



Able in my dreams

by Patrick Costeloe

"I am on a beach. It is a glorious summer's day. The smooth sand glimmers, golden ridges shaded with the wave shadows of the retreating tide. And I am running along the water's edge, splashing drops of sea water, pearls of it on my legs, jewels of it glittering in front of my eyes... and I am running... running... running..."

Rosalind's dream.

We have been on three research programmes, have looked at alternative therapies, have experimented with different drug régimes, have read anything and everything comprehensible to us on the subject of Parkinsonism and neurology. We have recently been introduced to the idea of surgery, namely pallidotomy, and are see-sawing between this surgical option and going for a pharmacological option in the form of Apomorphine injections. One of the neurosurgeons pioneering the pallidotomy came out with a very reasonable justification for it: "When L-Dopa was discovered as a treatment people were given the choice of an operation or a tablet. It's obvious which course of action they wanted to take." However my partner is now faced with a choice of an operation or a needle: not quite such an easy choice. It has been thirteen years now that we have lived with this unpredictable and bewildering condition called Parkinson's disease.





I am a 'carer', something I had not thought of myself as for the first ten years of my partner's Parkinsonism. Carer! A word so hated by so many. But it has meaning to any man or woman with a deep or intimate relationship with any other man or woman without regard of – ability or disability, but love, and love only. Why did it take so long for my status to become clear and have a name? Simply because my partner refused to think of herself as a 'caree'. I apologise for the word 'caree' because I am not sure that it is a real word; but the word 'patient' is so inappropriate to my impatient partner and the word 'sufferer', though true, just rubs salt into a hopeless wound when we are trying to find hope.

The state of 'denial' has acted as an extraordinary experience, sharpened by the fact that we are a creative unit. Rosalind, my 'caree', is a stained glass artist and I am a writer so we have had the added dimension of experiencing and expressing Parkinson's through the crafting of colours, forms and words.

My "practical project or proposed initiative to improve the quality of life of people with Parkinson's disease and/or their carers" is, on the face of it, very simple and is not my idea, but my partner's. It is a suggestion she made to somebody researching Parkinson's disease. If I remember rightly – my memory is terrible in comparison to hers – she had just done a series of tests for a psychological research team. These tests (number, word and memory) would have completely floored me, but to her they were easy. On the face of it I was the one who was impaired. She felt that everybody working in the field should spend at least a whole day with somebody with Parkinson's disease.

This seemingly very simple, practical idea I want to combine with my experience of many years as the partner of somebody with Parkinson's disease. Given that Ros was diagnosed with a condition

usually associated with old age at the tender age of 37, the progress of the condition has inevitably cut right across our working life.

My account of this experience is an attempt to put the reader of this essay right into the heart of Parkinsonism, and Parkinsonism as experienced by a carer. The metaphor running through this essay is that of a traveller in the 'Land of Dis-ease'. Understanding and accepting this 'Land of Dis-ease' leads to being a native of a 'New World' every bit as legitimate as 'The Normal World'.

Come to think of it, the idea of a traveller in the 'Land of Dis-ease' is not a true description. The word 'traveller' gives the idea of choice – as though the right equipment has been bought, route maps and guide books perused and the right currency changed.

Travel is too active a word, as though we were the initiators of this journey. I know I did not chose mine and blame my partner. But that is not fair either. She didn't have any choice and I think it would be better to describe her as the 'initiated into this journey'. She has become an unwilling native of this unpredictable 'New World', just as I have become an unwilling witness of it.

The predicament of the witness is more like that of a traveller than a native. There are times when I feel as though I have tagged along for the ride, on the journey neither of us wanted. It is as if some sadist has dumped us in the middle of nowhere and told us to get home. We have been left without a compass, matches or even walking boots. Even worse, Ros moves when she doesn't want to and cannot move when she wants to. This means that not only are we making the journey home very slowly but she is demoralised by despair and depression. This in turn makes the surroundings seem all the more bewildering and terrifying. Control on this expedition seems irrevocably lost.

On top of this, the outside world seems to be getting more confusing. The experts on this kind of journey are observers. They are one more step removed from 'The New World' than carers. Carers are stumbling along with the carees. And the experts are watching the carers and carees stumbling along and giving opinions and encouragement based on their study of the detailed maps which describe the landscape, and knowledge gleaned by their experience of watching a number of individuals attempt to come to terms with their surrounding landscape.

The experts are cartographers of the condition but are in danger of confusing parts of the maps as being representative of the whole landscape. Details such as forest and hill do not show the trees blown down in the high winds of March, the gorse and heather that flash gold and purple as the clouds scud across the sky and the sun bursts through. A map is a series of markings and is not to be confused with 'the thing in itself – 'der ding an sicht'.

The cartographers compete, and in so doing are in danger of losing sight of the landscape! Of the three research programmes we have been involved with one was involved with Parkinson's and perception (especially in artists), one with Parkinson's and psychology and one with Parkinson's and neuro-chemistry. The psychologists and neuro-chemists seem to be at loggerheads and the neuro-chemists seem to be at loggerheads with each other.

All these 'cartographers' I have met are perfectly charming on a personal level. It is the 'cast of mind' running deeply through the research establishment

that I question. As the areas of research become more and more rarefied there is a danger that the very real sufferings get lost in the science. Medicine is losing the sense of the whole person; I know this to be true in my partner's case because this plea I have heard for years and years. As bio-neuro-chemist-psycho-surgeonologists struggle through research and experiment so the rocket of knowledge seems to have lost sight of the travellers on the ground.

I have turned back many times to Oliver Sacks' book *Awakenings* because his patients are treated with a rare humanity, respect and imagination – an imagination so far reaching and sensitive when confronted with such a painful, paradoxical and devastating state of affairs that it turns to metaphysical poetry for illumination. It is not that Sacks is necessarily right, but the qualities he brings to bear in writing about Parkinsonism cannot be wrong. It is this strange paradox: on the one hand the sophisticated developments in the knowledge of biochemistry of the brain or pharmacology; on the other the despairing (almost suicidal) heap of human being, statuesque in stillness but as perceptive and sensitive as the decade before diagnosis.

In saying this I am aware of being in danger of biting the hand that feeds, of doing down the experts, the organisations and helping hands that are God-sends in this sorry journey. The travellers, by this I mean the carers and carees, are in a very vulnerable position. We may hold opinions we are afraid to express in case we alienate those we need to help us. The environment of those who help and research can never be the same as that in which we find ourselves.



For example, the six-monthly consultation with a specialist only gives a half-hour insight into what has been some one hundred and eighty days of struggle just to keep going. Of course we would like to be airlifted immediately out of 'The Land of Dis-Ease'. But we know that at best we'll get an adjustment to the tablet regime which will flatten out the gradients of the steepest hills and make the rivers flow a little bit more slowly. In other words, make the landscape a bit easier to be in and live with. I do know that all those involved in the research, help and care would also like us airlifted out.



My criticism is based on an opinion of the environment that the 'Old World' we once inhabited seems to be like. The statuesque heap in the corner of the consulting room is, in my case, the same heap that has watched as an exhibition of her work, a one-man show, has been hung in a prestigious London gallery. Oh paradox of paradoxes. And, to make us an even more difficult pair of cusses, we have existed for years in that wonderful state known to psychologists as 'denial'.

The confusion caused by 'denial' is total. Firstly, the carer is in the precarious position of going along with it because for 'denial' to be effective it requires absolute belief and collusion. This leaves the carer liable to accusations of not caring when situations crop up that are undeniable, like inability to move when some movement has to be

undertaken. This is even more acute, obvious and, at times, 'undeniable' for the caree. As for the visit to the specialist, let me just say that in my experience our two-person orienteering team has suffered badly from my partner's inability to suffer in front of the consultants.

On the contrary: she pulls herself up to her full height, the dyskinesia settles down, her rigidity is crushed by a fluidity born of pride and will, and as for being disarthric, well, words once swallowed are rolled on the tongue like sweeties. Since four in the morning (insomnia is an added bonus in this land), she has been worrying about adjusting her habitual drug régime for the sake of getting to the consultant, about what to wear, about whether we will get there on time (even though we'll wait for hours when we get there). All this anxiety, bad enough in itself, only serves to set off a stream of Parkinsonian symptoms which have to be overcome before we get to see the consultant or else he won't think she is very well!

This feature of our bizarre landscape I will call the precipice of paradox and it is one we will both have to learn to love because it crops up constantly. In fact it is a feature so constant that it is almost like a background or contour line that describes the rise and fall of the landscape.

So we present ourselves to the consultant. If she's going to deny she's ill, there's no way I'm not going along with it. It has been a strategy for survival for so long that I'm not going to pipe up that things are not so good. And so the poor old consultant has to analyse and adjudicate on a false premise.

"You're doing well ... How long have you been diagnosed now? Two... four... seven years ... And the prognosis?... Is good. Here is a traveller in 'The Land of Dis-Ease' who's traversing the terrain much better than one would have expected." The Consultant can't say "I'm surprised, you shouldn't be doing this well. The prognosis isn't too good."

So here we are, pretending it isn't that bad and is there any way that she can be tested, like a scan? No way, too expensive on a casual basis. As it happens the only scan, the MRI (we've been there on one of the research projects), is mainly used, at the moment, to test people who might

be faking Parkinson's. Talk about the precipice of paradox: there are people who would pretend to be in this 'Land of Dis-Ease' just as we pretend we're not in it!

The more I use the metaphor of travelling in a strange land to try and illuminate the predicament posed by Parkinson's disease the more apt it seems. One's landscape, one's environment, is so much part of one it is like breathing: miraculous, but taken for granted. A concrete example of this is the stained glass studio where my career and I worked for many years. The work is wonderful in every way: from the materials, particularly the coloured glass, to the rhythm of the stained glass craft which is almost as labour intensive now as it was in the Middle Ages. As for the studio itself, it was as magical as the craft practised in it. Old and Dickensian in some ways, but steeped in the Arts and Crafts tradition with fragments of old stained glass panels, framed drawings and designs, a stone carved by Eric Gill as a sample for a tombstone, etc. All this we took for granted until it was closed down very suddenly. And suddenly all the objects that were just part of our environment became something different. Our whole environment collapsed, breathing became difficult and we wondered what on earth to do. There was only one way forward: to build our own studio. And we did it. And now it is up and running it is just as wonderful as the old one. We can breathe again. This example, traumatic as it seemed at the time, is so minor in comparison to the process of adjustment provoked by the diagnosis of Parkinson's disease, but it is the closest I have come to having one world collapse and having to create another one.

There are times when I would not wish it on my worst enemy to spend a day with someone with Parkinson's disease. Needless to say, all those involved with research and treatment, the Parkinson's Disease Society and others, are lifelines, faint flashes of hope in the dark.



"I wake up. It's dark and cold and I can't move, can't even turn over. I try to go back to my dream. I was running by the edge of the sea, just running and running and... but I just can't get the dream back. It's gone and I can't get it back. Pass me an extra half tablet will you. I'm stuck. Have been the last two hours. But it's strange isn't it. I was able in my dreams."

Rosalind wakes up.

