

# HAPPILY DISABLED



**Stuart Rose**

# Happily Disabled

Overcoming unhappiness in disability:  
21 chapters portraying caring, mobility, sex,  
anxiety, anger, pain, relationships,  
depression and more

Stuart Rose

Private Internet Publication

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Front cover photo: Norfolk wedding in powerchair.

This is a free Internet copy of *Happily Disabled* for the enjoyment of all who wish to read it. If readers would like to make any comments about the book's contents these should be emailed to [sr.kaivalya@yahoo.co.uk](mailto:sr.kaivalya@yahoo.co.uk).

## What's been said about *Happily Disabled*

**MS Society Local Support Worker** 'I think your book is very special. It is a book of many depths, absorbing and brave when it comes to symptoms and realisations (i.e.: continence and sex) that even for those with MS are difficult to put into words and are thoughts sometimes kept within oneself and away from our nearest and dearest as well as health professionals. I find your writings very thought provoking and feel that this is a book to keep by oneself, to read when happiness seems a little distant in one's everyday life.'

**MS Specialist Nurse** '*Happily Disabled* is very well written and enjoyable. My first thoughts were that it was very thought provoking and challenged perhaps longstanding perceptions about quality of life and happiness! It could be a valuable learning tool for people with MS, their carers/families and health professionals. It would, I think raise some debate and discussion about what defines happiness. I did find it both poignant and humbling in parts and have what I felt was an intimate and honest insight into a person's experience of living with MS. There were also parts that made me smile and others that made me a bit sad!'

**Occupational Therapist** '*Happily Disabled* is very philosophical with much psychology, too. It kept

throwing up questions, especially the issues of happiness, freedom, acceptance and truth. I found it a very interesting and honest account. MS is not the easiest of subjects to read about at any time and some very valid points were raised.'

**Neuro-Physiotherapist** 'We take everyday activities in life for granted, becoming so easily frustrated when things "don't quite go as planned". This remarkable book provides such humbling insights into the daily struggle of a person living with a physical disability. The overwhelming depth of character shown to overcome this and retain a sense of perspective and happiness throughout is very powerful. A lesson that can be learnt by each and everyone of us who has the privilege to read this amazing personal story.'

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## Introduction

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Is it possible to be happy with any form of disability be it paraplegia, blindness, loss of a function or limb, chronic depression or neurological diseases like motor neuron or MS, for example? Every part of the experience is full of shadows and blocks; only occasionally is there a glimmer of something resembling happiness, and then it's usually only short-lived. Mostly there's gloom of various intensities, of struggling through each minute of the day and night. Or is this a description of everybody's adventures in life, able or disabled?

There's no break in this life and what it includes, there is no chink in the cloud, no way out. For those who have a disability it's usually forever. I'm disabled with MS, which means that if there's a holiday I take my disability with me. I take it to bed with me. I eat every meal with it. It does everything I do and meets everybody I meet. It's my constant companion. The only escape is achieved through getting lost in my writing or then, if I had these, there's the TV, alcohol or whatever. But sometimes even this type of escape isn't possible and, if achieved, it's only temporary.

Some days it's just not possible to be happy. There's nothing available to do to change how I feel and the only thing left to do is to sit and wait, to ride out the negativity until the vacuum or gloom passes, even until life passes if it takes that long.

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I'm tired of all this progressive disability. Tired, tired, so tired of pushing myself up increasingly steep hills loaded with increasingly heavier burdens. I want to stop, to rest, to put down my load, but there is no stop – life may slow down but it doesn't halt and so there is no rest. Where is the end to all this? Can't I get off this roller coaster for a bit?

2

Whether disability is caused through illness, an accident or birth 'imperfection', the basic story is the same. Happiness appears to be less available and what there is has to be fought harder for.

Is this correct? How can it be said that happiness is less available to disabled people than to the non-disabled? It's illogical. What has happiness got to do with disability and how does this compare to anyone who has lost something dear and precious, for instance a partner, a home, a wallet, a penknife or a cat?

Happiness is not dependent on ability or disability. This is proved by the fact that my happiness was experienced before the onset of disability and, if anything, it has only increased since, oddly mimicking my disability's long, slow progression, except in the opposite direction.

Yes, OK, disability can bring or increase unhappiness, but this is as well or the same as many other things, for example having one's home repossessed, missing winning the lottery by one number or breaking a leg. In all things that happen to a person

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there can be both happiness and unhappiness, and which of these opposites that dominates is up to the individual concerned to expand or shrink or bring to the fore.

Where do happiness and unhappiness come from? It's blatantly obvious to see that they cannot be bought, borrowed or stolen, although these activities have their effect. It's also obvious, when thought about, that they only come from one place, which is inside me – the stimulus may be external but the feelings about them can only be internal. These feelings are not in my limbs, my eyes or my bowels; they are only in my mind, which is why the physical condition of the body, although influential, is not directly involved. This means that the experiences of happiness and unhappiness are only up to me to fully bring about because I'm the only one inside me.

Unhappiness is shied away from, like the plague! Few people purposely want to be or go out of their way to be unhappy. Most of life's endeavours are targeted towards the production of happiness in its many manifestations (a main one is pleasure). And whether one is able or disabled makes no difference. Whether one is sane or insane makes no difference. This is because either or both can occur whenever there are thoughts. Even on a deathbed, a person has the choice of thinking happy or unhappy thoughts. Is there such a state or time when there are never any thoughts, sane or insane, that is outside of a certain meditative state, deep and dreamless sleep or a coma?

The decision to be happy comes down to personal choice. Whether I am able or disabled, the experience

of happiness is my choice. If I don't choose to be happy or unhappy then I won't be either – instead I'll float along through life in an indeterminate, neither happy or unhappy haze. Being anything is an active choice which has to be made!

Yes, I already have all the happiness there is to be had in the world – it's within my grasp, within me. Where it is can be described as a bottomless well or an endless encounter. Is that believable? If it's not, then where else can happiness be? Do I have to ask for it or beg for it and if so from whom? But no, happiness won't be found unless it has encouragement from within to help it blossom and bloom, unless I do the work. This cannot be delegated.

My disability is secondary progressive multiple sclerosis, which is not all that there is to me. Happiness need not be in some parts of me and not others; it can permeate throughout all of my being, the good bits and the not so good. It's up to me to tease it out and not to block its blooming and spreading throughout all parts of the mind regardless of what they are and what state they are in. It's a weird human phenomenon but happiness can be blocked from occurring for all sorts of reasons that are different for everybody at different times.

How does one make happiness bloom with disability? That's what this book is all about. And to do this every aspect of MS will be looked into in the form of eighteen blow-by-blow accounts of what has happened to me and how I have dealt with, coped with, liked and disliked them. The story is autobiographical and

therefore unique, but there are likely to be many commonalities in the experiences I have tasted, not only among other people with multiple sclerosis but among the wide varieties of disabled people as a whole everywhere.

### 3

A lawyer once said to me that if only something had been done in the beginning, the pickle I was in would not have happened. With hindsight we can always say “if only” this or that. Well, it never is. Can we say that we chose to get into a pickle? No, of course not, we wanted something better or different but it didn’t happen. And this begs another question that will pop up through the book which is, who is in control? This question can have a surprising answer, but for the moment the answer is that I’m in control!

This book is my story about not getting into a pickle now, not staying put, but always moving onwards and upwards, becoming more and more positive and accepting of disability, getting on with the business of living my life, enjoying it and about finding increasing happiness.

What is meant by ‘disability’? There are many different types and levels; some of these are common to the multitude of people who have it and some not. Yes, let’s be positive about disability. We have it, it’s not going to go away, we still have this life to live, and living happily and contentedly is a very much better way to live it than

the opposite way, in unhappiness and sadness or even in anger.

Disability can be purely physical or purely mental but it's often a mix of the two. I can only speak with certain knowledge of MS, which was diagnosed over thirty years ago in the late 1970s when I was just 30 years old, although who knows when and how it began. In disability as a whole there are also birth abnormalities, accidental disabilities, age related disabilities and so forth. How many of us are there? Is it a small percentage of the total population or are a majority of people disabled in some way or other at some point in their lives? Some people escape disability throughout their lives, but the percentage of the total who escape it fully is, I suggest, much smaller than one might at first imagine.

In this book I don't wish to imply that all disabled people are sad. The truth maybe is that as a whole we are no sadder than non-disabled people, but we do have a few special 'challenges' to work through.

Talking about finding greater happiness implies there wasn't enough in the first place, that there was too much of its opposite, unhappiness and sadness. In my case that's true, as I was unhappier when able and now have greater happiness when unable! Is it true in everybody's life that happiness comes out of adversity? Yes, there is happiness but sometimes or often it's difficult to find. What's left is either a nebulous in between or clear unhappiness. There isn't anything else than these three, and life fluctuates by flowing smoothly, haphazardly, slowly or quickly, backwards and forwards

through the spectrum. Does it ever stand still? Can it stand still solely on the upper, happy plane?

To tell my story, the best place to start is to look at aspects of my disability one by one, albeit with digressions, about how they have affected me and what has been found or done to overcome their results. This method looks at what help (or hindrance) I've had and what has worked well, what's been funny and not so funny. My life has been full of twists and turns like most people's, but I found a way to beat the pain of life. "Sock it to me", I now say, the pain (both physical and mental) won't make any difference, any lasting impact, any big dents, because there is a solid foundation of happiness and contentedness underlying all that is in my life.

There are three parts to my story. First, nine physically-based encounters are told. Second, nine mentally or emotionally-based encounters are told. The final part recounts and explores how my happiness has been found and how it can be maintained.

Through these pages I'll be using this word 'happiness' a lot. By the end I hope you will see what I mean and how increasing amounts of the 'stuff' can be found. I don't need to tell you that it's the best thing in life and that it's freely available to all. You know that. And this story isn't saying anything new or earth-shattering about it, it's about turning the bad into good, the blackness into light, and the looming emptiness and death into fullness and aliveness.

There is one trap that needs to be avoided. Its snares are everywhere. The trap is forgetfulness. It's surprisingly easy to forget happiness (although not so

for unhappiness) and when this happens, straight away the 'boat' starts sinking. Constant vigilance or constant bailing out is the choice. I've little strength left in my arms so bailing out is hard. If I stop the boat sinks. So then what to do: sink and let the fish have me (that's easy but why give them a feast) or swim to the shore which cannot be seen (that's hard)? So it's better to remember than to forget how to stay afloat in the first place, to keep remembering what's needed to maintain my happiness and equilibrium.

The descriptions of different aspects of my disability which follow are in no particular order but will build into a comprehensive 'dossier' of my experiences. I will not be talking about things I know nothing about, which means that some, although not many, aspects of MS are not covered and some incidences of the wider panorama of disability, as a whole, won't be included.

#### 4

Throughout this book little autobiographical snippets will occur but first some background information. I am 64 years old, had a short marriage, have three children and now live happily on my own. When aged just over 30 I spent three weeks in hospital with an indeterminate illness which was later diagnosed as MS. When the doctor told me the diagnosis, she was quite hesitant at what my response would be, but I didn't know anything about MS and at the time I felt fairly well so it wasn't a bombshell!

Life carried on mostly unchanged. There were relapses and the odd spell in hospital usually for steroid infusions. Some blindness in one eye occurred but went away after a while. In reality I was just too busy to notice if anything was happening and what I did notice was pushed to one side.

Before this time I had worked in many different fields but now I had a career in advertising and over the years rose to become deputy MD at an office of the world's largest advertising agency group. It was a good life but it took all my time apart from what I could spend with my children and so I stayed on my own. I felt that I wasn't a particularly attractive 'candidate' for romance because of the MS and what I might become and, barring exceptions which I relate, I was not particularly drawn to anyone and no one was drawn to me.

Then my career came to a turning point: to progress I needed to move and the options were vaguely stated as a brand manager for the Middle East, Europe and Africa based in Nigeria or creating a new role in an office in the North of England. The latter was more attractive as moving far from my children was unacceptable, but I also knew that MS was starting to become more invasive and could only increase so it would be better to change careers while I was on top.

When in my early 20s I had gone to university but not lasted very long because of family reasons and I had always wanted to go back and start all over again. That was my choice and it was financial suicide but I didn't care, it was what I wanted to do. So I went back to the same university in my 40s to study for a BA in religious

studies and while doing so it seemed appropriate carry on and read for a further three years for a Ph.D.

The MS progressed but I lasted the first course by just scraping over an 'obstacle'. This was because I was too stupid to admit that the physical act of writing in such a tight exam timeframe (degree finals) was beyond my capabilities and the result suffered, although not enough to stop me proceeding to the next course. After the final course I was medically deemed to be unfit for work and although some lecturing work was completed voluntarily at a different university, no job application bore any fruit, so I gave up trying. Since then my time has been spent in writing (with a few specialized books published) and living quietly, peacefully and happily, while the MS progresses along its course.

## Part One

### Physical Descriptions

## Caring

How can I be happy when the uncaring, half-asleep agency carer forgets to put detergent in the washing machine so the washing ends up unwashed. Or leaves half-filled urine bags lying around. Or when the carer goes off leaving me with the wrong cutlery and ingredients missing from my dinner. Or when they forget to fill my water bottle. Or when a strange carer turns up and knows nothing about me or what has to be done and I can't remember either. Or when there is an invasion of carers unannounced with one or more shadowing the main carer and my home is filled with untrained strangers all staring at me. Tell me, how can there be any happiness when all these types of occurrence continually happen?

How can I be happy when there is no continuity of carers or haphazard continuity? The carer doesn't get to know me and my 'peculiar' ways, they don't know or don't remember what to do, what to dress me with next, how to make the bed (a special way is needed because I'm 6ft 4ins tall), don't leave me with any water in the kettle, forget to dispense my medicine. Oh, the list is long.

How can I be happy when I have to get up at 7.30 a.m. each and every morning? The penalty of having a lie-in is having to stay put in bed until the next carer comes at lunchtime. And I miss breakfast. OK, the carer can put a new catheter bag on but if I defecate I would

just have to lie in it for hours. And it may not be a matter of choice that I stay in bed. I may be unwell. Come what may it's better to force myself to get up, but I'm not happy about it.

And at the end of the day how can I be happy when I have to start getting ready for bed in the evening at 8.30 pm and be actually in bed at 9 pm? If I want to stay up any later the penalty is that I have to stay up all night because, even if I slept in my clothes, I can't physically get into bed. And it would be cold. No matter what's going on, the curtain on the day falls without change at 8.30 pm and if for some reason I need to go to bed early, I can't, I have to sit and wait for the evening carer. And what a rush it is when she comes in the evening, especially if the call is at the end of her 'run' of half a dozen or more similarly 'fortunate' men and women. The pub, feet up and a cup of tea or whatever looms large in her mind (it's usually a woman) and the half hour visit is whittled down to ten minutes and she's out of the door as fast as she can.

How can I be happy when the carer's in a mood and moaning, usually about her employers, her work rota and the amount of travelling it entails, or that she had a heavy night before and had to get up early (to see to me or someone else), or that her new puppy has caused havoc in her home, or how lazy her husband is, or when she refuses to do a particular job quoting from the rulebook, mentioning those horrid words "Health and Safety". And when she reeks of tobacco first thing in the morning. Or just knowing that her perfunctory

performance is solely for her pay-packet and not truly out of much of a wish to help me.

The principal unhappiness is the inflexibility of agency caring (I've already been through three agencies), that whatever happens has to happen at a pre-arranged time at a pre-arranged quality, so removing much of life's spontaneity. How can this be transformed into happiness?

I live on my own and there is no family available to help me. Each carer's visit can be viewed as a one-way 'transaction' to help me, but that's selfish. There's plenty that I can give to carers and, in giving, I get happiness. What can be given varies with the carer, even with what time of day it is. Yes, out of choice, I would not normally come across these carers supplied by the agency, but I do and I need them to help me. So it's not a choice and I respect them for what they do. Cleaning up after me, particularly bodily waste, is not many people's cup of tea for employment!

Now I think, "Who's coming next" and prepare myself both to take and to give, mostly innocuous banter. Some carers are frequently critical of their employers (just like many employees) and I commiserate with them, or sometimes even scold them (tongue in cheek), getting them to look on the positive side. After all, they have a job with some security that they won't be laid off at any minute as there is a high demand for carers! Or we just talk and most prefer to talk about themselves, their lives, partners (or lack of), pets (dogs, cats, sheep,

horses, ferrets), gardening and even (if nothing else) about the weather.

Also knowing when not to talk is important. Several carers have said that they like coming to me because it's peaceful. I don't have a TV, nor radio or hi-fi. There's a natural quietness which pervades not just the ambiance of my home but all of the visit. They ask me, "Aren't you bored without 'entertainment'?" "No" I reply, "my company is best, I am happy with what life has given me and I don't need artificial means for happiness." OK, I could watch the television (BBC's iPlayer on the computer) and be happy. But does the happiness last beyond the end of the programme, and what sort of happiness is it (maybe laughing at another's misfortunes, secretly glad it's not me)? Usually this kind of happiness doesn't last, and another show has to be watched to maintain its momentum. Being happy inside is much more constant than this, it avoids the continual external input of pathos, 'canned' laughter or excitement.

There cannot be a peaceful quietness if I'm not this way naturally in my life. There cannot be much happiness in grumpiness. Because I'm happy with and in myself, it spreads to others. This is just the same way when someone else is angry or fed up and it spreads to others, where we need to duck out of the way so what the other person is spreading doesn't infect us. Carers experience the different moods of their subjects and bring it with them when they come to me. So I can take it as one of my roles as a 'service user' to carers to cheer them up or instil a little thoughtfulness on some aspects

(however mundane) about life, normally about thinking in a positive vein, not a negative one.

I'm not successful with everyone and forgetting to ask about carer's problems is not endearing. Principally, I try that by the end of their visit they have some satisfaction with what they've done. That gives them some happiness. And to always say thank you. Giving carers happiness spins off to increase my happiness – it's a win-win situation.

Initially I was unhappy at having to live my life by an external 'clock' but it turned out to be beneficial and the inflexibility is now also seen as good. How is this? Every worker has to get to work on time or risk the consequences. I need to work or do something to keep active and it doesn't really matter what this something is – it's the doing that is important. Yes, even being disabled there's work that can be done. In my case it's writing and to be able to write, discipline is needed. This means that having my day in a regulated framework, a top and tail, so to speak, of morning and evening carer visits (plus lunchtimes), enables me to order the day, and orderliness enables happiness – it allows it to flourish.

Knowing where I am in a time frame means that the number of choices that have to be made are reduced, which means greater stability and less worry and insecurity at having to continually choose what to do (when to start the day, when to have lunch, when to have supper, when to go to bed, and the rest). And I rest easy allowing continual happiness to be uppermost.

Sure, there are difficulties within the timeframe but these can be overcome with greater ease than if I was continually in an unregulated flap. And in all difficulties there's usually a funny side, which lightens them.

So the principal beef about inflexibility with carers is unfounded; it turns out to be highly beneficial. It's helpful for being a writer but if I were something else it would be equally good. An idle or an aimlessly meandering mind causes no end of unhappiness. That I write is unimportant; whether fit or unfit, filling the day in a regulated pattern is a great help to achieving whatever we can do, however small and insignificant it might seem, because at the end of each day there can be a sense of achievement, and this self-satisfaction automatically brings and increases happiness.

Now I have 'gone direct' with the help of my social worker and a specialist employment agency (who do all the nitty-gritty work like wages and deductions). This means that I now employ my own personal assistants who come when I say, do all that is wanted and needed without question – even if it's nothing but having cups of tea if required – and do things off their own 'bat' because they know what's needed. They don't need to dash off to another service user. They go shopping for me, take me out for a drive, even come on holiday with me.

PAs are still carers but much more so. They are happier, less stressed and paid more. The relationship between us is much more friendly and each of our lives

become more fully understood – we rely on each other, albeit for different reasons. This has obvious knock-on benefits for me in reducing my day-to-day stresses and allowing me to relax even more. Yes, going direct makes for a lighter and happier day at the mundane level, but doesn't change the fact that all lasting happiness is found within and in whatever circumstances we find ourselves. Going within to search this happiness out and bring it to the surface of the waking hours must always be the task at hand.

At present, I'm faced with the task of employing a new PA as one of my team of three has left. This is a difficult process but one that is well worthwhile giving a great deal of attention to so that, although most job applicants might be able to do the basic work, the right person is employed. The work on offer is varied because apart from the normal caring activities there are many extra things that need doing. For example, I've always done things myself so there are DIY activities, which has included making a new base for my toilet seat riser, repainting the front door, fixing the wheelchair and many other things. I'm the brains, but what I need is the brawn. Then there is driving long distances from my rural home to hopefully enjoyable destinations such as Liverpool Anglican Cathedral, places in London or the seaside. Currently I am having hydrotherapy and a PA needs to come in the swimming pool with me to help the physiotherapists so, obviously, the PA needs to be able to swim. The current PA who takes me swimming doesn't swim! I'm a demanding employer and so it's not an easy job to find a person who fits the bill completely.

In the past, mistakes were made. At the end in one instance, this person suggested that I would be better off living in an old peoples home and started telling me of one's that she recommended! She walked out straightaway in a huff at my retort. Now each applicant has at least two interviews so that we can start to get to know each other. Then there's a trial period or perhaps even two before things are set in concrete with an employment contract.

The task of interviewing job applicants is an odd one because the work at hand is very personal. It's replacing things that I used to do to and for myself, or what friends and family members might have done for me. In some respects, the interview process feels a little like selecting someone to be my friend or companion so the chemistry has to be right!

While it is very important to find the right people, this doesn't alter the fact that carers are an intrusion into my private life. The telephone rings and the PA hears the conversation, papers laid out for work are always in vision, my wallet and credit cards have common usage and when friends or family visit always the carer has to be introduced or asked to leave, which seems unfriendly or even rude. But it's my home and what goes on in it is wholly my choice, the PAs have their own home in which to do as they like. PAs are not friends or relations but the relationship between them and I can and should be friendly. The difference between the two can be a grey area but it's important for me to remember that PAs are employees, they are usually here solely for their wages and would not otherwise be encountered.

All in all, the relationship with each PA can be a happy and fruitful one. It's mostly up to me to make it this way, which means that I might have to swallow unpalatable things and make compromises but this is so that the result is happiness all round.

## Peeing and Catheters

How can I be happy when I need to pee and the flow cannot be postponed while, at the same time, I cannot get to the loo? Double whammy! This leads to all sorts of strange predicaments because the choice is wet trousers or do it here and now in the street. In public, people don't know what's going on and anyway what can they do except think I've had too much booze (I only drink water but it creates same problem). Not being able to hold my peeing or hold my liquor is seen as a disgrace, even a perversion in some instances. Anatomically, women have different problems but the result in this area is always the same.

How can I be happy when the first alternative is to keep the penis swimming in pee all the time, only surfacing briefly for a wash every three days? This is using a sheath, which is like a condom with a sticky inside and a pipe coming out of the end linking it with a pee collection bag strapped on a leg or around the belly. The very thought of using the sheath instantly made me say "no way" to this method as someone else, a stranger (female carer), would have to stick the thing onto my penis each time it had to be replaced because my hands and fingers wouldn't be able to cope. How embarrassing!

(The sheath method is used successfully by many more able men to give them the freedom to lead normal lives, particularly if there is a willing partner to do the sticking if needs be, but not all continence methods suit everyone.)

How can I be happy when I'm housebound for fear of peeing myself in public? So I stay at home or, if going out is unavoidable, I don't drink for a night and day, making it safer but not healthy. It amazed me how long one can go without peeing, especially in warm weather, by not drinking until safely back at home.

But even at home there are problems with the most obvious alternative, sitting on the loo to pee. What happened was that when I'd finish peeing and stood up, peeing would start again, straight into my clothes. Sitting to pee wasn't an option.

For months I managed by peeing into the bedroom basin. Doing it this way, my thighs were wedged on the basin holding me up, leaving both hands free and peeing was ok although I became more unbalanced as MS progressed. Then I fell, and fell again, which meant 999 calls and paramedics arriving to hoick me up. In the end, this way of peeing had to stop and I had to find yet another method.

The next method to try out was the American product, Bioderm. This is a novel stick-on 'pipe' which was developed by NASA to enable astronauts to urinate in a gravity-free environment. A pipe was stuck with special self-adhesive tape on the tip of the penis, thereby enabling it to stay virtually pee-free (not sitting in a pool of pee like the sheath method) all day and night. The carers had the sticking-on task of replacing the Bioderm daily as, again, my hands and fingers couldn't cope. The embarrassment had to be swallowed! Problem solved, or so it was thought.

How can I be happy when ‘welts’ started to appear on both sides of the urethra opening at the tip of my penis through using Bioderm. These were due to a vacuum created in the pipe by the flow of the pee. The British company marketing the product told me to stop using it. Help, what do I do. This occurrence was not unique they told me and it seemed a bit ‘not OK’ that a company could market a product with no warning that it didn’t live up to its promise for everyone. “Stick a pin in the pipe to see if that helps”, they advised. It didn’t. The makers phoned me a couple of times from Florida to find out more and said they were working on the problem, but silence since. Back I had to totteringly go to the bedroom sink. No one offers help, there was no alternative until desperation.

How can I be happy when a few days after inserting a urethral catheter (which runs through the tip of the penis to inside the bladder and don’t ask how that felt) to solve my problem, something went wrong. What happened was that I collapsed with a horrid infection, entailing another 999 call to be made and followed by a week’s stay in hospital. Antibiotic drips and many large injections of penicillin, then later back at home with yet more pills and still bits of blood coming out. Yuck!

Because of its circuitous route, having an in-dwelling catheter and being in a wheelchair it is a little like sitting on a golf ball in the perineum (which is in the crotch and through which the urethra passes) all day and the thigh muscles ache. Spasms and spasticity put more strain on the area by suddenly stretching and squeezing it. Although it worked well in continuously

draining the bladder (or intermittently if there was an on-off valve on the pipe), sitting on this pipe became more and more uncomfortable. For a man not so confined to a sitting position this problem would not occur so much and in a woman, the urethra is much shorter and isn't sat on in the same way, so this problem doesn't occur.

Later, it was necessary to go back to the hospital as an outpatient for a cystoscopy inspection of the bladder. This resulted in the necessity for a further bladder biopsy a couple of months later to check whether what was seen in the inspection was catheter damage (and repair it) or a tumour. It was the former. The doctor suggested, "Have a supra-pubic catheter, it will last longer and won't cause so many problems. It only takes five minutes to put a hole in the abdomen through directly into the bladder". I shuddered at the thought!

All this just for a pee.

Happiness is constant relief; happiness at not having to worry about peeing anymore. With a urethral catheter and pee bag, I can go anywhere, any time. But is this real happiness? What is happy in this: is the bladder happy? That sounds a bit of a nonsense. A bladder can neither be happy nor sad, it's just a thick conical shaped bag of muscle and sinew, a container or reservoir, temporarily storing unwanted fluid. What is it then that makes all the fuss?

When the bladder gets to a certain fullness, the muscles begin to reach their maximum stretch level and start sending messages to the brain informing it of the

situation. Then the clever brain recognizes this stimulation and automatically connects to another mechanism which registers that a pee is required. There is nothing happy or sad in this, it just is.

Where the happiness or sadness comes in is where the mechanism is relieved or frustrated, but it's not the mechanism itself which has these feelings. It's me and it comes from the thought that I 'own' the bladder, that the bladder is me and mine. Well, if I think this way then there's certain to be both happiness and sadness, but if I understand what's going on, that the sensation is just the mechanics of this part of the 'engine', this body, then why does there need to be any ups and downs in feelings? It's illogical.

To achieve happiness all of the time means that there has to be a conscious separation of the body from the mental sense of 'I-ness'. Only in this way can a constant happiness be achieved, which won't be affected by changing characteristics and sensations of the body. It doesn't mean that what is happening in the body won't be noticed.

Using the analogy of a car and driver, the car is not the driver and the driver not the car. The car is a machine with predefined abilities, for example in strengths and weaknesses (it won't fly, won't drive under water; it will rust, it will wear out). In driving the car, the driver is usually acutely aware of the sound of the engine, the sound of the tyres on the road, whether a window is open, whether there is a steering rattle and the rest, but the driver is none of these. At the end of the drive, the driver leaves the car. If there was a strange rumbling or

vibration, the driver takes the car to a mechanic to find out what's wrong. The driver doesn't go to the mechanic without the car.

This story is told to show by analogy that I am not my body, which means that if the search for happiness is made through the body it will ultimately fail because nothing is constant there. The fact that I have had lots of difficulties peeing need not affect my happiness because they are two entirely different things. If I allow one to overlap onto the other, then I will allow mechanical, impersonal events to impinge on and unsettle the status quo of me.

What does it matter if the engine coughs and splutters (has spasms and spasticity), what does it matter if the engine gets tired and can only travel short distances (fatigue), what does it matter that the tyres are threadbare (no feeling in feet and hands), what does it matter that the body is all crumpled and bent (falling), what does it matter that the engine is always choked (cold)? What does it matter or, more correctly, to whom does it matter?

The final episode in my peeing 'saga' was the unnatural and invasive fitting of a supra-pubic catheter because the urethra became more and more uncomfortable and inflamed with a plastic pipe running through it (which had started to feel like a garden hose). Although the indwelling urethral catheter is not natural, at least it uses a natural 'pathway' to the bladder and there is no surgery involved. Punching a hole through the tummy is certainly

not natural. A transport ambulance took me to the Day Surgery Unit at the local hospital.

No, I didn't want anaesthetic and while you are doing the cystoscopy and diathermal bladder repair, would you please cut a hole for a supra-pubic catheter, I asked. The surgeon was not aware that I would make this request at this time. Yes, I could have the supra-pubic but only if I also have anaesthetic. He asked me why I wanted one and my answer was not that I wanted to have sex which, I later found out, is a reason to have one in situations like mine, but so that I could pee more easily, more safely and without discomfort. Oh well, I begrudgingly agreed to have the anaesthetic but ask that not too much was used as it disturbs all the MS symptoms like a sudden wind through a pile of leaves!

All went very well with the procedure and there wasn't too much disturbance with the anaesthetic. After the body repaired itself there is now pure comfort in that it's not possible to tell that anything is happening except that the pee bag gets full and needs emptying every so often, particularly if a long time passes when I get carried away using the computer!

Well, yes, it's not all plain sailing as infections happen, particularly at three-monthly catheter changes, although only once to date for me. The urethral catheter caused not only bladder infections but a long-lasting epididimitis, too (inflammation of the testicles). Now months have passed in peeing with the supra-pubic catheter and all the difficulties and problems hopefully have been consigned to history. My hope is that this

peace lasts forever as I think all other options for peeing might have run out. And I'm happy, so happy.

Well, not quite so! Infections have to be an accepted downside of this unnatural means of pee removal. The type of catheter is now revised in an attempt to reduce infections. Now a silver-tipped variety is used which needs to be changed in four-weekly cycles by a nurse and so is less traumatic (on the basis that the longer it's in, the harder it is to get out) in its removal. This came about because another hospital infection stint made me determined not to have to repeat it as these places, good that they can be, are not set up for disabled people. And the food!

In all disability matters and although there is help and advice available my experience is that it's necessary to be proactive. No one helps unless asked and, as every person's difficulties are different, self-executed research is essential to find out what's available. As an example, the silver tipped catheter was not offered and the professionals had little or incorrect knowledge of its benefits and usage, even on a urology hospital ward! The Internet is an invaluable addition for self-education.

Happiness is not having to worry anymore about where and how to pee – its amazing how such little and seemingly inconsequential things, that actually aren't so little nor inconsequential, influence our lives so much. Everyone able or disabled has the same bodily functions and excretion is a necessary and vital part of the whole. No one likes it, but the relief when it happens well when it needs to is the epitome of physical happiness.

## Cooking and Eating

How can I be happy when I can't cook anymore and have to rely on others to do it for me – cooking and good food as a whole is one of the great joys in my life. Now I can't stand or sit near the cooker because the wheelchair is too big and I drop everything picked up; any form of cooking is just too dangerous to attempt, even using a low-level kitchen, even boiling a kettle.

How can I be happy when the expertise of many of the agency carers who cook for me is limited to the controls on a microwave oven and what the ready-cooked, processed or supermarket meal instructions say on the packet: cook on full power for three minutes and serve! This type of food and cooking is what most of their 'clients' accept; it's what they're used to and is maybe what they want, but not me. With PAs, at least I have the chance of training them.

When asked what the agency 'cooks' I had chose to cook for themselves and their families or partners the answers were worrying. One seemed only to eat main meals from the fish and chip takeaway, another mainly from tins and another from supermarket sandwiches. Certainly, their understanding of a healthy, balanced diet was in many cases zero. "What's this?" said the cook holding up a long green 'thing' from the fridge (a courgette). I cried in disbelief!

Food is vitally important not just to me but for everyone; it's essential for the body and the mind. In

fact our bodies and minds are made and grow from what we consume, whether it's healthy or unhealthy, whether it's solid, liquid or gaseous, and this includes sounds, sights, smells or tastes. The adoption of this widely known philosophy means that I try to eat good, fresh food all the time. This way of eating is good for anyone's health and logically must be more so for someone not in good health or in variable health.

I don't insist that anyone else follows my present diet. From birth, I was brought up in a meat-eating home with roast beef and Yorkshire pudding at most Sunday lunches. Later in my life, many, many different types of animal, bird and fish flesh were eaten and, at odd times and places, things like biltong, badger, pigeon, oyster and so forth plus, in my advertising career, there was a fair amount of 'meaty or fishy' client entertaining in snazzy restaurants. My Brooke Bond meat-engineering client also involved a lot of recipe testing!

For all sorts of related reasons, I moved to eating a vegan diet over twenty years ago as my career ended. Years previously, I had spent almost a year as a relief herdsman milking and looking after cows and calves, so unintentionally learning and experiencing how they are treated. Later, when married, we kept goats for their milk. Much later working on new product development in advertising, I spent time at England's largest cow abattoir (the way in was through the kill zone), and time in a pig abattoir. From what I had seen, I knew that if I was going to eat meat and meat-related products (including milk), I would have to care for, kill and prepare the animal, bird, fish or insect myself.

How can I be happy if I instinctively know that killing my food is ethically and morally wrong and unnecessary, all the more so when I know there are better alternatives. Delegating these onerous tasks to others (supermarkets, butchers, farmers and the like) does not absolve me from the overall responsibility of the killing tasks. Veganism does not allow the compromises that vegetarianism accepts, such as the dairy industry supplying the meat industry with calves or treating chicken's eggs as non-meat. What's more, MS dietary advice clearly says that vegetarianism, or at least a diet without red meat and saturated fats, is beneficial. My doctor describes me as her most healthy patient. I'll get off my soapbox now!

Faced with carers who don't know or care about the value of food, I have had to set about the task of cookery 'classes' each lunchtime visit. Recognition of vegetables had to be accomplished first as most of what I ate was, to be fair, strange to them: courgette, aubergine, fennel, squash, sweet potato, sun-dried tomatoes, avocado, olives, rice of different types (but mostly whole rice), millet, salads, root ginger and more. I eat nuts and seeds at most meals, too, for their protein value, and both these and fresh and dried fruits for breakfast. Lots of different foods.

Because they don't much agree with me or the food value is low, I don't eat vegetables the carers were most familiar with, such as potatoes, onions and cabbage. Luckily the carers and I knew some of the same things, mainly carrots and tomatoes!

Then the method of cooking was strange to my cooks who seemed to think that all vegetables have to be peeled and boiled to death. I steam all vegetables to retain goodness, even potatoes on the rare occasions I eat them, and only peel anything when absolutely necessary as most of the food value is in the peel. This was novel to the carers who thought peel was waste but they were pleasantly surprised at the results.

This whole process of broadening the carers' knowledge of foods and cooking methods has been entertaining. OK, there have been disasters yet on the whole these have been few although, even after several years, a careful watch has to be kept on what and how they do things. Now, to give them their due, many have taken up eating healthier meals and trying greater variety in their meals, like mangoes, squash and sweet potatoes, and even, like me, baking their own bread because, as with dairy, my digestion has a wheat intolerance.

Next in the re-education process came waste control and food presentation. Waste levels were high because carers had no or little value and respect for the food they were preparing or presenting. They probably think that I'm mad or a scrooge but I don't allow them to waste a thing and I always finish each meal completely – not even a grain of rice is left on my plate!

When food is presented looking good at the time it is served up, it looks appetizing and is a joy to eat. However, most agency carers (with one notable exception) just tipped the vegetables and rice onto my plate in a heap without any thought. This had to stop but, by the end, only mixed results were achieved.

Sometimes I shied away from 're-training' carers and bided my time for the right opportunity because many were deeply entrenched in their ways and I felt lucky to have the food cooked properly at all.

Following on in this vein, when I sit down to eat a meal cooked for me I now feel very much as if I'm in a hotel or something similar. I was happy cooking for myself – I found it creative. Then, when disability progressed, this became fraught with difficulties and dangers. Now, with my own PAs, I eat like a king with everything done for me – even the washing up and some food shopping. This has improved even more due to increased mobility in being able to get out to the shops and choose my own food rather than giving carers and PAs a list.

The downside of a progressive disability is that eating can become more difficult in a number of ways. First is holding cutlery or a cup in hands that don't grip, although there are many aids that can help with this. The next difficulty is lifting a hand up to my mouth because my arms prefer to stay in my lap. Occasionally, I have to be fed and this will happen more often no doubt but, in the meantime, I prefer to avoid it. Biting my tongue, cheeks or lips occurs frequently because the very precise movements of the mouth become fractionally distorted. Concentrating on what I'm doing (mouth movements) is the way I reduce this.

Finally, by far the most dramatic and one of the potentially life-threatening sides of eating, comes choking. Somehow the similarly precise action of swallowing can become compromised and a particle of

food or drink goes down the wrong channel. With me this also happens with acid reflux that occurs due to weakness of the sphincter muscle at the bottom of the gullet, thereby allowing some of the stomach's contents to come back up and then they're drawn down the windpipe. The result of both is suddenly not being able to breathe, which is frightening and thereby adds to the 'catastrophe'. Eating and drinking is problematic but it has to happen and enjoyed for obvious reasons and it now has to be undertaken with great attention.

As has been said, I like my food, I respect my food because it's what I'm made of. At the meal table I think of where it comes from and all the people and growing sequences involved. At the start of every meal I recite to myself the prayer which says words to the effect that everything comes from a power greater than me, the food is grown and prepared by this power, is eaten and digested by this power and, at the end of the cycle, returns to this power. Everything.

## Walking to Wheelchair

Oh no, I don't need one of those. I'm alright. I'll get by on my own two feet. If I have to have a wheelchair it'll only be used for emergencies. I'm not disabled, that would be very unhappy.

Walking was a major activity. Not walking on pavements necessarily but struggling through untamed wild countryside, or tramping along deserted sands (North Norfolk and the Gower Peninsular in Wales were favourites), or over hilly moors (the Bowland Forest when I lived near Lancaster), or through the bush in Africa and the beaches of India. Anywhere out of the way.

What was it that drove me to this love of the wild and desolate? It didn't come from my youth because that was spent in a London suburb, although it was always great to get out of the city. Family outings were mainly in summertime to Brighton beaches or Box Hill in Surrey on a Sunday and no further except on annual holidays, in those days always spent in Britain. But I had a wanderlust which, as soon as I left home at seventeen, started to blossom and the first destination was Africa. My adventurous middle brother had it, too (I'm the youngest of four), but he did his on water by yachting around the world or motorcycling over continents. So, maybe it's in the family blood.

Over the years this blossoming flowered. Never again did I live in a city, except Bath, but that's very small,

Johannesburg and Bangkok. Always tramping and travelling somewhere, that was where I was happy. I'm happiest in Britain but I've travelled extensively and lived abroad: South Africa for two years, overland through the Middle East to the East for a year ending up in Thailand, and India for almost two years, meeting with many different cultures, peoples and religions on the journeys.

The end of free wanderings started with occasionally tripping up and a slight dragging of my right leg. After a while I realized that life would be safer with a walking stick as the thought of breaking a leg or something similar through falling, together with the inevitably long repair process, was a nightmare. That was an unhappy moment, where was it going to lead, where could it lead? It didn't feel as if it was going to be temporary because MS isn't.

How can I be happy trundling through the undergrowth with a walking stick and trying to stay upright? And when I walk among people somewhere I can sense them looking at me curiously and asking themselves, "What's up with him, he looks OK?" I want to tell them to mind their own business but can't because it will make things worse. I start to feel how a person with leprosy must feel, socially ostracized. And this feeling comes from people known, even from loved ones as will be talked about elsewhere. Where is the happiness from people?

Getting a walking stick long enough was the start of another difficulty. It seems that there are no tall walking disabled people, or rather so few of us that it's

not worthwhile for a company to make anything special to fit. My height is in between normal and giant, which means I don't fit either. Finding the right clothes, shoes and now walking aids (even cars) is like looking for water in a desert!

How can I be happy when I face up to the fact that driving is becoming difficult, that my days of getting to out of the way places (or anywhere) are numbered? I enjoy driving and have done so since the legal age or even before. (At sixteen years old I had a job erecting TV aerials in North London, working on top of and seeing the inside of all styles of people's homes: Rackman-type ghettos, TV personalities penthouses, suburbia – hence the early driving tuition.) 'Wheels' have played their part in my life. First (as a passive Rocker) I sold motorcycles in London, then British Leyland and Mercedes cars in South Africa, then showroom preparation of Fords and bangers to see me through college in Norwich. My youngest daughter has inherited this love of cars and driving.

Driving is great because, for example, the no entry signs at forestry land and the like can often be ignored and virtually untouched places be reached (OK, there's no place to call for help buried in muddy tracks and the bottom of the car gets bashed), but what a joy and harming nothing and no one. How can I be happy stuck at home.

All this feels as if I'm dying before actually dying: not a rehearsal, but a little like the real thing in slow motion. I kept on driving but was ever more fearful of causing harm to others. I knew it had to stop.

How can I be happy having to use two walking sticks? I wasn't. I tripped over even more because I couldn't keep both sticks vertical as my hands couldn't grip the handles firmly enough. Not using two wasn't an option and I was still standing. The next step was a crutch with arm support to keep it vertical and avoid tripping.

There's a huge difference in people's eyes between a walking stick and a crutch; their questions now changed to, "What did you break?" A crutch meant something serious whereas a walking stick didn't. I wasn't 'pulling the wool' anymore. But I could still drive and, with a blue parking badge, it was a joy parking legally where previously it was illegal.

How could I be happy using two crutches? Now mobility is seriously impaired. Now I can only drive to places and look out from the window, but these outings were only when it was safe to leave the vicinity of a loo. I stayed mostly indoors.

How can I be happy trying to carry the smallest thing – a cup of tea, carrier bag, book, a pair of glasses or a wallet – or push a trolley when both hands and arms are fully occupied with the crutches holding this body upright? And how can I be happy when it's difficult to get in or out of the car, let alone trying to use the foot brakes? How can I be happy peering out of the apartment window seeing others walking freely and driving? This was a low time, everything had to change.

Can I only be happy when I've got legs and am able to move about unaided? Of course the answer is no. I can be happy at any time. Without disability I was

happy in my sleep, happy eating a meal, reading a book, making love, the list is endless. Happiness is not in my legs but somewhere else, which means that with or without legs makes no difference to the amount of happiness I can have.

There's one word which keeps cropping up in my mind, and this is 'acceptance'. Happiness is most disturbed when there is no acceptance of how I am. And this doesn't matter in whatever happens to my (or anyone's) life, whether I'm hail and hearty or sick and feeble. Happiness is always available in unlimited quantities just so long as I accept what is happening to me without question.

What is it that I've got to accept? The simple answer to this is that I must accept who I am physically and mentally; who I am includes all that is going on in my life, which includes being disabled. OK, it also includes lots of other big things such as, this is my wife or husband or partner, this is my child, this is how I look, this is how intelligent or not that I am, this is what I own and so forth. Yet these are, in a way, periphery to the main question: Who am I? Once this is known or simply starts to be approached, happiness grows and becomes unlimited.

My ability to walk and drive came to an end. So what! I still have life, I can still enjoy myself, I can still love, I can still do all of the important things I want but, where necessary, in a different way. This means that along with acceptance there has to be adaptability. Where's the difference between having MS and not? Whatever has happened to me I have had to accept and

adapt to, only then am I able to move on. I don't intend to stagnate!

Where is the happiness in watching a stranger and his wife drive off in my lovely car. It was a sudden and shocking end to driving even though the big Volvo car had been sitting outside my home untouched and unused for two years. Is it another 'nail in the coffin', one step further to the edge of the grave? Perhaps for the car but not for me. Now I much enjoy being chauffeured with the added benefit of being able to concentrate on what's going on around rather than the road ahead. The fact that the mode of transport is usually an ambulance doesn't matter. In the future this will change, as I will explain.

I went to see an organization called Forum which helps, assesses and advises drivers with disabilities and told them of my application for help obtaining a powered wheelchair. My arms did not have the strength for a self-propelled chair. I was told that 'this particular' chair (a Balder) was most suitable for my physical needs. So it may have been but it was about three times the cost of the one I eventually ended up with (an Invacare with many fewer helpful features) – as I live on State benefit there has to be acceptance of what will be sufficient at the lowest cost.

After measuring and months of waiting, the first new electric wheelchair arrived. It was a little like the delivery of a new car, except with this one I mostly drive inside my home. The chair's arrival didn't feel serious because I was only going to use it for emergencies.

However, because I'm tall, adjustments had to be made. After a year or so it became obvious that this chair wasn't so suitable for my needs and a review was held. Yes, I needed a larger chair and no, I could not have the ideal one recommended by Forum.

The new chair was big and heavy (an Invacare Storm 3). The publicity material for it didn't show photographs of it in a person's home but in a street setting and public library. It was mainly an outdoor chair and this one, too, still had insufficient features. Again, being tall was a disadvantage in disability.

I tried to keep on my feet for as long as I could with crutches, which meant lots of falls. This was madness. Legs were mothballed and the chair adopted. Where is the happiness in this? There was and is lots. In my chair I am safe. Everything is now done from the chair, except in the bathroom. Driving to the bathroom or wherever replaces walking, it becomes the norm, and I can relax. I can go out for a ride or sit in the garden with a parasol attached if needs be. If I lived in a town I could go to the shops, down to a bar or wherever with almost complete peace of mind.

I say 'almost' because driving a powerchair is similar to driving a car – I even had to pass a driving test to be able to use it outside and third party insurance is necessary, although not a legal requirement. This is because pedestrians may not see me and step in front of me or I may not see them and then a crash. At a maximum of nine miles per hour I'm not likely to kill anyone but someone might get hurt. And then the recriminations!

The long decline from free to assisted mobility is over, or so I thought. I was happy at the beginning before it all started, then accepting and adapting (with a little bit of persuasion where appropriate) through all the different stages and at the end of this part, I remain happy. Ok, how I am now is not the same as I was before and mobility isn't the only thing that's changed, but I'm still me, I still have a life to lead, so what more is there?

## Normality

How can I be happy if I'm not normal anymore? I look around and see others leading a 'normal' life and understand that it's not me, that I'm not like this anymore. Yes, I used to be normal but now being disabled I'm abnormal.

What do I mean by abnormal? It means that, in comparison to others, I can't run and jump, I can't even walk, can't dance, can't make love, can't look after myself, can't go shopping, can't have a normal pee or a poo, can't have a job, can't play with children, can't get into bed, can't drive a car, can't give someone a hug or a kiss, can't converse with someone because they stand behind or at the side of me, can't sit with someone on a sofa, can't play games, can't garden, can't use a knife when eating, can't get dressed by myself, can't get a letter into an envelope, can't handle coins, can't sit at the dining table, can't use a mobile phone, can't write legibly, can't make a cup of tea, can't cook a meal, can't keep warm, can't remember things. Phew!

Then there are the normal things I can do but only in an abnormal way or with great difficulty, and abnormal things I can do normally. It includes some of the things already mentioned and others such as turning a page of a book, having a shower, emptying my urine bag, getting undressed, eating a meal, typing into the computer, going out for the day or going on holiday.

Yes, I can watch TV – that’s normal – but I don’t have one! To be fair, there are other things I can do ‘normally’, such as brush my teeth (with an electric toothbrush), talk on the telephone with the speaker on, shop on the internet, talk to my plants, dream, but the list isn’t very long.

Oh, woe is me. There is so much abnormality in my life. How can I be happy?

No, this isn’t right. The meaning of the word ‘normal’ is what regularly happens to me. It’s not about what happens in comparison to other people because everybody’s normality is a different normality, in some cases just slightly different or in other cases widely so. And because one person can never experience another person’s normality (or abnormality), no one can evaluate whose normality is better or worse. People look at me and I can ‘hear’ them thinking, “Oh, I wouldn’t like to be him” and I respond equally with my thoughts, “Oh, I feel sorry for her or him, I wouldn’t like to be like that”.

This means that whatever regularly occurs in my life is my normality; so the long list of ‘can’t do’ things listed above is not a statement about my abnormality, but a description of my normality. The list is a statement of how I physically am, and to evaluate it negatively, as an unhappy normality, is not conducive to happiness. It’s as I am and it’s my choice whether to make it a happy normality or an unhappy one.

The list above is mostly about physical can and can’t do’s, it’s not about the mental me. Whatever the physical disability I’m still me and no different in essence from

anyone else, sick or hearty. We all have a basic 'set' of senses and emotions, a way of thinking with some intelligence (i.e. the power to think and communicate), a memory, and a loose understanding of 'who I am-ness'. It's the latter that's most important to find out more about, to tighten up, answering the question already posed: who am I?

Why should I choose to be happy? This sounds a daft question as who in their right mind would purposely choose to be unhappy? We don't (except perversely). We allow the 'can't do' list to build up and overwhelm us, to cloud our clarity. For anyone, happiness is often something that has to be worked towards because it doesn't necessarily increase automatically. Short-term happiness can be bought, but is that real happiness? Long-term happiness can never be bought and this is because we already have it or have the ability to generate it – it's a 'built-in' feature of being human. If I am unhappy, I have lost sight of my existing happiness and this happy 'sight' needs to be restored. It's certain that I have my own normality and it's also certain that I can be increasingly happy within that normality. It's because with MS and disability I'm normal and I'm happy.

## Transport and getting out and about

How can I be happy if I'm trapped in my home every day? Gone is most of the use of my legs. Gone are the crutches. Gone is my car. All that's left is me and my wheelchair. In a year, I've been out five times: once for a birthday picnic and four times in various ambulances to hospital. My home is rural and shops cannot be reached. People, other than carers, visit only occasionally. There is no TV, no radio, just the computer!

This situation might drive some people nuts but I prefer peace and quiet although the social worker has raised the idea of me living in social exclusion. How can I get out of this 'trap'?

The answer is quite simple: get a wheelchair accessible vehicle and a personal assistant who will drive and care for me. Achieving this I will be free to do and go wherever I please and the world, instead of the world being 'out there', can become my 'oyster'. All of a sudden ideas rush into my mind: I can go to the seaside fifty miles away; to the vaulting sacred space of cathedrals; to galleries and just out and about. Yes, and do my own shopping.

The reality of bringing this simple idea to life is daunting but not impossible to achieve. Lots of people and organizations are involved. And two things cause further obstacles: first is that I don't have any money, and second is that my height (over six feet four inches) makes me non-standard (as it has throughout my life). I

just don't fit into a standard wheelchair accessible vehicle, not even a standard wheelchair!

I am so fortunate to live in a country where there is a Welfare State. Over the years I have visited or lived in over forty countries (third world – South and East – and the West) and I know for certain my luck at being British and disabled! The two ingredients to getting out and about will be provided. Even the roads and pathways are the best and smoothest anywhere, which is important in a wheelchair. However, the processes involved in achieving the desired result are not straightforward and contain many twists, turns and compromises. The happiness is that there are no dead ends, although sometimes there may appear to be.

The two elements in achieving this end are not related and have to be dealt with separately and involve different assistance and lots of people. First a change from agency or local council carers to employing my own personal assistants who will not only carry out the necessary caring needs but do much more, including driving me about, staying away with me (overnight or longer in Britain or abroad) and become a fundamental part of my life. To achieve this the social worker needs to become involved together with an agency which advises and manages me to become an employer. To do this, I have to establish precisely what my PA's will need to do so that a job specification can be worked out to provide worthwhile employment. This, on its own, is no easy matter and there's no one to advise me. What time of day would I like someone to be here, for how long, how many times a day? And how can I plan a schedule

of outings and shopping trips far enough in advance so that the PA concerned will know what I want and be free to help?

Then the criteria for what kind of persons would suit the imagined role. Here I come across another hurdle: my preference is for mature female PA's but I am told that the law says I cannot stipulate gender or age in employment advertisements. The way around this hurdle seems to be to select what I want from whoever applies but this makes a bit of a mockery out of the law. Clarification is required. Lots of twists and turns.

The second path, to acquire a suitable vehicle, proceeds in tandem. The application to Motability, the vehicle provider to disabled people (a national charity), is made and a positive result is achieved in no time. Two vehicles are suggested and it's left up to me to arrange demonstrations and select the most suitable. Then the first hurdle crops up. I have always had travel sickness in cars, boats, trains and even aeroplanes. In cars, the way round the problem is to sit in the front passenger seat next to an open window but neither of the vehicles suggested catered for a wheelchair user to sit in the front.

Back to Motability who need a letter from my doctor outlining the travel sickness problem in order that my application is reconsidered. Again a daftness; my word cannot be believed but if I ask a doctor to write a letter about something they know nothing about (my travel sickness) all is okay! This is done but, having looked at various vehicle specifications, it may not be possible to find a vehicle where I can sit in the front because of my height! What would solve the problem is

to change my wheelchair with one that goes up and down.

Some years ago, when the wheelchair prescription was established by an occupation therapist (who did not take the advice from Forum previously described), I queried it, requesting a chair which went up and down so that I could get my legs under tables and so forth, and stand to transfer easily. This was refused and one which tilted was provided. The reason, I am certain, was one of cost; what was provided was not completely right but would do at the time. On the surface, life is full of compromises which have to be accepted (although some don't). It's full of happinesses and sadnesses oscillating like a yo-yo or seesaw. Is there a way to be happy all of the time?

Will I have to go through the lengthy process of agreeing a new wheelchair prescription (which, in my case, is refused)? It will mean the delivery of a wheelchair accessible vehicle will be delayed, maybe for a year or so. And what about employing a PA to care and drive me? Is everything falling apart?

How can I be happy when presented with a vehicle like a municipal truck or a parcel delivery van? I suppose I should be happy that there is something to drive me about but the first demonstration was a big shock in two directions. Apart from the overall size of the vehicle (a Renault Master), once inside I felt worse: claustrophobic and sick. The chair was on its own in the middle of this big box, tied down at four points, then I was tied down to the wheelchair at three points. The windows didn't open and, in any case, they were out of reach. A black

wall of the front seat backs faced me, again out of reach. A captive in my own vehicle with the aesthetics of a prison!

From this bleak position things could only get better. Well, that's the hope. The demonstration questioned whether I wanted to go out at all. Oddly, being strapped down at seven points (designed to keep me safe) made me feel less safe because I could never get out of the vehicle on my own in an emergency. To go out, I will have to have complete trust in who is taking me. Can that happen? What does it mean to trust?

The answer to this is in three directions: first, trusting others; second, trusting myself; and third, trusting my Maker. Trust is about assessing the risks involved. Trusting others is the biggest risk because there are so many imponderables and unknown facts which are subject to a multitude of influences all beyond my control. Trusting myself is better because, although ignorant of many things, I know my limitations and can act accordingly. Trusting my Maker must be best because the Maker knows everything there is to know and no risk assessment is required.

We can think that we know everything but, when looked at closely, it's surprising just how much we don't know. I'm typing this book with one curled finger. How does the finger get to the desired key almost every time. It's not by chance. This (and much more) tells me that trusting the Maker is the best option regardless of what I might think and regardless of what happens. I have MS. It didn't come out of the blue but by the Maker's pre-determined effort (and this is the same for everyone

able or disabled and everything). Oh, that's a biggy to swallow, where's my justification? It's simply that there has to be a Maker (or some-such) because there isn't chaos. In place of chaos there is a definite order – from the smallest most minute physical things up to a fully-grown tree, or planet, or universe – this is plain to see and experience both out there and in me.

Maybe the Renault Master is not such an awful vehicle to have after all. I will 'play the field' and what results will be what the Maker has determined. I can trust that completely.

Very soon two different choices with 'up-front passenger solutions' and sufficient internal height arrive from Motability and the vehicle selection process continues.

One choice, when contacted, did not have a demonstration vehicle so it would have been impossible to find out in advance whether it was suitable. The second choice did and so a demonstration was arranged for a Volkswagen Caddy Maxi with an upfront passenger solution, as it was called. In theory, this van looked suitable but very tight on room for a tall person and a large wheelchair.

Came the day of the demonstration, there was no means to tie down my wheelchair and so it was not possible to go for a drive. The tailgate opened and a ramp folded down and I could drive straight in although there was a hump over the rear axle and the sort of chicane before I got the front position. A very thin cushion had to be used on the wheelchair instead of the normal thicker and supportive cushion so that I could enter the

vehicle without ducking my head and, when at the front, I was able only to just see straight out of the windscreen.

The enthusiasm to squeeze myself into the vehicle and the lack of an alternative choice persuaded me to accept compromises involved in being able to get into and out of the vehicle. The colour was chosen and everyone was happy. Because of tightness of space in the front of the vehicle it was not possible to have the normal tie-down system of straps and an automatic lock-down system had to be fitted, necessitating a grant extension from Motability.

There was a long wait for conversions to take place but, five months later, the van arrived with the concomitant freedom to be able to go out and about. Great!

So, with my PA driver, the first excursion took place, then the second and the third. On returning, my neck was hurting more and more and I couldn't understand why. Contact with was made with the vehicle suppliers who could offer no help. The pain felt something similar to a whiplash injury that I had endured some years previously. And that's exactly what was happening!

The van stood unused outside. What to do? The problem was that I was too high sitting in the wheelchair in the car and the only answer was to get a different wheelchair similar to that which was originally suggested. I talked to my wheelchair occupational therapist and it was clear that while seating improvements could be made no change would be made to the wheelchair itself to compensate for the vehicle.

The wheelchair organisation was only interested in getting me mobile; their remit did not include helping me to go out and about in a vehicle.

Another brick wall and more unhappiness one might think. To me it was yet another challenge. The wheelchair that I needed, a Balder (which was the chair originally suggested by Forum), was about the cost of a car! Perusing the Internet one day, looking for second-hand Balder wheelchairs, three were found. Two of these were still too expensive but one just might be affordable somehow. This wheelchair had belonged to a tall man, a 60s and 70s pop star, and his widow needed to dispose of it. A meeting was arranged to see the chair at a motorway service station and it was bought on the spot.

Of course I didn't have the money! One of my problems is that I'm too impetuous and have to sort out the problems my actions cause later. When the chair was brought home, screeching noises came from one of its operations, which was very worrying. Straightaway the wheelchair had to be checked out at a wheelchair 'garage' and the noises were found to be normal and acceptable for a Balder, which was a great relief. During all this, the Multiple Sclerosis Society was very generous in providing about half the funds for the purchase, which added to my savings meant the deal was concluded.

Now I could put the vehicle and the new chair together for the first time and being able to raise and lower the height of the chair straightaway did away with the neck problem. Other benefits also occurred: being able to raise up and down at home gave me much greater independence in transferring and reaching things – even

in being able to get things from supermarket shelves when I was out of and about. Happiness reigned!

Well almost! The next few months saw many trips out in the vehicle but entry and exit remained a problem and became more difficult because of my declining ability to finely control movements of the wheelchair with the joystick. I found that in manoeuvring the wheelchair into the van over its hump and reversing out, it was tipping over onto two wheels and in danger of tipping over altogether with me underneath it. Not a happy situation, which was made more uncomfortable by the fact that the new chair did not fit the lockdown system for the old wheelchair and travel meant that the new chair was not securely fastened in position and probably illegal. What to do now!

I was advised to contact Motability again and to my great joy the suggestion was that I made a new application for a different, more suitable, vehicle given the difficulties and the changing medical condition. The surprising thing was that Motability now sent both an assessor and a demonstration vehicle to help sort out the problems, which they did perfectly and the not-so-old van would be found a new owner under the contract hire scheme.

The new vehicle, a Mercedes Sprinter, was immediately given the nickname of 'Tank' because of its size and height, which prohibited entry to car parks with height barriers and gave it speed restrictions. Now going out and about happens easily without entry and exit problems, without wheelchair height problems, and I'm a very happy man. Years ago when working in

advertising I wanted a Mercedes company car but it wasn't allowed for all sorts of reasons, not least that the one selected (albeit second-hand) would be a better car than the Chief Executive's. The dream is answered, well sort of!

## Spasms and Spasticity

How can I be happy when my body starts jerking almost every night for hours on end in bed and frequently in the wheelchair in the afternoons. Most often it's the right leg that jumps every twenty seconds but the left leg is keen to take over if the other takes a break. What happens within each twenty seconds is either a slow build up like a tightening of the particular muscles or a sudden stinging pain (like standing on a lighted cigarette), either are then followed by an inward jerk (flexor) and a squeezing tight of the muscles involved, finally a few seconds rest. About three sequences a minute. Spasms are not painful in themselves, unless something is kicked, but they are grossly uncomfortable.

Only occasionally do the legs do a duet but one of the shoulders can join the dance at any time making a trio. Sometimes the jerks cannot be seen by others (which doesn't mean they can't be felt) and, at the more visible times, both legs come flying up. To instantly stop them I need to stand up which usually isn't possible or practical and I lie in bed, not able to sleep, not comfortable, wondering what this is all about and where the happiness is in the body.

This is half of the story. At the same time as spasms are doing their thing there is spasticity. This is uncontrollable and extreme stretching and arching. All the leg and some back muscles go hard and rigid and there isn't much that can be done except to wait until

they relax again. This happens when I have been still for a while either in bed or in the wheelchair. Spasticity does stop spasms for a few moments.

Either with spasms or spasticity, legs being drawn up or pushed down, and in bed, the heels are forced to press into the bed sheet causing friction burns on the heels and the resulting blisters make rest and sleep more difficult until they heal. Also on the heels there feels like bedsores but this is a neuropathic pain caused by the wrong messages being sent by a bundle of crossed wires in the nervous system. The result is restless sleep and continual turning in the bed, which itself gets more and more difficult to manage.

I get very tired and ready for bed yet bedtime is not met with much enthusiasm because I know what's coming. On other days, after sitting in the wheelchair all day long, I don't get physically tired, only mentally tired. Avoiding bedtime doesn't work because I need to lie down. In bed, eventually I do get to sleep and whether the spasms or spasticity continue while asleep is not known. For many years in younger days I smoked cannabis, so it's easy to see where this (or Sativex) might help with sleep and muscle relaxation. Spasms soon click back in when I'm awake again. For some unknown reason and just occasionally the spasms take a night off or even more. That's heaven. In the day they occur much more in the later afternoon and evening, which means mornings are best in this respect. Everything is constant in disability but to lesser or greater degrees and only a few are temporary.

There is medication which can help and I've tried some. However, the side effects of all of them, for me, outweighed the benefits. That is until one day it changed to the other way around and I started taking a low dose of Baclofen, the standard treatment for spasms in MS, which reduced their effect.

Years ago I trained, but didn't finish, to become a psychiatric nurse. It was a great job and life experience, perhaps the best I've had, and I witnessed the extremes of mental distress in all its shapes and forms, in young people and old. Also, I learnt a lot about what many drugs do and saw their effects first hand, particularly the epileptic ones used for electro convulsive therapy (ECT, which I helped to administer) that seemed to help depression, abreactions and just to sedate 'excited' patients. Many of the psychiatric patients became permanently half asleep or half aware of what was going on with their medication. Using cannabis, twenty years of my life passed by on automatic – living my life and building a successful career but soporifically. I don't want a psychological sleepiness along with my MS which is now legally on offer, I want to be awake and happy with my life and so drugs, which *may* help, are avoided until absolutely necessary. This might be the right or wrong approach but it's my way of dealing with this physical condition.

Now also some of the thigh muscles (adductors) pull inwards and I force a small cushion between them to reduce pressure. In bed, the legs get into a scissor position. Transfers are more difficult.

Patience is essential, not a forced patience but a natural one. Yes, OK, life in this body is not a pleasant experience but it will pass. Some people have to be coalminers, which is better? Happiness can be in both.

Next to try is 12 Botox injections in various muscles every three months. Will these calm the thigh muscles without side effects?

My physiotherapist referred me to a nearby spinal unit. The consultant identified that to have Botox would incapacitate me and on balance was not thought to be beneficial. Instead, I was referred to the physiotherapy department for hydrotherapy. The queue was a year long but that passed and therapy commenced. At first I thought that bathing in a large swimming pool full of hot water was just a pleasant experience albeit debilitating because of the heat! But after a few visits and lots of stretches under water I began to see my leg muscles relaxing and the pincer tightness pulling my knees together seemed to reduce.

Other 'swimmers' included people who had strokes, who were debilitated through car accidents and so forth. In the group at the sessions attended I was the only person with MS. Everybody's problem was movement of some form or other. Overall it was found that there was no long-lasting benefit in hydrotherapy for me, although it was beneficial for long-term body maintenance.

So, where is the happiness in this body? Is it in my legs or any other part? Can this body and 'me' be separate

entities? The answer to these difficult questions can be found through experience.

When I see a fish, a chicken or a leg of lamb in a shop for example, it is obvious that what lies on the counter is simply inert flesh. It's not difficult to project that it will be the same for this body when it's laid out on the mortuary slab. It won't be 'me' on the slab, just flesh, which means that although I am contained within the body and wholly dependent on it, I am not the body.

The body exists as a 'tool' for me to use and to play with, as a frame to hold this invisible entity called me. Seemingly, I can do anything I like with it that it is capable of, pour anything that takes my fancy down its gullet, climb a metaphoric mountain and so forth. Just play. Take some medicine, enjoy the experience, and it will pass. Everything passes and changes, just like a picture show.

If I'm not the body then who am I? From experience it's certain to identify that this body (as all bodies) has a 'driving force', but this force is also not the body. Additionally, the driving force is not dependent on this body as is clear to see in that life carries on regardless of whether this body is alive or not. What is this driving force?

Happiness is not the body, we can conclude, which means that whether I have MS or any disability or not need not alter my ability to be happy. The two are separate. If I allow myself to think that 'I am the body that is disabled', then it's probable that I will be unhappy; if I think that it's me having a spasm and not the body, there is likely to be unhappiness. Alternatively, if I realize

through understanding my own experience that I'm not this body with MS but something else, then happiness can more easily be found. Where it can be found means looking into and answering the question about who this 'me' really is.

## Sex

How can I be happy when I can no longer have sex? Sex is the greatest physical pleasure I can have. Whether it's the same for women or, indeed, for all men, I cannot tell, but it has been for me. This is not just intercourse that I am referring to by the word 'sex' but all physical contact with a woman, all sensuality, and that's what has ended. Of course, maintaining sexual activity would have been helped had I kept with a partner with whom physical contact could be had, but I haven't been able to primarily, in latter years, because of the disability with MS.

In this section, I'm just going to talk about the physical aspects of a relationship and this from my male perspective. In thinking more about it, yes, things are quite different for a woman. We only have to look at the animal kingdom to draw basic comparisons and see the differences! A woman has much broader life interests than a man; a man needs to make conquests, if he doesn't there is dissatisfaction and frustration throughout his life, including his sexuality.

The unhappiness began to start ten years into MS when one night I found I could not get an erection. It was 2 am somewhere in Bristol and the woman I was with (an old friend, both of us hoping to start something closer) was so 'upset' that she asked me to leave there and then. I never saw her again because I, too, was hurting and in need of solace not rejection. In a moment,

trust that the rejection wouldn't happen again (the first loss of trust was when my wife went off with another man) had vanished.

My MS is progressive. Now I cannot get out of my wheelchair to curl up with someone. And even if I could, my hands are like claws without much feeling and I can no longer caress and experience that wonderful feeling of touching someone else's body. Now, without looking I would not now know where or what I was touching. This body has hardly any strength to lie supine and be together with an understanding partner; I'm sure this still happens for some or even many disabled people, but not me. There is reduced sensation left in my private part and some other areas have disturbed sensations. This does not mean that I cannot kiss; it's the getting into and holding a position where a kiss is possible that is difficult.

Sex has been a big thing in my life but actual incidences of sexual contact have been sparse. From my twenties I wanted a long-term relationship with someone but each one I tried to start didn't last, even marriage. The 'big thing', therefore, has been more mental than physical.

At thirteen, virginity was lost on a kitchen floor somewhere in Tooting, South London, with a girl who isn't remembered. The only thing remembered is that the floor where we laid was chequered black and white lino! We did it there because this girl's granny was upstairs! I walked away thinking, was that all there was to it? One of the few highlights was at eighteen and I tried so very hard to make something more out of that

relationship but it just wasn't to be. A son was born. Over forty years later this person and I are still in contact; strong feelings never end. On meeting another woman some years later, almost immediately we decided to get married. That marriage ended twice by my late twenties, almost no sooner than it started but only after two daughters had been born. That seems to have been its purpose. Then came MS. Since that time, apart from three relatively short exceptions, I have had an unsatisfied yearning for all that is contained in the word 'sex'.

In desperation to maintain at least some physical contact at the last 'short exception', I turned to chemical help in the form of Viagra, a pharmaceutical aid to enable an erection. This was helpful for a while but, because of the two-hour time delay it took to be effective, all spontaneity was removed. The headaches it gave as a side effect were bearable but my declining ability made the drug less effective. Other avenues such as a mechanical pump for the same result didn't feel right for me. I just gave up trying in the end because the benefits became less than the effort and the other person at that time wanted more, which meant that that phase of the relationship ended.

With the arrival of MS over thirty years ago, whatever physical attraction I might have had to the opposite sex was smashed (an emotive term, but that was how I felt). People with disability are generally not desired; partners, on the whole, look for virility and strength, they don't want weaklings or 'damaged goods', which of course is instinctual in every animal species.

We all have basic instincts and sex must be one of the strongest. It's innate. The desire for sex doesn't go away no matter how hard one tries to make it go, even though the reality may become physically impossible. Even on the deathbed it is still possible to have sexual desires. Even the most religious celibate persons have this difficulty. There seems to be no escape. So where is the happiness in the physical life?

The unhappiness I have experienced over the lack of sexual encounters has not just involved the one sense of touch. All five senses have been involved, although touch may be the most valued and, with MS, the least easy to achieve. With the five senses generally, the most desirable sight throughout most of history has been the physical form, particularly the naked female form. It is the same with the female voice throughout all of the musical arts; the countless millions spent on perfumes to make women's fragrance more appealing shows how important smell is; and what truly compares with the taste of a loved one. This is our experience. Our senses are our physical delight in life and when any one or combination is impaired we can feel as if we have lost something very valuable indeed.

Losing one's sexual powers over the years is – again in emotive terms – akin to a slow death. I am a physical being; the prime physical 'purpose' of this and all life is to make new life. Once this is achieved, the instincts and senses don't finish but carry on to the end of life and may even be instrumental in the cause of death. There is no happiness or sadness in this because

it's just the fact of life, the experience of all people, each in their own different ways.

But is this all? Is physical life solely about having sex and its related activities such as rearing children? Is everything we do (for instance, eating, drinking, achieving, etc.) subsidiary to this one physical activity as Sigmund Freud thought with his idea that everything in our lives revolves around the 'pleasure principle'? It would seem as if he was right. When I was a director in an international advertising agency, my boss once exclaimed about a specific campaign proposal, "But is it sexy?" he asked. Much of the physical side of life has been made to appear sexy everywhere, even subliminally!

Sex is not dependent on being happy or sad, sex can be had in any state of mind, whether violent or peaceful, loving or hateful. Yet if life were solely about having sex, one would think that the declining ability to have it would lead to the end of life, but this is not the case with me or with most human beings. There's something else to life that keeps us alive and it's not physical. This means that the physical effect of being disabled need not interfere or influence my life in any real way. It means that happiness is not physical and need not be affected by not being able.

## Falling

How can I be happy if I keep hitting the floor with my head? I have lain on the floor several times laughing at my predicament and stupidity for having fallen in the first place. However, the laughter didn't last as neither the predicament nor the stupidity was funny and I could do nothing to get up. It was also an embarrassment for causing others the trouble of lifting me up, which (in India) happened once naked in a sheet pulled up by four men and more often by a short but burly night watchman! With many of the falls there was some luck. I lived in India for fourteen months and my room floor was tiled, which meant that it wasn't difficult to slither snake-like to the door and holler for help.

This period was the worst for falling. It was the transition period between crutches and wheelchair. I marvelled at the resilience of the human body to absorb these falls without any breakage, but it bruised well!

Falling started first with tripping and nearly falling countless times as I progressed from no walking aids through walking sticks to crutches. This was both in the home and out and about and depended on the surface walked upon. A flat, firm and smooth surface is best; walking with two crutches along a soft and hot, sandy beach in Fuerteventura, one of the Canary Islands, for example was not so easy but at least the falls were cushioned.

The first public performance of falling was in the middle of the road in a town centre while crossing it on two crutches. A little trip and wallop, down I went, but almost immediately two unknown men appeared out of nowhere and hoisted me back to my feet, shaken but nothing broken. Before then falls were at home, the worst being when I fell onto a large flower pot: my stomach went black but the plant, a Christmas cactus, survived!

It is surprising just how fast a fall happens. One second all is OK and the next second one is flat on the floor and there is no chance in between to try to save oneself or even to think about what is happening. Falling or the fear of falling restricts one's activities. My main fear has always been about breaking something because I will be considerably worse off if that happens. This is why I have been so glad to 'retreat' to the safety of my wheelchair on a full-time basis. However, this has not stopped the falls because I still need to get out of the wheelchair to transfer onto the bed or a different seat, or do something, mostly when I needed to use the toilet. Two or three 999 calls later, and paramedics suggesting I get a hoist, the need for peeing had to be removed (previously described), which meant that most, but not all, need to get out of the chair was curtailed.

Falling is always in a one-way direction: down. And there are two types of falling, either physical or mental. With physical falls the limit of the fall – the floor – is seen and known. However, the limit or extent of a mental fall cannot be seen, and the fall or falling can only or mostly be seen by the faller. Mental falling can seem like

descending into a bottomless pit except when it's falling in love!

A further difference between the two types of falling is time. The physical fall is instant but the mental type is much slower, perhaps continuing for months on end or perhaps seemingly never ending. Awareness of mental falling may not even be realized because its onset can be subtle. These types of mental falling are not specific to people with disabilities, everybody has them in varying degrees and are mostly very much the outcome of life's vicissitudes.

Whereas practically nothing can be done to prevent physical falling once the fall has started, there is time to do something about mental falling during the falling process as long as the fact that a fall is occurring is known. Specific examples of the types of mental falling will be talked about elsewhere, here I will mention perhaps the most fundamental fall, that from happiness to unhappiness.

It is our everyday experience to know when we are happy and when not. Although we may know what it's like to be happy, an understanding of what happiness itself is may not be readily known. It is possible that we know more about what unhappiness is because its cause can be identified through tracing the unhappiness backwards in time to its specific and varying origin.

Happiness, or contentedness, is different from unhappiness because it is our natural state and so has no identifiable cause. Our happiness starts to be realized with birth and it continues up to our death. Happiness does appear to have peaks but it doesn't have troughs,

the troughs that can be experienced are caused by unhappiness overshadowing or superimposing itself on happiness and thereby creating what appears to be peaks. When there is no unhappiness there is always happiness, it exists within each of us all of the time.

What is more, we don't know the upper limit of our happiness. In fact, it may be incorrect to talk of an upper limit, about it being limited at all. Unhappiness is limited because it is created by events of one sort or another that are variable and changeable, and we 'fall' from our natural happy state.

There's a lot in life, with or without disability, to make us fall into unhappiness but this happens only when or if we allow it. Why do we do this? My MS is progressive and so it's possible that over time I could become increasingly unhappy. But MS (this body) is nothing to do with the real me because, as I have said and will say again, I am not this body with MS. It means that I have unlimited happiness as I am.

Enjoying happiness all of the time does not mean to say that there won't be falls, they are inevitable. The key to maintaining a happy state of mind is knowingly fully who I am. In anything in life, the more we know about something the better we are equipped to deal with it. It's where we have insufficient knowledge that the 'troubles' start and we trip over, thereby risking a fall into unhappiness.

## Part Two

### Descriptions of Emotions

## Introduction

How can I be happy being disabled? Some people are naturally happy no matter what happens, some are the reverse, but it is fair to say that having a disability is completely testing, particularly with regard to enjoying life and being happy. Trying to force happiness is not possible, it's like trying to hold a balloon under water – yes, it can be held under for a little while in an artificial situation but one way or the other it slips away, shooting to the surface where it's blown, pulled and pushed, in every which way. Yes, happiness can't be forced, it has to be a natural occurrence.

Being disabled isn't the basis for just one big unhappiness; the mind is cleverer than that because it always produces numerous variations and varieties with this stimulus. Why does it do this? This is an incorrect question, like most such questions, because all questions assume that there is an answer. It assumes that the mind has a reason for what it does, but where does this idea come from? Where else but from the mind! There's no escape from this circularity or infinite regression.

From our individual experiences we know that disability has nothing to do with the mind. Scientists have determined that cognition and memory disturbances are not of the mind itself but are disturbances in particular parts of the brain. Think about it: the mind is purely a succession of thoughts, one at a time, even if each lasts only for a split second. What else

can the mind be other than thoughts? Or, put another way, when there are no thoughts where is the mind? Disability is not a thought but a bundle of physical disturbances about which the mind has thoughts. If MS, for instance, were a thought it would last only as long as a thought and no more. How long does the average thought last? And how long disability?

And what is happiness? Is that simply a thought, too, with happiness lasting just as long as happy thoughts last? Is there anything other than a thought that can make us happy or unhappy and if so where and what is it? These questions will be met with.

The mind, being a bundle of multifarious thoughts, means that there is huge interrelation between them. To look at groups of thoughts individually takes them out of context. Nevertheless, what follows looks at a selection of mind events that are often encountered with disability. Nothing happens in isolation from the physical and the mind always has a thought about it!

## Anxiety and Stress

The first place anxiety and stress rears its noticeably ugly head is in the physical – for me it’s in my stomach. I have a stomach ache. “Why’s this” I ask myself, “What have I eaten that could have produced it?” “If it’s not food then what is it?” “Nothing’s worrying me” or so I think. Then I find that there is something unsettling the status quo, that it is causing a rumpus, and it can be the silliest little thing.

Anxiety and stress are not peculiar to disability; it’s likely that every single adult and child anywhere gets it at some or many points in their lives with its intensity varying on a day-to-day basis, if not minute-to-minute, and it’s usually always about many different things and combinations of things. In trying to assess levels of its intensity many questions can be asked. For example, what’s the anxiety and stress difference between losing one’s job and being diagnosed with MS? The answer is that each person copes with events in their lives in a different and unique way, which means that the question can only be approached if the same two events happen to the same person at exactly the same time. The question is unanswerable and therefore assessment of anxiety and stress levels is meaningless except in each individual situation.

The past is not affected by anxiety and stress, neither is the future. These feelings may arise from something that did happen or that may happen but in

every case the feelings (all feelings, sensations and thoughts) are only ever experienced in the present. It's likely that when something is actually happening, for example poohing (defecating) in my trousers, the anxiety and stress felt is very different to when the experience is based on thoughts about the chance of a future event occurring, such as the possibility of poohing in my clothes. Fear of a future event happening, regardless of whether it is insignificant or tumultuous, can bring on anxiety and stress perhaps more than anything else and time, of which in this instance there is plenty, allows it to amplify. If the event is actually happening in the present it's much more of a fact to be dealt with right away (there's no time for its amplification); in the future it's fiction and future is the 'home' of the inventive imagination and its seemingly unending convolutions.

This MS caused event just described is the most dreadful, most horrible thing that happens to me with the disease. It's not life-threatening, not painful, just completely distressing. It's the worst scenario. Peeing myself never brought about such feelings of revulsion as does poohing myself. The anxiety and stress caused by this possible occurrence determines how each day is lived and even how each minute is lived because there is often little fore-knowledge of the event actually happening, which in turn determines how far away from my toilet I can be at any one moment (not any old toilet as my toilet seat raises and, separately, is hands-free, which means it washes and dries me on command). An anxiety and stress-free day in this subject's regard is one

where poohing occurs shortly after getting out of bed in the morning. The day is then mine, usually!

Oddly, there is no anxiety and stress about the very real future possibility of such poohing happening on a daily basis in a 'nappy', on it becoming the prepared-for norm. If the body does this, "so be it," I say, like all else that has happened in the MS experience (and in everyone's whole life). The reality of regularity can be prepared for but chance events cannot.

Is this particular anxiety and stress rational? No. Is any anxiety and stress rational? No, but every one is a real experience. Does disability have anxiety and stress? No. Who has it? Me. Who or what is this me?

There is a chain reaction: I fear something and the potential something creates anxiety and stress, which in turn creates either more thoughts about it or physical disturbances that are very real or both. One of the physical outcomes of anxiety and stress is irritable bowel syndrome. Another is depression. There are many others. My IBS is not about defecating in my clothes. Frankly, I don't know what it's about or from where precisely it rises. Mentally and emotionally I can feel fine and then another bout of IBS will start up, catching me unawares. If I churn up my mind to see what's going on and/or talk to someone about the problem, in the end a cause will be found and it can be dealt with or at least the attempt to deal with it can be made and, after a while, the IBS usually subsides or reduces.

There are common roots to anxiety and stress, and these are based around the seemingly infinite varieties of fear that the mind can imagine. Fear is unhappiness.

There is nothing about fear, taken on its own, that provides any happiness. Fear is primarily about one thing: my survival, my security, and ultimately about losing, or the end of, my life. It's a biggy! If life was everlasting there would be no fear of losing it, but it isn't, so there is. This will be talked more about in later sections.

How can I be happy when I'm frightened, when I'm anxious and stressed? Is there a solution? Yes, there is but it has to be worked for and it doesn't necessarily come easily.

There are three parts to the solution that work for me. The first is knowledge. Within every aspect of anyone's life, decisions are made on what is known – obviously, clear decisions cannot be made on what isn't known or what is thought not to be known. However, what we know is very limited. Take any example and it will be seen that what is known is dependent on something else which isn't known, perhaps just anticipated or hoped for, even only imagined. All we have is incomplete knowledge. We get by through all of life only on this.

A mundane example is the need to go to the kitchen to make some tea. This decision presumes that the kitchen exists, that there is electricity or gas, light, water, ingredients, crockery and so forth. We presume it all exists but are not one hundred percent sure in every case that this is so until we get there and actually do the necessary preparation. Do I have the ability to make tea, will I spill any or might I burn myself on the kettle? Yes, it's more than likely that the kitchen does exist but the

likelihood of completing the task without upset is less certain. Where there is less certainty there is greater anxiety and stress.

There are many other examples. For instance, I can lift my arm, it's easy, but I haven't the foggiest idea how it happens and just assume that it will. When arm movement is lost or reduced – for me this is practically every afternoon – the automatic assumption that it will do its work comes into question and I worry about how I will scratch my nose, put on my spectacles or lift the kettle and so forth.

I know when I'm happy or unhappy but I don't know how either comes about, although I do know some of the things to do or not do to make one or both happen temporarily.

All this means that we live our lives in incomplete knowledge of how things really are and this is what makes us insecure thereby producing anxiety and stress. The cure for anxiety and stress must therefore be to have complete knowledge about it all. It's that simple.

However (a horrible, doom-laden word sometimes), attaining complete knowledge cannot be achieved by anyone. Not ever. This is because everything throughout the Universe and beyond (if there is such a place) is always relative to something else. No matter what, everything is always imponderable and indefinite. Once this capacity and characteristic of knowledge is firmly understood, the way out of the dilemma, which will dispel anxiety and stress and its cause of fear, can be aimed for.

This takes us to the second part of the solution and is something already mentioned with regard to the section on my progression from walking to using a wheelchair. It was said that happiness is most disturbed when there is no acceptance of how I am. Anxiety and stress will not reduce until there is acceptance of each fearful or insecure situation. What does acceptance mean in practice? It means to know clearly what is happening – not why it's happening – and being satisfied with that.

I have MS. At present there's nothing I or anyone else can do to change this. MS is progressive in my case. It won't go away and no matter how many drugs or treatments I have, which may reduce some of the symptoms, it will not alter this basic fact. For everyone who has life it's the same because of the fact that everyone will die at some point. I have MS and by accepting everything that happens during its course only then can I enjoy it.

Enjoy it! You must be mad I hear some say. Yes, enjoy it, be happy with it, relax with it. This is what is meant by acceptance: it is being satisfied with each and every aspect of life with whatever disability or ability – accepting everything no matter what – and then, when this happens, where's the anxiety and stress, where is the insecurity and fear? This, of course, does not mean that one does nothing about what is accepted.

There's more involved in order to come to a full understanding and appreciation of what's involved in acceptance and this is, as has been said, knowledge. Knowledge is limited and the acceptance has to be of its limited nature. Acceptance is not resignation to this fact;

it's not a negative or evaluative concept but a neutral one – acceptance is neither good nor bad.

It seems better to steer away from opposites like considering whether something is good or bad because this activity is the seed of fear, of fearing which one to choose for the best, and hence for anxiety and stress. Yes, we don't want the bad but we do want the good. No, the fact is that one cannot be had without the other – albeit not necessarily at the same time – which confirms the notion that acceptance has to be from a neutral position. Paradoxically, this does not mean the end of happiness; we will come to see that this seemingly wrong or backward-looking idea of acceptance actually creates greater happiness. Accept the good and accept the bad as they arise but with disinterest: this is the idea. I watch them, as if from a distance, as they come and go – laugh with them, cry with them (not at them), never getting involved with them, and move onto the next. This is not being a cold fish, it's accepting things that happen in life for what they truly are, which is known through knowledge.

The final third part of the solution is trust. What is meant is not a partial trust but complete trust. Trust is a rare commodity, difficult to find and easy to damage or lose completely. Even with those closest to you – partners, parents and children – complete trust may be impossible because of insufficient knowledge about them, because those others are subject to their own life's changes, because trust is out of one's control. I learnt this lesson earlier in life; I didn't know that I trusted my wife completely until that trust was lost and the result

was devastating. This means that trust has to be greatest in oneself for the simple fact that each person knows himself or herself fully. Or is this the case?

No, it isn't. How can I trust myself when I don't know very much about myself? I don't know how my body works, I don't know where my thoughts come from or how they are shaped – in reality the deeper I look into myself the less certain I am about anything. Without doubt, this uncertainty about me causes the greatest fears and insecurity, the greatest of life's anxiety and stress. How can I have complete trust in this me?

The answer to this question is that I can have the most trust of all in me but even that cannot be complete trust. To find complete trust it's necessary to look deeper within because it's certainly not outside. The purpose and result of having complete trust is the 'rooting' of acceptance and knowledge in something one hundred percent reliable and unquestionable. Where is this 'deeper within' in me?

With complete trust and with knowledge and acceptance in who I am, regardless of what happens to me in my life, I am content, completely and fully contented and happy without unhappiness. This doesn't mean to say that there won't be ups and downs but these are just on the surface of me; deeper, under the waves of life's vicissitudes as it were, there is peace and calm, an unruffled happiness. Being in continuous contact with this deep certainty dispels all anxiety and stress and makes light of what happens on the surface.

## Memory and Forgetfulness

How can I be happy when I forget to be happy, when my mind is completely filled by, clogged by, all the ups and downs of being disabled? Forgetting to be happy may sound nonsensical, nevertheless it can frequently happen, but the question raises a further one of whether happiness is our natural state or whether something else is. If happiness is not natural then I need to remember to be happy, but if the memory is impaired in some way this may not happen. Everybody's memory lapses sometimes but its heightened occurrence in MS increases the frequency and extent of the dilemma.

Another water analogy: when water is at rest then all is calm and peaceful. It's the same for the mind. When I'm calm and peaceful there is much more opportunity for happiness than anything else but it still has to be remembered if it isn't apparent, otherwise the mind just wanders aimlessly all over the place always wasting the opportunity to remember happiness. At the time when I'm calm and peaceful there's a neutral, even or level state that is neither happy nor unhappy – it certainly isn't miserable but neither is it particularly rapturous. This is our natural state.

Unhappiness comes about because the mind contains unpleasant thoughts and these can easily dominate pleasant ones. This is very much in the same way that newspaper and news broadcasts are dominated by catastrophes that people have and rarely by their

successes – the domination is mostly difficulties, unhappiness and scandal more than easiness and happiness. The former is seen as ‘newsworthy’, exciting and titillating, the latter is seen as dull and boring!

The biggest, most stupendous thing I forget (and I suggest it’s the same for most people regardless of their state of health) is who I am. As has been said, the mind gets clogged up with every trivial thought: what will I wear today, what shall I eat, where will I go today, will I be late for work or the hairdressers, what needs to be bought, who needs attention (children, parents, partner, friends, work colleagues, the dog, the budgerigar and Uncle Tom Cobley), how do I feel, how do I look, who can I beat, I need to scratch, I need a pee, what’s on the TV, have I enough or any money. There are countless millions of potential thoughts whirring around the background of the mind at every moment, although there is only one at the forefront at any particular time, and these all go towards obscuring or overcoming what’s important. Remembering who I am is the key to happiness and forgetting who I am leaves the door wide open to every kind of unhappiness imaginable.

It is quite possible that many people would admit that the question ‘who am I’ is best forgotten because answering it is thought too difficult. Avoidance of the issue and answering something more manageable and tangible, like the question “what’s for tea?”, is preferred. Forgetfulness can be seen as beneficial in some instances. Or, put another way, many avoid complete happiness opting for partial and temporary happiness, which is as easy to gain as switching on the television!

The predictable response to the title of this section is one about the frustrations and anxieties caused by the short-term memory loss often experienced in MS. It is annoying and infuriating. What happens to me is that I do or think something and a moment later whatever it was is somehow wiped from my memory. Frequently, some of this memory does return but often not without strenuous mental searching to find it and this can be minutes but, more likely, hours or days later. It's very frustrating. The main bank of memory remains untouched.

This frustration can be seen in either a negative or positive light. When I look at what happens it often makes me laugh. Although the actual event in itself may not be funny, in standing back and looking at it from a wider perspective the funny side can be seen. Is this a warped sense of humour, I think (hope) not! It's simply seeing what happens in life from outside of myself, as it were, from a part of me that's not so closely involved in the blow-by-blow daily living activities.

Why is it funny? Life need never get serious no matter what happens, no matter if it's my turn to die. Life can be compared to a 'dance' and a dance is enjoyable (even with two left feet). We dance with another person, lots of people or on our own and in a crowd of other people and things. Or it can be said that life is like a game – snakes and ladders, chess, netball or tiddlywinks. Overall it's fun, albeit that there will be twists and turns, some seeming decidedly unfunny and some out-rightly hilarious. But it's easy to make it not fun through forgetting or not realising, what the game

is. Through not knowing the rules. Everything I do or think has more value the greater the effort that is put into it – it's the same with life as a whole.

## Invisibility and Freedom

When I lived in India for over a year some time ago, invisibility was very apparent. What happened was that when being pushed in my wheelchair around the yogic hospital's corridors where I was living, people would stop my friend who was doing the pushing to enquire from her what was the matter with me. An inquisitor on one side of the wheelchair, my friend on the other and me piggy in the middle! Not once did an inquisitor ask me directly why I was in a wheelchair; I was ignored and apparently thought of as someone who couldn't or wasn't able to speak for himself, who wasn't sensible. At the beginning, this invisibility was found upsetting, belittling and humiliating – an affront to me as a person, to my ego. Then I realised that if I said nothing it would release me from being forced to answer and becoming involved with usually inane conversations with people I had no wish to talk with. My friend had no escape but I could act the 'dumb' part and be free. That was fun!

Invisibility is a substantial part of the social life of many disabled people. For a start, being in a wheelchair puts that person down to the height of a child. I went straight from a towering six-feet-four down to four-feet-eleven overnight – seventeen inches shorter. Instead of looking down on people I now have to look up, which gave me a crick in the neck that had the effect of bringing me (my self-esteem) down a peg or two and that was a shock. There's a whole new world and new perspectives out there when it's viewed from a wheelchair.

I have become invisible to many members of my extended family with whom now there is little or no contact. The saying 'out of sight, out of mind' is true. It doesn't have to be this way because contact with the world could be made, but it takes 'two to tango' for any meaningful contact and, on the one hand I became fed up with dancing on my own, while on the other I just stopped dancing.

Happiness doesn't come from others, it can only come from me, which means that invisibility is actually a great aid to being able to spend time getting to know myself, to start liking myself and answering some of the questions about life that would otherwise be avoided. Invisibility is freeing and can therefore be strengthening.

That's the positive, optimistic approach. I know only too well that there's also a negative and pessimistic approach. Somehow at times it seems easier to be negative than positive, somehow easier to be self-deprecating than self-approving. Why should this be? The answer must be to do with how the self is valued and it's so easy to conclude that I am worthless, useless, a waste of space and stupid because I'm disabled. But is this the truth? Nobody should answer yes to this because it simply isn't true (and it's no different whether I'm disabled or not). OK, I may not be able to be a window cleaner, footballer, driver, librarian, farmer, office or shop worker and breadwinner anymore. So what? Does this make me any less of a person? Does being disabled have to mean that I will be unhappy for the rest of my life? Yes it does, if I think negatively. No it doesn't, if I keep positive and optimistic.

I have come to like invisibility because it allows much more freedom to be me. This might be considered as selfish but it isn't. Everything anyone does is done for themselves whether it's done in a crowd or with another person or on one's own. For example, I want to give to the homeless or starving. That will help them in their predicaments, but it's me who desires to give something and my giving is because I want to, it's for no other reason. I give in whatever shape or form because I choose to, because it benefits me in some way. This is not to say that such actions are wrong, they are laudable, but the motivation for each and everything we do and think is because we do it for ourselves (although the reasons for what we do may be obscured). There are no exceptions to this. None! All this means that my freedom is hugely valuable and the more freedom that can occur increases its value. Invisibility might be seen as detrimental to some disabled people but I find it greatly challenging.

Looking back on my study year in India it is clear to see that invisibility did give me freedom but this was through being forced to be independent. I went to India with two crutches and a self-propelled wheelchair and I wanted someone to push the wheelchair because it was quite hard going over dirt roads. I used to come out of where I was staying and wait for other members of our group to pass by and for one of them to push me to the class. In the beginning it worked quite well but then a change happened for no apparent reason. The number of people passing who would push me to the class became fewer and fewer. I could see them approaching from a distance and then notice that they deviated in

order not to pass me by on the way to the class. Instead of passing close by they passed within sight and hailing distance 50 yards away but I never called and they never came. I found this upsetting, it made me unhappy, and I sat there waiting and waiting until I was forced to get to the class under my own steam as being late was frowned upon by our teacher. I felt that asking people to push me to class forced them to give when they didn't want to, so I waited for volunteers who didn't come.

The route I had to propel myself over included at least one traffic-calming hump (silent policeman) in the road where I had to get off my wheelchair to use it as a support while I pushed the empty wheelchair over the hump. Then I had to get from the back of my chair to the front in order to sit back in it. This required some agility and acrobatics because walking even one step unaided was impossible! And other people walked past me all the time without even an acknowledgement.

I felt so isolated but I came to understand that I needed no one to help – and wanted no one to help – with the pushing if they didn't want to because I had to use what ability was available; this lack of help and isolation freed me, it brought back happiness. It forced me to be independent, to 'stand' on my own abilities and it made me feel less of a beggar waiting for someone to help. It made me stronger and I secretly thanked the people involved for this very important lesson which had to be learnt – freedom and independence, whether physical or emotional or both, went hand-in-hand.

Freedom can be seen as frightening and the preference can be to stay comfortably cushioned by what

we surround and insulate ourselves with. These surroundings appear to be thick and very secure 'castle walls' but in reality they are flimsy and paper-thin, breached easily, and the security they provide is a smokescreen. Take life, for example: it's here one second and will be gone the next. Freedom allows me to 'get real', to have knowledge and acceptance about how things really are. And this in turn means that the more freedom there is, the greater can be the trust.

## Pain

Many years ago I contacted the MS Society in the UK for information on pain treatment. There wasn't any and it's only in recent years that such institutions have woken up to the fact that MS is painful. Now there seems to be plenty of help on the subject.

Everybody's pains (plural) in the experience of disability will be different because it depends on what parts are affected and one's tolerance levels. That sounds as if I'm saying that all the different pains I have in MS are physical, of course they're not, as there are just as many different types of mental pains which are particularly associated with the disability. This is on top of the 'normal' range of both sorts of pains that everyone encounters in daily life. It's a fact, someone with MS or with many of the other disabilities lives a life that has considerable pain.

The opposite term for pain is pleasure and having an increased amount of pain in my disability-driven life concomitantly reduces the experience of life's normal pleasures and their availability. This means that I have to work harder to enjoy a reduced or restricted 'menu' of pleasure, but doesn't mean that I should be any less happy because having pain does not exclude happiness, as we will see.

It's relevant to list a selection of pains which occur in my body and mind so that we know what's being discussed here. With regard to physical pains and

starting from the top of my head, there is neuralgia of the trigeminal nerve across parts of my face and in one other cranial nerve which feels like open wounds and sores; retro-bulbar neuritis in mostly the right eye at varying strengths; long-lasting, low level and sharp short head pains; neuritis of the front of my neck which feels like a nettle rash; reflux oesophagitis, which feels like a lump and burning in the gullet; lots of unspecific aches in the torso; frequent stomach aches and pains; sporadic pains in the arms and fingers (some quite strange, feeling like boiling ice-cold water being poured over me); pains associated with sitting all day in the wheelchair; pains associated with weakness; undefined chronic pain in the rectum; pains in spasms and spasticity throughout the legs and groin; hamstring aches in the thighs; neuropathic pain as well as friction burns (caused by spasms) in the heels; and, right at the bottom, sharp pains in the soles of my feet which feel as if I'm standing on a burning match. Collectively, these pains are either constant in varying degrees of severity or frequent through each day. There are also any number of allied pains caused by MS and itches all over the head, body and limbs.

The varying degrees of pains range from dull aches to the excruciating. An example of the latter happened when I slid off the bed and became trapped and unable to move between it and the wheelchair. Then uncontrollable spasms started from head to foot and there was no option but to call for the paramedics yet again. Once lifted out of my predicament there was relief and nothing was broken, except the upper part of my

toes had friction burns and whole body additionally ached for a couple of days. This may not sound all that much but by golly the muscle pain, particularly from long dormant leg muscles, was extremely painful at the time. I was screaming!

Pains that occur in my mind, that is emotional pains caused through MS, are less easy to define but usually involve thoughts and moods arising from physical pains, my ceaselessly churning introspections and my relationships with other people, the latter two of which are not necessarily separate subjects and, in principle, are not that different from everyone's emotional pains in life. The difference lies in the additional subject of pain that MS creates and the effects of the disease, as it would with any other disability. The experience of emotional pains is quite different from physical ones because they don't necessarily (but often do) have a particular place of occurrence. Emotional pains have many different levels just the same as physical ones and their effects can be sharp to dull.

One result of the ceaseless churning of my mind is the pain of stress. It doesn't happen purposely but I've found over the years that my confident attitude to life has been undermined by an inability to control the onset of anxieties about the silliest of things. Perhaps this always has been in my character but suppressed by a more dominant and self-motivated, positive attitude to life; perhaps this change is a natural aging process, but it doesn't feel so. The best way of describing what's happening is that my confidence is increasingly being undermined with anxiety. It feels that the two traits are

happening simultaneously – my confidence is not diminishing – and this seems to further build stresses because of the conflicts between them. These are either directly or indirectly related to MS and also have their own physical and painful expressions, as in irritable bowel syndrome (IBS).

The subject of my relations with other people, on all sorts of levels, must be a prime focus of most thoughts in one way or another regardless of disability and these people are more frequently but not necessarily always known personally (or fictionally). This subject has its own section which follows.

Then there are mental pains which have a close connection between the physical, and vice versa. All pains are, in fact, mental pains in that they are only experienced in or by the mind. The aches in my hamstring muscles are not felt by the muscles themselves but are sensory responses in the mind to particular physical conditions and messages. The hamstring muscles, for example, do not experience pain as they have no mind of their own, although a particular pain usually feels as if it's in a specific place.

There is quite a lot of crying in disability (a subject which is also looked at separately as sadness) and much of the tears stem from pains of one sort or another. They also come from weakness, either physical or emotional.

The mind controls all pains and their levels of intensity. What is more, the difference between physical and mental pains (if technically there is one) is made in the mind relative to their source. Perhaps it's enough to say that MS is a disease the effect of which riddles the

body and mind with various pains. The intensity of the pains can be controlled at their centre, which is the mind, but this often isn't easy. Analgesics and the like can relieve, make dull or suppress some pains at the physical point of their effect and anti-depressants or others can temporarily lift a mood, but rarely does any pill address either the cause of the pain or what's happening in the mind that interprets and reacts to all situations.

Pain, any painful experience, is also blinding in as much as concentration is focussed on it when it occurs, which can be to the exclusion of all else. Pain usually doesn't invite inquiry as to why it exists, it 'begs' to be relieved here and now if at all possible. My MS pains are long term, lifelong, and allowing them to be at the forefront of my life all the time deflects or seriously interferes with all of life's other experiences – it influences or colours them (usually with shades of grey), that's if I don't do anything about them.

The greatest mental pains that I feel in disability arise out of feelings and thoughts such as: I will never be able to do this or that (any or all of those pleasurable things) ever again or be with whoever I want, how I want, or I will be trapped here physically and/or in unwelcome situations helpless until the end. Pains arising out of feelings of loss through the MS disease, almost like the experience of bereavement, invoke related emotions such as anger, depression and fear unless again I do something about them.

Throughout history it has been said that all life is suffering for everyone without exception and pain is a considerable contributor to suffering. However, pain is

not suffering. Pain is a remarkable in-built feature of the body and mind systems that is designed and operates primarily for its self-protection. Just like anything that's been made, we have to carry on living in the most optimum way until the body-mind 'machine' wears out and it's the experience of pain that helps and guides us to achieve this. When my body is in need of something it tells me clearly with sensations such as hunger, thirst, fright, burning, freezing, aches, hurting and so forth and it's the same for the emotions, because they work together in pain's assurance or survival activities. When the 'machine' needs attention, specific parts feel pain or are painful and 'point' to where the need is most required.

MS is a malfunction in the central workings of the body-mind machine for reasons which are as yet unknown and may never be known fully. This is in the same way as all other breakdowns of this nature – we might get to know how to 'fix' it but not why it occurred in the first place.

Pain is not a diabolical curse, it is the mind that might come think like this or something similar. Pain is not personal, not targeted specifically at me, which is an obvious fact because it's easy to see that every living being, even plants, have this self-protection in their own particular forms. It's the ego, the personality, the sense of 'I', me and myness that doesn't like the feeling of pain, which is not surprising as it's not comfortable. Pain is not meant to be comfortable – that's its whole point – and once this is understood its experience can be accepted as necessary (a necessary evil!). The body-mind

machine does break down and wear out; we fear this occurrence because it points to the imminent demise of the ego, of me, and I thought I was, I hoped I was, invincible and immortal!

The common denominator of these feelings and thoughts is me. They are my thoughts about myself and my predicament and, as such, I can and have to do something to diminish them in order to be able to lead a pain-free and pleasurable life as much as possible and to the greatest degree. And because the 'greyness' of pain always exists, either prominently or lurking somewhere in the background, it means that I have to do something on a continuous basis to maintain the 'colour' in my disabled life, so to speak.

Pain is not the opposite of happiness, the two are not mutually exclusive. This means that while it can be enormously difficult to be happy when there's pain, it also means that it's not impossible to have both pain and happiness at the same time. I can show this to myself all the time with MS. I'm basically a happy person and (like all people) I'm constantly in pain of one or more sorts or the other. I see, understand and accept that pain has nothing to do with happiness (and vice versa); I manage them both so that they don't interfere with each other and this thought process works most of the time. When I was trapped by my bed and wheelchair the pain dominated but I could also laugh at my stupidity for getting myself in that position. Yet, at intense moments, I was overcome by the pain, I screamed, which was a demonstration to me of just how destructive pain can

be and how aware and strong our resolve needs to be to manage it.

Happiness is indestructible and this can be seen even in life's worse events if it is looked for. It is far stronger, bigger and more all-encompassing than this puny little me and any amount of pain that life can send my way. The more I see this the more that I laugh at pain. What else is indestructible?

## Anger

This subject is a grey area for me but I know that many people with disability are angry at the fact that they have the problem and angry for what it's done to their lives. Anger includes a range of emotions such as frustration, aggression, hatred and rage that may have either or both mental and physical manifestations. The reason that anger is a grey area for me is because I have not directly experienced it; the closest I get to it is becoming frustrated by losing patience in trying to do what used to be easy things. However, the range of emotions stemming from anger can be understood because of being able to see from where they originate.

Some years ago I met a woman with MS who was very angry, deeply angry. What is remembered most is that she was aggressively vocal and outraged at the effect that MS was having on her life. She felt that her life was devastated although, at that time, she was still active and mobile (what has happened to her since we met is not known). She could see no rosy future for herself, only doom and gloom; she appeared to be fighting the acceptance of MS with anger. This brief example shows clearly where anger comes from. This woman took the disease personally and looked at what she had lost, she saw no possibility of any future prospects of gain or happiness.

What the details of the devastation were in her case is not important, the major losses for anyone at the

onset of a disability can include loss of employment and livelihood, loss of partner, inability to care fully for one's children, inability to move freely, inability to care for oneself and completely unwanted changes in lifestyle. The loss that a person faces, either imaginary or in reality, particularly in the early stages, can be seen as total and, hence, overwhelming and devastating. In response, some people react with anger.

It's understandable that some newly disabled people don't want to take the news sitting down and just accept things as they come; they want to do something to make what they're feeling go away. A little later these feelings may increase with vehemence, but at some point the realization that they are helpless to do anything about the onset dawns, that in reality there is very little that can be done to ameliorate their situation. Then anger in any of its many expressions can grow or its opposite 'partner' depression can start to cast its blackening shadow. As discussed in the section on pain, anger is one of the first emotions (after shock) identified in the experience of bereavement and the similarities with disability in particular are obvious. It can be thought that disability is the end of me, or so it seems, and I don't want to go, yet.

Does the anger go away with time? The answer to this must be that it depends on each person. Some disabilities occur fully all at once, for example with a spinal injury, but MS for example is often progressive (as it is with me). This means that my frustrations don't recede because new disabilities continually create new frustrations, but this emotion becomes more and more

manageable and more short-term in parallel with higher degrees of disease acceptance. Resignation or defeat is usually negative but acceptance is positive.

In all instances, anger of whatever type is solely based or stems from the ego. Disability itself has no anger. It is me who is angry and anger (in this example) is the only way to cope and deal with my devastation. Trying to tackle anger is attempting to change the effect – that is to stem the flood, so to speak – after the wall of my defence has been breached. It can be a losing battle, whereas working to change the cause by strengthening and increasing my defences and resolve, heightening the wall, to continue the analogy, will be more positive and have more lasting effect for happiness.

“Why am I angry?” “It’s because I’ve lost everything”. “What have I lost?” This last question is an interesting one. Have I lost my life? No. Have I lost my mind? No. In reality, the experience of disability doesn’t entail losing these two vital parts of life but it does mean that I do have to accept change. I have to change and fighting against it won’t help matters. There is no choice in this matter if I am to survive. However, change doesn’t necessarily mean loss, that’s a negative way to look at it; the positive response is to view change as a challenge because even through devastation much can be gained.

I wasn’t supposed to have that job (as an advertising director or whatever) any longer because there’s a new occupation or life to build. I wasn’t supposed to have that husband or wife any longer (because I didn’t realize the marriage was finished) as now there are new relationships to develop, even if it’s

just with me on my own. I can share raising my children and give them what they need but in a different way.

It's not necessary to walk anymore as wheels (scooter, wheelchair or powerchair) save all the effort and danger, or to cook and clean up after myself as people can come to manage these things for me if there is no family or anyone else to help. Phew, what a relief that is! There is light at the end of the 'tunnel' of anger, lots of it.

I, me, myself doesn't change. I am still the same person I was before the onset of MS and I've never been angry with myself, except only a little bit at odd moments. So where is the anger coming from because, as already pointed out, disability itself cannot get angry? What is it in me that reacts in this way?

If the precise answer to this question is realized, anger could never or hardly be felt in the first place. Anger is one of the emotions experienced when the self, me, is not fully known or understood. When I don't love myself, when I'm not happy with myself. This is because although much of the anger appears to be directed outward in its manifestations, it is in reality focussed and directed at myself. With disability I am blemished, not perfect and not invincible. I am soiled, tarnished, damaged goods, worthless and cannot be, exist and live in the way I want to be. I'm finished. I am angry with myself for being this way. Somehow, I don't know how, being disabled is my fault.

A principal antidote to anger is loving myself and happiness. Can there be any angry person who loves and is happy with her or himself? The difficulty is not getting

trapped in the downward spiral of negative anger, which does offer some short-term relief from the hurting feelings; stepping off the spiral is easy just so long as a step can be perceived. Corny as it may sound, such a step is loving oneself and being happy with who I am at all times.

Mention has been made of the way life's passage can appear to twist and turn, that becoming disabled is one of its unforeseen events and that anger is one form of response. Looking at anybody's life passage, in fact all life whether human or not, two interrelated things are certain. The first is that everything that happens to anyone, from birth onwards, happens by external accord, that is its happening is not in one individual's control or influence although sometimes it might seem that it is. The second is that there is complete order, which means that everything that happens, whether thought to be good or bad, does so through a pre-determined plan. Individual experience will verify these two certainties although some may find the facts about them difficult to swallow.

In the first certainty, it is easy to calculate how staggeringly huge the odds are that anything can happen without some external controlling influence. In meeting my future wife, for example, I had to be born (and to be born, my parents also had to be born and meet and so forth back through time) and grow up in such a direction that twenty-four years later I would be at the same place (hundreds of miles away from my family home) at the same time as my then future wife. We then had to be attracted to each other. This couldn't happen by chance.

In the second certainty, within my body there are an uncountable number of individual cells, more than a trillion, and each is being born, living and dying in perfect harmony while working together to build and maintain this wonderful whole 'edifice', my body. This could not happen the same in billions of individuals by chance.

Anger, therefore, is not something one thinks about and decides to do. It is part and parcel of one's whole make-up. Some people will be angry and some not, regardless of what's happening. Letting anger rip may temporarily ease the pain but unless a more concerted and knowledgeable recognition is achieved, anger can be hugely damaging not only to one individual but to all the people that individual might relate with in her or his life. I have to protect myself from me!

## Relationships and Family

How can I be happy when I'm all on my own facing this tsunami of disability with MS? How can I be happy when the only help is paid help and while family and friends stand on the sidelines, often feeling both helpless and unwilling to help (and guilty about it) at the same time. Some people are lucky to have partners and family around to support them, where disability makes no difference to the status quo (or might even strengthen ties). But then others might say they were unlucky to have this company and wish everyone would go away to allow them to face the tsunami on their own, as they want to and not as others think it should be faced or try to face for them.

It's obvious to state that for most people human relationships in their many shapes and forms are the happiest and most loving, most desirable and most pleasurable occurrences out of all events that can happen in life. They encompass our innate, gregarious nature. However, every up has its down. Human relationships can be the most deadly, diabolical and disastrous that might happen to a person! Relationships are rarely one or the other of these extremes but are mixes of the two, like the infinite variety of colours made from an artist's palette. And each moment of each relationship is different in that no person has constant, unchanging moods, which means that what we see and interpret has no lasting substance. Life is nothing but a tasty swirling

‘soup’ in which each person swims! Is it a wonder that some people choose cats and dogs (or more unusual pets) for love and companionship!

Everybody’s life story is different. Briefly, mine is that my short marriage finished about four years before the onset of MS in my very early 30s. I have three children, a son from an earlier relationship and two daughters from the marriage. These relationships ended without war and a strong bond is held with my children, now long grown up and multiplied.

Having a disability, any disability, doesn’t usually add to a person’s attractiveness and desirability in the attempt, or ‘game’ played, to form new relationships. This is because there are always added difficulties, added inequalities, between the able and disabled – one can feel like damaged goods which nobody, or only the desperate, buy.

When still in a relationship through and after the onset of disability (whether sudden or gradual), an enormous physical and emotional strain is added to it. Some survive but many don’t. The ‘fit’ one still has ability, the balance is upset and the relationship often crashes, which can be a happy release for the able one, but for the disabled one it frequently isn’t and the break can be more like a doubling of the bereavement. Yet one thing that disability engenders – which is a surprise – is mountains of resilience, unending resilience, and all storms are weathered in one way or the other, primarily because there is no choice. Life carries on relentlessly and regardless of its contents, just like a fire which is warming but devours everything. This strength in

resilience can be compared to what happens at the outbreak of war: each person digs deep, finding previously unknown personal depths.

We are all different but some may find similarities from the following three illustrations of my experience of relationships while having MS.

One day I walked into a sombre get-together of an Irish family brought together by tragedy and, across the room, my eyes lighted upon a woman. Fireworks exploded dazzling in my head and my legs instantly turned into jelly and my knees metaphorically buckled; the feelings were overwhelming and I escaped into another room on some pretext or other to restore my calm. Oh golly! She immediately followed. The feelings were the same for her, instant strong magnetism. We introduced ourselves. We fell deeply in love there and then. It was wonderful. Disability existed but was out of sight at this time so it didn't come into the picture. Everything that was happening in each of our lives vanished; there was only the two of us and we were one.

A relationship bloomed in all its glory but it had geographic and other big complications – she was just married and just pregnant – that prevented us coming permanently together. The weeks, months and years rolled past. She had now separated from her husband and I flew to be with her at weekends yet we were unable to spend much time together. I wanted to be with her all of the time, for her to bring her daughter to England so that I could keep in contact with my children – my heart was yearning and pining for her – but it never happened (even though she did eventually come to live in

England but not with me) because there was an unmentioned block. It happened that this person had spent some time caring for people with severe disabilities in the past and she thought everybody disabled would be the same (how wrong she was). She didn't want the heartache, didn't want the caring and didn't want the restriction to her lifestyle, which she imagined would occur in me quite soon. In the end the relationship ground to a slow and painful halt.

For about 30 years she used to occasionally phone and I felt the continuing surprise in her voice that I was still alive, still the same person and still mentally intact. Did she feel regret in us not getting closer together? The question was never asked, but I did sense some regret on her part in what she said. What happened was what happened! A convincing thought is that the past is never meant to be anything other than what it was. But, at the time, for a long time, living without that relationship was so very hard.

A second illustration and some years later I went to a weekend medicine wheel (American Indian) and healing workshop with about a dozen other people. At the end, I gave a fellow participant a lift home and that was that. Never had I met someone with such similar likes and dislikes. We were definitely falling in love. We both had health problems but these didn't interfere. The future, the rest of our lives, easily laid itself out in front of me. It was a rosy, happy future as we were so well suited.

So what went wrong? On my own in a train somewhere in Germany came the out-of-the-blue

realization that there was something enormous missing in my part of the relationship which wasn't able to be filled and that, even though everything else was exceptionally good, we couldn't and shouldn't go any further because she would be hurt. She was dumbfounded, deeply shocked and very unhappy when I told her on my return, but we're still friends and that's important.

These potentially fruitful encounters are described to demonstrate that even with disability, wonderful relationships can be had with another person – how long they might last is not necessarily dependent upon ability. Disability will only be the end of the world if a disabled person allows it or unconsciously wants it to be. The most important part of any lasting relationship between a woman and a man is not physical as the mental or emotional aspects are usually far bigger, much stronger and more all-encompassing. If a relationship fails because of physical reasons, like the inability of one side to have sex, then maybe that relationship was not strong enough in the first place to succeed and, however initially painful, it's entirely possible that greater happiness can be found on one's own rather than by staying in a relationship with less potential for it.

A final illustration. I wanted to move home from Somerset in the south of England. Replying to my advertisement for somewhere new to live was a very rural place. It was ideal and I moved in. A woman was already in an apartment there and a friendship then a relationship soon developed even though one was able-bodied and the other not. Our attraction to each other

was very positive and we started living together, although not formally. I started to want marriage but she did not because she had recently ended a very long marriage and had never lived on her own, never got to know herself fully, meaning that she didn't view our togetherness as being potentially permanent as I wanted it to be.

Our living together ended primarily because the balance of the physical was upset. From my side and after a long decline in ability, it was the end of this physical, sexual relationship. Sex had lost its fun, was no longer pleasurable and became too difficult to take place anymore with her, not even with chemical help. This was a hard, although not bitter, pill to swallow because, even though the 'machinery' didn't function as I wanted, my mind and desires hadn't changed. It wasn't bitter because I was realistic about what was happening to me. Loss of sexual ability can leave a big imbalance in the mind if it wants and craves for something that is not practical to have. Even so, just because the sexual element is impaired, it does not mean that strong relationships cannot bloom and in this instance, through working together, we have now built a strong and loving friendship separately.

Where are my adult children in all of this, where is my family? Isn't it true that all people have a life of their own to lead – particularly, with my children, when there is geographical distance as well as another younger generation (their children) demanding more immediate and louder attention? Out of sight can mean out of mind, although not necessarily completely and regardless of ability or disability. This is the same to varying degrees

in all families and part of life's progress and process. All this means that contact with my children is mainly telephonic and what family had started to grow in the beginning of marriage ended when it collapsed. Dysfunctional families are nearly always disabled in some way or other!

I see my eldest daughter (who lives in London) when she visits maybe once a year; my granddaughter is seen less often because disability and children, unless one's own, don't mix very well because of marked differences in activity. My youngest daughter has never visited and she, with my grandson, are only ever seen when I visit them in Spain, which is getting impossible now. My son, the eldest of the three, is mostly solitary in Prague but visits annually.

There were three siblings in my family. My two brothers (both now in their 70s) are older by eleven and nine years, one is very established in the West Country and the other has recently been killed in a traffic accident while wandering on his own around the Americas astride a motorcycle. Communications with my elder brother are occasional. There is closeness with my sister who is three years older than me and who lives in France but since the onset of disability the gap has widened – as it has with everyone – and there is no physical access to or in her home, in fact not to any family member's home. All other relatives are geographically distant (UK, Europe, Brazil and USA). A particular trait in our family is a solitary streak that has come down through several generations and which can only be accepted, as to fight it would be a losing battle.

Where is the happiness in this? It might be thought that there isn't any but that would be incorrect. If a family were hankered after then there would be unhappiness in this situation because the hankering could not be fulfilled. If the family were still together but excluded me, then that would be a rightful cause of unhappiness. However, neither is the case for me. I am happy if my family is happy doing whatever it is they might be doing. Unhappiness would only occur if I knew that there was unhappiness with them.

Many people have close families, mine is disparate and some people don't have any family. I make the best of how I find myself each day. What else can anyone do? I try not to dwell on the past or spend wasted hours imagining how things could be: the notion that 'if only there was something else' doesn't exist, it's fiction. I engender my own happiness and anticipate that everyone else, able or disabled, does the same. My happiness is my responsibility (even in a relationship) and to have it dependent on someone else means that I would be stuck with the vagaries of their happiness. No thanks.

Working solely on my happiness may sound selfish but if I don't do it unhappinesses will intervene, which will dilute and obscure how I most want to be. It's certain that only I can do this work. It cannot be left to anyone else (partner, parent or child), the TV or the local pub because the desired result simply won't come about. What's more, if I'm not happy, how can I make another person happy? What would occur wouldn't be true, it wouldn't be honest and it would only be partial or short-

lived. Being selfish in this way is OK, it is even commanded in the New Testament!

Whether a disabled person is on her or his own, with a partner or a family, there is unlimited happiness if the mind is kept clear of distractions, diversions and attachments. Then there is the freedom to be happy. I don't want to be unhappy because it isn't nice, isn't a pleasure, isn't any fun. What happens in every moment of my life is there to enjoy, to be happy with. Even if there were a partner, or children and siblings all around, would this automatically result in happiness? I don't think so. Real and lasting happiness isn't outside of me in a relationship or friendship but in me; however hard I look, it will be found that it's nowhere else.

## Weakness and Fatigue

There are tremendous strengths and hidden depths which particularly become apparent in disability, but this is coupled with its opposite, the strengths and depths of weakness. Can my happiness be weakened? Can it be strengthened?

Yes, happiness can be tempered or overshadowed by weakness. This is in just the same way as it is affected by other emotions, although happiness itself may not be weakened or strengthened by such influences. My happiness (like the concept of beauty) seems only to increase or decrease in quantity not quality.

Weakness and its partner of fatigue run right through all the physical and emotional sides of a person whether able or disabled. My physical strength is in decline: arm movements, moving across the bed, tired eyes and so forth. Particularly in emotions and unlike the physical, my experience is that where once there was strength it can appear to evaporate instantly at times, but strength can also rebound back - the passage of both is a little like a seesaw! What makes my strength disappear so quickly is shock – the greater the shock, the greater the weakness.

There is an imaginary scale in which shock may be seen as the greatest creator of weakness, but heading to the lower end, stress (yet again) in varying degrees also creates weakness. In my disability there is a great deal of stress, but often it's so subtle and insubstantial that it

goes unnoticed, or is hardly noticed, until collectively it creates its devastating effect.

Emotional weakness is physically debilitating and can be completely so, but this is not necessarily the same in reverse. Parts of my body become weakened by MS, for example in the control and movement of my arms, hands and fingers on most afternoons, but my emotional resolve remains unchanged and doesn't fluctuate so regularly simply because of the physical.

Fatigue is a special form of weakness and is particularly prevalent in MS. Fatigue isn't tiredness although it frequently manifests in this direction, it is a comprehensive weakness which may appear to be solely physical, but it's both physical and emotional together. I am much more prone to tears in fatigue, and fatigue itself can only be got rid of through bed rest. For me, lying down in the afternoon for an hour or two has to take place every day. Yes, one day can be missed occasionally, but there's usually a price to pay of longer-term exhaustion.

How is it possible to be happy when I'm weak? Weakness signifies a reduced ability to cope with the effort that living demands. When the bare essentials of living demand enormous effort, which is heightened in disability, where is the spare energy capacity to enable happiness going to come from?

Major shocks may not happen very often, but little ones can be frequent. Little ones, apart from life's 'normal' shocks, can happen throughout each day and may, on the face of it, seem insignificant and easily able to overcome. However, disability means that I live on a

knife-edge balance and the slightest upset can have seemingly excessive ramifications.

Take for example the daily stresses involved in pooing. It goes something like this: “Will it and when will it occur today?”; “Will I make it to the loo in time?”; “Will I be able to unbutton my belt in time?”; “Will I mess myself?”; “Can I go out safely without needing my special, hands-free loo?” and so forth. Minor as this train of thought may seem, collectively its importance is magnified thereby creating unwanted stress, which in turn weakens me. It’s a cycle!

The greater the stress, hand-in-hand the greater the shock and as a result the delicate or unsteady equilibrium of my emotional balance is upturned. Here is an extreme example.

In the past, I have been attacked by an individual with harassment. This man wanted me to vacate my home, which had been converted for my disabilities at great expense of public money, for reasons he would not divulge. On occasions he harassed me with shouting, swearing and physical domination, which went on for more than two years.

This person was also my next-door neighbour, which meant that whenever I left my ground floor apartment to sit in the communal gardens there was the danger that he might be there or come out after me and aggressively harass me. I knew this man for over ten years, the first half of which were friendly and neighbourly, but for the second half this changed without any known reason or activity on my account. Something

happened in his life to make him an angry person and it was very worrying for me.

When he ranted at me his large frame towered over the wheelchair in a menacing manner, showering me with the spittle of his rage. Living on my own, I felt certain that one day he was likely to hit me. One 'attack' was particularly physical and although not actually causing bodily contact or harm, it forced me to dial 999 for the police to come to my defence. While that episode held his harassment in check for a little while, the fury returned, causing yet another 999 call. Then another incident happened but luckily a visiting friend was available to defend me.

These were unusual situations and are described wholly to demonstrate my weakness. When this person ranted and raved I could hold my ground but when it was over the tears, the shaking and the shock came. When the last such event happened I was still crying and quaking the next day. I said, "Come on, Stuart, pick yourself up", but it wasn't so simple. I knew what this man was trying to achieve with his intimidation and verbal bludgeoning – I knew that standing firm was best – but there was no way to be strong once the episodes were over, there were no reserves left and I ended up a snivelling wreck.

I can live happily and manage progressing disability with confidence because, as previously mentioned, there can be found seemingly unending depths of fortitude and courage, of both physical and emotional strengths but, when a highly stressful and threatening situation occurs, the bottom falls out of the

reserve 'bank' and it goes bust. Perhaps psychologists have a name for this sort of event or perhaps it is part of everyone's nature in varying degrees and is nothing to do with disability *per se*, but with human vulnerability.

But is it? Through weakness the desire is to run away and hide and get comfortable and safe again. That's the easy way out, but it's no way out because another situation will occur no matter what the instance and then the weakness will come flooding back. "Turn the TV on quickly, pretend it's not there and all will be well again". This is not good enough; the weakness can and must be fixed, I think and hope.

The age-old questions raise their heads again. If I don't know who I am, how can I expect all to be well? I have concentrated on having positive and loving thoughts about the person referred to above and they come about quite easily, but do I love myself and what does loving oneself mean. What are my really major weaknesses?

With the latter, cowardliness is tops. I always have run away; there are numerous examples. It's no excuse, but it's very human not to face up to ultimate questions and responsibilities, which are so easy to skip. This weakness is a family trait. My father was weak. He would not stand up to the women in his life, his mother and his wife, which in turn made him a dominated person. Perhaps he inherited this from his parents. Some of my siblings, too, have similar characteristics and perhaps this has gone through to our children. Perhaps weakness is prevalent in a large proportion of society – even all societies – who knows?

With the man at home, there was sufficient strength for confronting him but not for confronting me! There is absolutely no help in the end but to face up to, and come to understand, me and my weaknesses for myself. It is only by so doing that the weaknesses will slowly be reduced. This is the theory, putting it into practice is something else.

Knowing intimately and fully what my weaknesses are can only make me stronger and thereby remove their burden. The word 'acceptance' has been used before: it is only by accepting and knowing myself completely – and trusting that knowledge – will the weaknesses be overcome. But this doesn't mean that weakness will disappear. Weakness and strength are natural phenomena, just the same as liking and disliking and so forth. My life is possible to be lived by trying to avoid the unpleasant while at the same time concentrating on the pleasant yet accepting both with equanimity. What seems to work for me is metaphorically taking one step away or back from the experience of either strength or weakness to simply watch it from that distance and thereby not get personally involved. This is a little like standing in the middle of a seesaw to maintain its balance!

I'm trying to achieve this and ordinarily the result is ok (although not perfect), but when it comes to events like the aftermath of the raging man, I crumble. There is still work to do – isn't that the joy of life!

## Depression, Loneliness and other Lows

Can I be happy if depressed, lonely and the like? Are all these mental states manifestations of unhappiness? Perhaps it's dangerous to link all these states together under one umbrella because of their differences, but it's certain that I cannot be fully happy at the same time as having these kinds of experiences. Being lonely or depressed can be thought of as something like swimming the crawl stroke: most of the time the head is under water in a low state and only occasionally does it come up for a gasp of air, of relief, of happiness!

In this chapter I talk of depression and loneliness, despair, tedium and isolation separately. Everybody experiences some of these in various forms and various mixtures during life, but for a disabled person what occurs does so at heightened levels.

I'm not a one hundred percent happy person all of the time. I experience depression and loneliness and this is sometimes in response to a specific reason or sometimes for no known reason at all. Sometimes I go deep down, sometimes not so deep, and I also go up to great heights! It's called 'being human'! All people's lives, as has been said before, are a series of ups and downs in varying degrees – the analogy of the surface of the sea was used – happiness is much easier to come by on top of the waves. However, when thought about, logic tells me that happiness exists all of the time whether I'm up or down and that it's something else in my persona that

temporarily obscures it. So the name of the game of life – and life is a game that we all can and do play – is to identify this something else and get rid of it.

The trouble is that again I know all this in theory but putting the removal into practice is a different matter. When cloaked in the pall of depression, I cannot see what to do or how to do it. And I stay stuck in the trough between the waves, so to speak, and the only way to go seems to be helplessly down, sinking further and further down. Down is easier than up!

Where the bottom of this pit is remains unclear. There seems to be no end to the misery, except in suicide. Earlier on in my MS life I wanted to know how to end my life easily in case I decided to take this option at some future point. This was because an earlier attempt to end my life for a different reason failed dismally and uncomfortably. It was a way of shouting, “Help me”, but was doubly unsuccessful in that I didn’t die and nobody came to help. That was a very low time. So I joined the English Voluntary Euthanasia Society to find out how to do the job properly, but they couldn’t tell me what to do, although the Scottish VES could because the laws were different at the time, so I joined that. Now the Internet tells me graphically what to do and most public libraries in Britain hold a selection of DIY books on how to end one’s life.

Then I read somewhere about the scriptural teaching that (if reincarnation is believed) if a person commits suicide, in the next life that person would have to return to and re-live (albeit that the circumstances would be different) that very same situation all over

again, *ad infinitum*, until the hurdle of wanting to prematurely end the life was overcome. That was even more depressing. There really is no way out of life except to live it to the last delicious drop (it's delicious if I want and choose it to be and sour, poison or some such if I don't). Whether the teaching is true or not, it certainly isn't worth the risk to me of finding out the hard way, if ever that were possible. Reading this did it, it was enough, no Swiss clinic or the like for me. I could not bear the thought of having to re-live this life all over again even once, so I resolved never ever to think of a premature ending again. Paradoxically, that made me happy: yes, there is a way out of life's seesawing joys and sufferings and all that is necessary to be done is to sit back in equilibrium and enjoy the 'show', to live it through whatever comes. Easy peasy!

There is a difference between solitariness and loneliness. The former state can be intensely happy without an upper limit; the latter seems also to be without limit, but is a bottomless pit of unhappiness. Being in one or the other seems to be a matter of balance – being solitary is an individual choice, while being lonely usually isn't; it is wanting company and not finding it and it's not by choice. Sometimes, more so in the past, I have yearned deeply for someone to come and love me, care for me, stroke me and tell me that everything is all right, but it never has happened, not permanently, not even in the beginning and the yearning is still there.

This aloneness and unlovedness I know because my mother told me on two occasions. She said, "I was

an unwanted child”, to which she added that if abortion had been legal at the time of her pregnancy with me (the end of 1946), I certainly would not have been born. It seems I just scraped in before the law was changed and before the contraceptive pill was introduced! I was put up with, but not loved, and this coloured my whole childhood. Mother did not wish to go to a back-street abortionist primarily, I think, because she feared any kind of pain and particularly never wanted to experience physical pain if she could avoid it. She gave birth to four children and didn't have any pain because she insisted that the doctors “knocked me out” for each event, which meant that she didn't fully experience childbirth.

The ramifications of this unwanted start in life has been a feature all the way through (so far)! This makes me very sad on one level because I am certain that I've so much love and happiness to give to another person, yet all my relationships have not yielded what I would most dearly have wanted, the mutual long-term interplay between two people. This has nothing to do with disability, but it's particularly marked if the person is 'damaged' because, as mentioned earlier, nobody wants to buy damaged goods, so to speak.

The level I referred to is one of many and dependent on the degree to which I want to be on my own or with someone else. When we want something and cannot get it we're sad, and when we do get it we are content. Then it starts over again. I have lived on my own for most of my adult life. I enjoy life and am happy when it's solitary but not when I crave for love and

affection from someone else. It is the unfulfilled craving that brings the morose moods and feelings of loneliness.

Crying helps. Crying allows some of the built-up pressure of loneliness and sadness to escape. Ultimately though, the loneliness and sadness build up again and again and life can be lived like this. Then we're really glad that the end is in sight! In the meantime, until I changed, I just kept drinking or otherwise avoiding making any changes. I was comfortable in the hole I had dug for myself and didn't want to come out. This is how loneliness works; it allowed each day to pass in an anaesthetized or foggy state and, by constantly repeating the exercise, years passed.

It's easy to understand why people don't want to buy damaged goods. One principal reason is that, for example, a relationship between one able and one disabled person can limit both lives. For the fit one, going for a walk or swimming together, having sex together, if at all possible, are fraught with difficulties. And it feels like the less able one gets left on the side of life's road and loneliness sets in. That's if I allow it!

Another low is tedium. When I am restricted by inability to do certain things – going for a walk, picking up a piece of paper, cooking a meal and so forth – then my life activities have reduced variety. With a progressive disease like MS, life's 'menu' can become increasingly boring and the tedium of being restricted to the same few activities day after day spreads dullness. And dullness can lead to heaviness and lifelessness.

I don't have a TV and don't listen to the radio or music, nor do I read fiction. Only occasionally will I read

a newspaper. I do have a computer and the Internet. One might think that this lack of amenities would exacerbate or even be a cause of tedium, but that isn't the case with me. I am rarely bored, rarely without something constructive to do and rarely with an idle, vacant mind (except in one situation which will be described in a later section). And this latter point is probably the answer. A pointlessly meandering mind usually ends up stuck in 'mud', in the mire of useless and often denigrating thoughts, which more often than not are negative and destructive. And from this negativity all kinds of pains and problems evolve, which spiral and pile up on top of each other producing multitudes of lows and unhappinesses.

I have talked about despair but not specifically and this is yet another low. Despair is feeling completely helpless in the predicament of progressive disability or with one that simply won't repair or change. My disease will progress, it will never go away, there is nothing that I or anyone can do to halt its relentless passage. It's a huge and unavoidable obstacle in my life's path and I despair, I submit, I yield and give in. There is no hope in this despair. What to do?

Despair is another word which is used to describe the ever-downward and slippery slope which can happen mentally in disability. It occurs not only in progressive diseases but in all disability because, whatever the problem, what has taken place has to be lived fully together with all the other normal vicissitudes of life such as getting older or encountering more 'normal' bodily disorders. Some disabilities stay irreparably static but

some continue getting more invasive. Depressing, isn't it. No, not necessarily. People don't usually get disparaged when life is going well, so why is despair allowed to get a foothold when things aren't so good? The answer is that I mustn't allow it to happen because I know just how easy it is to start sliding. In a different way it's like knowing what the effect of taking heroin is: it's madness to continue because the slide towards craving more and more and the means of the addiction's fulfilment is steep and as slippery as ice.

My despair is simply rejected because it is known that it actively harms my life. I don't allow it anywhere near because, like heroin addiction, I know the harm it does. How is this done? Primarily it's by keeping happy and this is firstly achieved by throwing out anything that dispels happiness, by metaphorically keeping water bailed out of the rowing boat, to stop it sinking, to keep afloat. I have said that as people we are naturally happy, naturally content, just as long as the basic necessities of life are available. By reducing desires, I reduce yearning and find that I already have sufficient. Then happiness blooms and despair, although I know it will always be lurking somewhere in the recesses of my mind, will be kept at bay. Happiness is light and brightly coloured, despair is dark blackness and suffocating. I know which is preferable.

At the opticians a short while ago, the optician kept addressing my companion, not me. At the supermarket, the cashier said hello to everyone as trained, but didn't say hello to me. This scenario was first encountered when staying in a hostel in India previously described. Being

in a wheelchair is isolating, and this is the final low described here.

Yes, being disabled is isolating, although all individuals, whether able or disabled, can feel isolated at some point or for all of their lives. This is because, although mainly gregarious by nature, every person is separate and individual: only I have my thoughts, no-one else can remotely understand what goes on 'up there' in the attic of my mind; only I can smell through my nose, see through my eyes, hear through my ears, taste through my tongue and feel what I touch. However, with regards to disability, the whole of society treats the wheelchair user in a different way than it does for any 'upright' person. Yes, it is the whole of society and for a range of reasons, some of which are positive but the majority are negative. This treatment can be compared with a plague carrier: some people make it their business to manage and help the person, for example some family members and health and social service professionals; the majority fear contamination and, apart from idle curiosity, make special steps – obvious or covert – to avoid any form of contact.

The picture being painted is of the external and mainly physical aspects of isolation, but internally the effects of isolation through disability are much greater yet, as for everyone, they go completely unseen. From one perspective, isolation can be felt to be like an existential revolt. To be more specific, for everyone this can mean a deep questioning of, or evaluation of, who I am, why am I like I am, why am I doing what I do or not do here in this life, what is my purpose and, for many,

what value do I have to myself and to society. If I, as a disabled person, were a creature in the wild, Mother Nature has a very effective and non-lingering way of answering all of these questions as there are copious numbers of other creatures who would make a meal of me sooner rather than later. As a human animal in Britain, I have no predators except of my own species and even these don't completely devour me. I'm stuck.

This inner-felt isolation can be experienced in either a positive or a negative way and is more likely to be a mix of the two. Through taking a brief sample of what the majority of people (able and disabled) in society watch TV or read newspapers and books for, it is clear to conclude that the human preponderance is for pain in all its various forms (which includes titillation). All these pains are seen erroneously as pleasure, the kind of pleasure that 'entertains' and passes the time in such a way that it helps to avoid looking into inner reaches of the mind or persona. In general, this 'pleasure' replaces or is superimposed to cover the feeling of isolation that is felt in some degrees by all, at least for as long as the programme or novel lasts. When the TV is switched off, the book closed, isolation resurfaces – it never goes away – so something new is made to happen in order to occupy the 'vacuum', which is usually vacuous!

On top of this are the additional and specific feelings a wheelchair or bed-bound person can feel – the utter uselessness of living because there is no usefulness in me in this state. (Of course, the question of life having usefulness or a purpose in the first place is debateable, but answering this is beyond our scope here although it

is illuminating to ask where this question originated from and why.) Perhaps mental isolation for a disabled person has no significant difference to that which an able bodied man or woman feels. The feeling of uselessness can afflict everybody in much the same way, it's just the variety of uselessness which differs.

The question, 'what use am I?' presupposes that I have a use, so it is the wrong question because nowhere does it say in life that I have to have a use. Throughout history, various purposes and uses for life have been determined but these are all without hard, verifactory evidence to support them. I just am and acceptance of this basic fact leads to far more happiness because, without a use or purpose, the feeling of uselessness is automatically cancelled thereby making it much easier and much more free to feel happy!

## Happiness and Sadness

This is the final part of the second section of *Happily Disabled* and, judging by its title, one might think it would be the most important because happiness is what this book is all about. Yet, on analysis, it is clear to conclude that a person with a disability, any disability, need not be any more happy or sad than the rest of the population. Happiness and sadness are not particularly dependent upon MS or any form of disability and, although these bring on distinct forms of happiness and sadness, the happiness and sadness that is experienced during a person's life is very much up to that individual. A disabled person can be one of the saddest in the world or one of the happiest and all the varieties in between.

Happiness and sadness are two sides of one coin; there is no happiness without sadness and no sadness without happiness. To put this another way, if there was no sadness in the world how would it possible to tell whether one was happy or not? There are degrees of each and each of these degrees overlap each other – at extreme ends of the scale is either unalloyed happiness or unalloyed sadness but most often there is a mixture of each. That's life!

Life is in three parts: past, present and future. Someone once said that we live half in the past, half in the future and very, very little in the present. Each of the three has their own degrees of happiness and sadness, but one thing is for certain: every happiness

and sadness is experienced in the present without exception, so it is in the present that concentration to create more happiness and less sadness needs to be made. That is if one desires to be happy. This is the point – happiness is inherent but much depends on what's going on in one's mind at any one time and if conscious effort can be applied here in order to deflect sadness, there will be fewer barriers to greater happiness.

So it is the mind that is the real arbitrator of whether I'm going to be happy or sad in any particular situation regardless of what it is. The mind is always active in storing and sorting memories and either in planning or imagining what is to come, which means, as has been said, there is precious little time left in the present to work on what's actually happening now. Remembered or imagined happiness or sadness have already been or may never come, what's real is here right now!

My mind is made up of a rabble of wild horses dashing here there and everywhere, manes and tails flying, teeth bared and hooves stomping, all going on in a cloud of confusing dust! This has to be controlled not just for a minute but always and that's a tall order for anyone. Without control there is chaos and a chaotic mind cannot be completely happy. Without control sadness festers, getting more and more all the time like a cancer, leaving less room for happiness. Without control my mind wanders into the past or more often into the future, scant attention is paid to the present. The horses need to be corralled, fed and watered, loved and cared for!

What goes on in my mind's corral is particular to me and it's the same for everyone regardless of their state of life and health. Yes, MS or any disability brings certain difficulties which need to be met with: many or most of which can be faced in a happy or sad frame of mind. Sometimes life gets so sad that it's difficult to see a way out but there is always one when there is the energy to make the search. So that's the answer: to keep strong and positive regardless of everything. How can I do this? The answer must be by knowing the reality of my situation. Yes, I am severely disabled. Yes, I can do very little physically for myself. Yes, there is continual pain and discomfort. But I know that within this there are happy moments which can be multiplied and expanded and the sadness which always lurks can be subdued.

What is happiness and sadness? Imagine a sliding scale, at one end happiness and at the other end sadness, with a neutral middle. At either end there is extreme and unalloyed happiness or sadness while in the middle there is neither happiness nor sadness. Extreme happiness or sadness is possible in theory but in reality how could it be known? Greatest happiness is where there is the least amount of sadness and where there is greatest sadness is the opposite. This means that the greatest happiness can be defined as the state with the least amount of sadness, as it is in the reverse for the greatest sadness. If this is the case, more happiness can be found by reducing my sadness.

Continuing the use of the sliding scale analogy, it would also seem that the more extreme 'measurements' that are reached may mean a greater unsteadiness

because of a lack of balance. In turn, greater happiness or greater sadness might be unstable conditions and not the most desirable (or undesirable) states as was at first assumed.

In the middle of this scale there is a point of neutral balance, which is neither happy nor sad but which is perfectly stable and secure, unmoving and unchanging. Is this then the happiest state?

## Part Three

### Future Encounters

## What's Happened So Far

What follows is an extraction and summary of all that was said about happiness in the first two parts of my story.

The beginning started with a question. Is it possible for me or anyone to be happy and disabled at the same time? On the face of it, the answer seemed to be that it isn't possible to be happy and disabled. But is this true? A second question asked what my happiness has to do with disability because it seems obvious to state that all people can be happy regardless of their physical condition. And then a third question was asked to establish where happiness came from in me and the only answer possible was that it comes from inside no matter how much I might try to get it from somewhere outside.

The physical sections started with a moan and didn't sound particularly happy. This was where agency carers had to be used to help me until a different way of obtaining the same help was found. Yes, agency carers were a pain, although not necessarily the people themselves, but usually whoever cares for me does so for money and they are happy to have the work and I am happy that they do the work. Happy happy!

Whether I am happy or sad about the performance of the body depends on my attachment to it. The suggestion was made to separate the body from the mental sense of I-ness, of me and my-ness. Yes, but my leg, arm, head and big toe hurt! Such separation of body

and mind takes a great deal of strength and I don't have this amount all of the time, or even some of the time. The theory is great, but its practice is impossible! No it's not; there isn't much in life that doesn't come without a little effort and, disability or not, perseverance leads to improvement in every case.

Mention was made of a power greater than me. This idea takes some getting used to! It's just that when thought about, very little of my life, if anything at all, is created or done by me. With regard to food for example, I don't grow it, eat it, digest it or do anything about getting its goodness to all parts of the body, or dispose of the waste (refuse workers and excretion). I'm very happy that all this is done for me, but it leads to the question: How is it all done?

Then more questions: where is the happiness from people when I am disabled? Where is it when I can't do as I wish, be as I wish, come and go as I wish? Everything has to change with disability. But does it? Isn't there something constant in this changing world? Does happiness change?

The concept of normality was turned on its head because, with or without disability, to me I'm normal. Maybe to able-bodied people I am abnormal but it doesn't matter because what others think is not relevant to how I am. In my normality, there can be happiness or unhappiness – it's my choice. So what do I want?

It may be that I think I know everything that is needed to be known, but in reality I know very little and I have a trust that things will work out, all types of different things. But I don't consciously and completely

trust anyone, I just take what happens in my life for granted or I actively go out and achieve things for myself. No one helps. I'm on my own. Is this the case and if it's not, who or what is it that I need to trust to help me achieve what happens in my life? Maybe I do trust but don't know that I do and take what happens for granted. If someone gives me something I say thank you, but as things happen automatically (such as digestion) who is there to thank? Why should I say thank you?

In any case, I'm not this body but something else, although the body itself plays an enormous part in my life. However, what this something else is is difficult to get to know and understand, and through much of my life I have avoided trying to find out. Ignorance is bliss, so they say! But it isn't, ignorance is unhappiness and I don't want that.

Where my body is most important is in eating and drinking, moving about and doing things and having sex. It's a source of pleasure and satisfaction but at the same time it's also a source of all that is not pleasurable and unsatisfactory. When it works well, pleasure is usually taken for granted, but when it doesn't work well, pleasure is not so easy to achieve, yet it's not impossible to have pleasure regardless of the state of the body as much depends on the mind as we will see.

Happiness is everywhere but it seems to fall away through life's vicissitudes and this falling is usually downwards to varying degrees of unhappiness. Physical falling usually has unhappy consequences but I can 'pick myself up' both physically and mentally. Falling usually isn't fun!

It was asked whether happiness was just a thought, a mental process or a reaction against some physical stimuli, and if happiness wasn't just the thought, what else was there. It's certain that there is no happiness without thoughts, but what is it that intervenes in the gaps between happy or unhappy thoughts?

From here onwards the attention is turned away from the physical to the mental, albeit that the separation between the two is unreal because they are both intimately related.

It's not possible for me to know everything and this incomplete knowledge leads to fear and anxiety, which in turn leads away from happiness and towards unhappiness. It's obvious to say that the more I know something, the more confidence and acceptance I will have about it. This means that the more I can know about how to produce happiness and how not to produce unhappiness will make me more confident in being happy for more of the time, it will make me less anxious and less fearful. Knowledge, acceptance and trust are my three ways of removing anxiety and fear, of finding more complete happiness. These three words are big words!

Absurd as it may sound, I can forget to be happy because neither happiness nor unhappiness seem to come without some form of effort or activity. When neither are present what is there? I fill my head with all sorts of thoughts (which Freud said are usually about some form of pleasure or other), while thoughts imposed or interjected from the outside are often not so pleasure-

filled in that I have to do some work, someone wants me to do or get something and so forth.

Getting to know who I am and similar such questions are avoided like the plague. Anything is better than nothing to fill the silence left when there are no answers and no thoughts. Who am I? I mean really who am I? Oh, don't ask! And in any case, how am I supposed to know?

Now I know how Griffin, the original Invisible Man, felt! What a treat to be able to move about unobserved or unnoticed and just be myself, with nobody to care or interfere – a wheelchair is a passport freedom.

Everybody at any age regardless of disability or non-disability experiences pain physically, mentally or both at the same time in hundreds of different ways. There is no escape, but pain has nothing to do with happiness. OK, pain is normally equated with unhappiness because it's not normally a pleasant experience and it detracts away from being happy. But happiness is separate from pain, which means that I can be happy yet in pain. I can also be unhappy and in no pain! A disabled person is no different from an able person in this matter.

MS isn't my fault so why should I be angry and, if I am, who am I angry at? It's me who suffers most if I'm angry. It means that my happiness is lost and I live a 'dark' life. If MS isn't my fault then it must have been 'planted' in my life by an external force, which means that I can freely continue living my life as it presents itself in complete happiness.

Complete happiness only comes from within me because it doesn't come from anyone else or anything

else – where else can it come from? As it comes from within me it is 100% mine to do with how I please. Happiness can be shared or not: sharing does not diminish it – it might even increase.

Happiness can be stimulated within me from anyone that I am with or in contact with at any particular moment, but that happiness is always dependent on them in the varying proportions of what they can give to me. It cannot be relied upon because everything changes, time passes. I have felt very alone and unhappy in a relationship and at another time happily free when on my own! My happiness cannot be dependent on a relationship with another person but it can be and has been influenced by them.

If I ask whether or not disability has been influential to my happiness that has been engendered by another person (family, partner or friend), the answer is both yes and no. The results have varied according to every different situation: in more than one instance it has had catastrophic results (the ‘scars’ are still visible) yet in other instances it has made the ties much closer and more strong. There are many ‘shades’ to relationships and no rules – this is true for everyone everywhere.

Physical and mental weakness doesn’t necessarily mean that I cannot be happy, although it may attenuate it. It might take a little extra effort to encourage, because weakness is another of those shadows which overcast the metaphorical ‘sunlight’ of full happiness.

Usefulness is a misnomer! Where does it say that I should have any use at all? If I feel I should have some

use but don't have any, I will get depressed, lonely and isolated. I don't think this way now. Shakespeare said it perfectly in *As You Like It*: 'All the world's a stage, and all the men and women merely players'. Nothing is serious. There's nothing to do but enjoy!

Happiness and sadness exist regardless of whether a person is disabled or not and a person, any person, has the ability to find happiness in their lives. Happiness is right now in the present; it's over and gone in the past and hasn't yet come (it's fiction) in the future. In the middle of happiness and sadness is a point of perfect balance – is this something other than happiness and sadness?

## The Future

I'm no soothsayer. Who can tell what the future will bring. But some things can be anticipated with a certain degree of sureness. I have multiple sclerosis today and if tomorrow comes I will have it then because it's incurable and, as yet, no one knows that much about it. Researchers are chipping away at finding its cause – or lucrative pharmacology that will relieve its symptoms – but a successful cure is not likely to be in my lifetime. So the future is surely to bring more of the same, which in my case is a slow and basically uneventful progression into greater disability until the body gives out because it can no longer defend itself against infection.

What could be more than now? I'm already classed as severely disabled so there's only the addition of words that increase the degree – like 'even more', 'grossly', 'extremely', 'acutely' and so forth. They're just words which don't in any way describe how I feel about my predicament.

For many people disability is static because it was caused by an accident or birth defect or the like, which means that there is likely to be little or no change over the years except the normal changes everyone experiences in growing older.

Death could come today or tomorrow so my disability might not increase. I know what life is like today and that's enough.

But I'm not dead yet, I'm very much alive and kicking! However, nearly all people treat me with kid

gloves and do not approach me for whatever reason, which includes fear of what they may do to me or of what I might do them or both. And this means that it is rare to meet someone on an even basis. So I stay on my own with very few friends and very few family. OK, it is always difficult to go out to meet people or go places because of physical barriers for a wheelchair user such as steps, door widths, head height differences and the rest. Plus, there are the natural age-related barriers, whether one is disabled or not. I tend to hibernate all year round.

There's a queue starting to form! This queue is being led by the occupational therapist who has my safety and well-being at heart and who feels that I need a shower wheelchair and a hoist with, no doubt, more to come. These items are about to arrive and will sit there unused until needed, telling me that this is what will be required soon, maybe tomorrow, that this is what I will be like tomorrow.

It's not just the machinery which foretells my future but what comes with it, which is principally the increasing loss of independence. It is highly probable that at some point I will no longer be able to go to bed when I want, get up when I want, shower when I want, go to the loo when I want, eat when I want – basic things – because people (carers) will have to be around more than they are at the moment to operate the equipment and do the necessary preparations. In turn, this will further limit my daily schedule, so what's coming is not going to be little changes but big ones!

I must prepare for this because, if I don't, it could be quite unhappy. How do I prepare myself for

something that may never happen or for something which is unknown? When or if it does, I must be ready. (The word 'must' is not one that I like but here there is no choice, so 'must' it has to be.) Here the imagination clicks in for poohing in different and unusual places (in bed, on the floor, in my trousers in the supermarket), being bedridden (a laptop computer has already been bought for this event), being fed, being washed, having my teeth brushed and my hair (not that I have any) brushed.

The one thing that might be difficult to come to terms with is waiting. Normally I'm quite a patient person but being stuck in different situations waiting for assistance could be quite frustrating. The answer, I think, will be to ignore the body as much as possible and to drift off along on some train of thought or other, not getting into a pickle or getting upset with the physical, which is something I can do relatively easily because I have an inventive and creative mind.

The future will come, of that I can be assured, and it is likely that the disease will progress over time, that it will become more invasive and debilitating. This is the future that I need to look forward to in the right frame of mind so that I will be happy when increasingly less able.

One thing which needs to be settled as far as possible is where I will live until such time when independent living becomes impossible. My present home is ok but it's not warm enough and there is no pleasant outside, although the views from the ground floor windows are good (miles of open countryside).

Where I live has a lot going for it but also a lot against it. What to do and where to turn for help? Against my better judgement I've been investing a little money in the National Lottery in the hope that funds will become available to make some sort of movement possible – what a silly hope!

Maybe it's too late to move and I should accept that my current home (if I am allowed to continue living there) is sufficient and improve it as required. It would be an enormous effort to move, a huge upheaval, and getting things back to normal would take years, not least re-establishing myself with the very necessary people who would help me. I have moved frequently in the past, never settling, never building solid foundations for a long-lasting home, and this relates to the fact that I have never been able to have a long-term close relationship with anyone. Homes usually revolve around people and if the people are not there or were not there in the first place, homes are difficult to establish.

The thought of not being able to live independently is a difficult one as I am not naturally a gregarious person and am probably too selective with the people that I befriend. This might not be possible in the future and a retirement or nursing home may be required. I can accept this providing, and it's a big proviso, that I have a single room with a window that opens where I can be myself and live a normal life as far as possible. That would be the difficult request second only to an easily accessible garden, which might be easier to find.

My life is not over, far from it, and what is yet to come is likely to be full of surprises. Disability makes no

difference here, it's just the content of the surprises which will be different. Accepting everything (or making things acceptable) is very necessary to me as it enables a peacefulness to be maintained, which is so important for a contented life.

But the end will come, as it will for everyone. Accepting this, too, becomes much easier the older I get. Now approaching my mid-60s and, knowing from surveys that the average lifespan for a man with MS is somewhere between seven and eleven years below the average age of 78, I can easily work out that if I were average (which is fiction) there may not be many years left. I don't particularly want to die but, like everyone, I know I will at some point and I am happy with that. I certainly do not want to stay living longer than is natural, that would be very unhappy, but as I have said, I have no wish for a premature and self-inflicted ending.

The future for me as a disabled person will be different from what it would be like if I was not disabled, but the basic fundamentals won't be that much different to anybody else. I will still need to eat, sleep, occupy myself, enjoy myself, give what I can and all the rest. The future can be happy or unhappy but I would prefer to be happy!

## How happiness came to me

All through this book I've talked about happiness. What happiness means is likely to vary by person so here I want to talk about my happiness and unhappiness.

I'm not unusually different to anyone, which means that my mental state is the normal ups and downs following a 'mean line' where everything is basically ok. My life has not been a particularly happy one but it's important to try to unnaturally separate out my life without disability and with disability. MS came on classically in my early 30s. Up until that time my life had been eventful with not much happiness, some parts of which have been described earlier.

The main thrust is that I am not very good at maintaining human relationships. I lost my childhood friends in my early teens and, finding myself on my own, I never recovered. Yes, friends and lovers were found but nothing stuck, nothing lasted, even marriage and children. Looking back it's easy to see that life could have been lived differently, but it wasn't, what happened was right in those particular circumstances with those particular people. It seems that it's mainly with other people that happiness can be mostly had – we live in pairs because it's comfortable and easier and we basically fear the alternative – but I found out that real happiness can only be had on one's own.

Then when MS struck it didn't make much difference to my life – perhaps because the diagnosis took over one year after hospitalisation (MRI scans had

not been invented) – which meant that it was pretty much ignored as there were other things to do to keep me occupied and amused. Not making much difference, ‘normality’ carried on and the style of my life didn’t – and still hasn’t – changed much. In some respects, I think that’s the same for everyone: we are who we are and it’s virtually impossible to change that no matter how hard we might try or how our physical states might change! The ‘surface’ of my mental state is not very happy but also not very unhappy, I have no comparative yardstick but I expect it’s similar for most people. However, ‘underneath’ there is now a deep, deep happiness. This is new.

What brought this on? Earlier, mention was made of three vital ‘components’ needed for deep, inner happiness: knowledge, acceptance and trust. Knowledge of who I am, what I am, where I am and how I am – the truth of me. Acceptance of this truth. Trust in this truth completely and absolutely, incontrovertibly.

Finding these three components took quite a long time but I was not particularly looking for them. I am spiritual and philosophical by nature – I have an enquiring mind – so that’s the route my life has taken but that’s not to say it’s the only route or that it’s the right route. There is no right route. It just happened to be the route that I took. The conclusions that I came to anyone could come to because they are based on life’s experiences, looking at myself in great depth or deep self-analysis, learning what wise people have found in the past, using some basic logic, applying some wisdom of my own, and some directionless determination.

The way for me didn't take five minutes, but years of introspection in a disciplined way, but for some people it can only take five minutes and not be particularly disciplined. My route maybe doesn't sound like much fun but I've enjoyed it because it suited the way I am. It was looking deeply into me and beyond me, and reaching a point where everything was known beyond any chance that what was known might change at some later time. Once this point was reached, I knew that nothing could adversely affect me. This is not to say that there won't be adverse things and situations occurring, but these would be 'surface' things, life's vicissitudes including disability: it meant that there would be happiness and unhappiness because that's how life is. Yet underneath all this came a solidity that could deflect anything and everything.

So, yes, disability has affected me. It's made my life full of physical pain, it's hugely influenced my mental life, but it doesn't matter because the foundation is solid. This isn't new. It's what each person knows deep down but doesn't often think too much about.

In conclusion, I can ask has disability made a difference to my real inner life, if it can be so called? The answer is that no, it hasn't. My real inner life cannot be affected by anything. Only that transient, variable, inconsistent me on the surface gets battered and pushed around. I have learned the difference between the two and the value of each and that's what gives me true happiness.



Playing King Canute with crutches on a Welsh beach



Self-propelled in India on a one year course