful and I found that my tennis, badminton and squash had become very slow, always thought I was pretty good at these games! Soon became aware that the feeling in my legs was not good, numbness knew all about that. Visit to GP, '...think it is time you were told about this, it is in your records in 1972 that you most certainly have MS'. Explained that the only definite way of making a diagnosis was to look at the history. It was possible that it may never have recurred, note that this was pre MRI scans.

Hospital appointment made, two months away, would not wait that long, phoned the GP who arranged for me to see the consultant after his ward round the next morning. "It is MS but you will never be in a wheelchair and will have a normal life span". He was very helpful gave me just enough information and assured me an appointment would be made at his clinic.

With a great sense of relief, always good to get a name, I left the ward only to see a long, seemed long, row of wheelchairs along the corridor, how I would have loved to have pushed the whole row and sent them flying down the corridor.

So how do I feel about not having been told for nearly 20 years? For me it was the best thing, No worries about having children, continuing studying and many other things. No worries about my health, still don't worry. Things have been slow which also gives me time to get used to each change. And not everything is bad about being in a wheelchair and being disabled, people are so kind.

So what is life like now? Pretty good. I do use a wheelchair almost all of the time I am outside, but not in the house. My MS has continued to be slow as predicted. All the usual things, poor balance, eyesight, can't drive anymore, poor sense of feeling. I could go on and on but anyone with MS will be aware of many of these things.

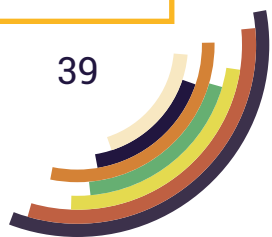
So what are the perks? Mixing with other people with MS has become very important, the MS exercise class at the hospice, MS Group meeting in Lichfield, contacts when I took part in a drugs trial and the kindness of people.

Then there are the discounts at the theatre, concerts and exhibitions which I also enjoy. And travelling on the train is another bonus. I have no qualms about travelling on the train alone in my wheelchair – this is one of the places you see how caring people are. So everything is not bad!



**Reflect on this Me and my MS - or to be told or not to be told.**

What key messages do you take from the story and what will you do differently as a result?



## Conclusion

### Professor Sue Read

Emerita Professor, Keele University, Staffordshire.

This was the first time we had worked together and organised a short book around the lived experiences of those with MS, and it was an incredible learning experience for us all. The stories originated from lived experiences and demonstrate the breadth and impact that multiple sclerosis has on those whose lives it touches.

Whilst the research paper will document the findings from the research, there were a number of common themes throughout the stories that were submitted:

**Resilience:** where the impact of MS, however profound, can be overcome.

**Loss:** we know that loss is not just about death and dying but encompasses a whole range of life experiences across the lifespan. Reading the experiences of MS from a number of different perspectives provides powerful, human insights into this condition and its rippling effect across the family.

**Knowledge and understanding:** when we held the writing workshop, people with MS were fearful of what to write and how to write it, and questioned who indeed would want to read about their experiences. We were all hugely impressed by the quality of the stories, the knowledge, insight and understanding of this condition and how the authors of the stories wrote in such a confident way.

**Compassion:** inexperienced writers wrote their stories with thoughtfulness, dignity and compassion. Who better to help professional carers to appreciate what it is like to live with a condition that is so variable and unpredictable than those who are experiencing it – the expert people with MS themselves.

Each story ends with a guided reflection; and the learning points at the end of the book are to encourage the reader to share and consider what they have taken away from reading the stories.

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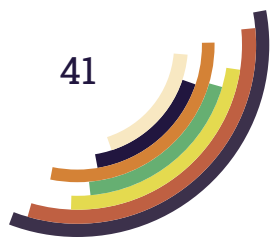
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## Links

[www.mssociety.org.uk](http://www.mssociety.org.uk)

[www.ms-uk.org](http://www.ms-uk.org)

[www.mstrust.org.uk](http://www.mstrust.org.uk)





## Learning points to consider:

1. Do you often consider the impact of a diagnosis on people with MS and the family?
2. What resources (people, organisations, charities, booklets etc.) are you familiar with to support people with MS?
3. How often do you consciously reflect on the people with MS you support?
4. Think about your life now, and how losing just one of your senses might affect it?
5. How might you help someone with a life changing diagnosis to come to terms with this news?
6. How do you think labels and language can empower or disempower people?
7. How do you support people with MS to reflect and have sensitive conversations?
8. How might we educate the general public about long term conditions and their wider impacts?

9. What can people with a disability teach us about life?

10. How might you sensitively encourage resilience and determination?

11. How important is it for professionals to reflect on what they do and how well they do it?

12. How might you encourage your colleagues to learn from people with MS, from their journeys and stories?

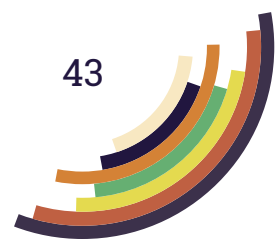
13. How can we possibly estimate the losses associated with MS?

14. What advice would you give to a newly diagnosed person with MS about the roads ahead?

15. There are many examples of determination and resilience in these stories, how might you translate this to helping other people with MS?

16. Because MS is so unpredictable, how does this influence your ongoing support?

17. How can peer support help people at different stages of diagnosis and illness to navigate stages of denial, anger and acceptance?





A St Giles collaboration with Keele University



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The proceeds raised from the sale of this book will help fund vital care for local people and families living with terminal illness.

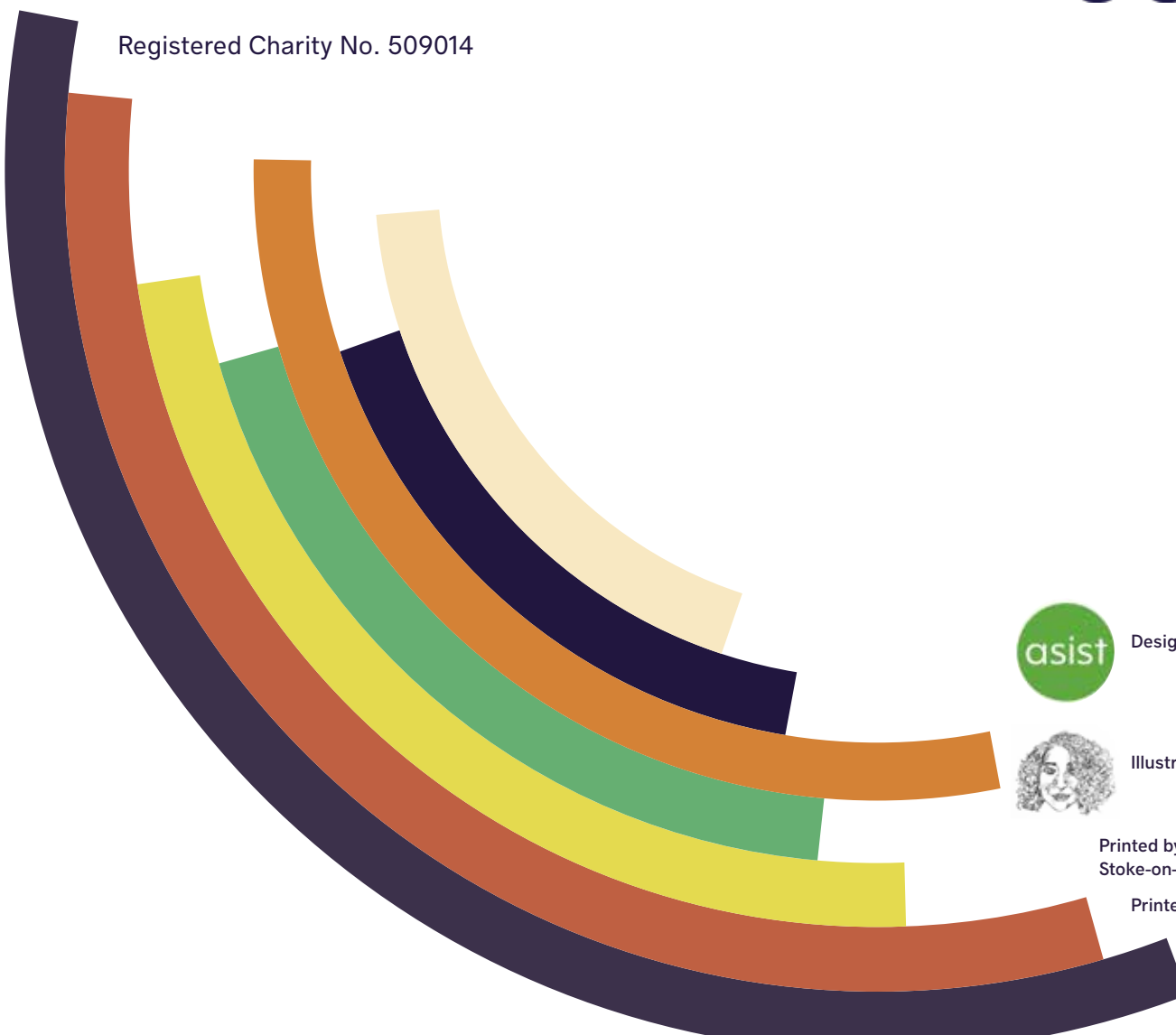
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