



D.J. Ludlow

Email djudlow@bigpond.net.au ♦ Website <http://www.geocities.com/mistmann/geof>

Island Places And Bridging Spaces

Address By D.J. Ludlow

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AN ISLAND PLACE

Mine is a world of open spaces,
Of outer walls and quiet places.
Not for me the bustling mobs
Of shops and theatres and nine-to-five jobs.

Mine is a land of island oases
In a chemical sea of polluted places.
To island hop my only escape
From four walls, a yard, and a garden gate.

Mine is a land where time must wait
As I take life at a measured gait.
My mind racing on with nowhere to go
Trapped in a body that must move cautious and slow.

Mine is a world my family must share
To be together, to love, to care.
But there is no cage to keep them here
Just a band of gold and hearts more dear.

There are others here in this island land,
Distant specks on their islands stand.
People I may never know,
Trapped in places I cannot go.

Yet all of us gaze with distant eyes
On a bustling world of bustling lives.
A world we can no longer share,
But a world we hope one day will care.

For those left along the way
As it hurries to seek a brave new day.
For those who must live in an island place
And take each day at a measured pace.

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Hello!

My name is Don Ludlow. If you look over to the microphone you will see an empty spot. This is because I must speak to you from another time and another place because I cannot survive in your here and now. I have a condition commonly known as Multiple Chemical Sensitivity or Allergic to the 21st Century. Whilst there are, by various estimations, probably in the order of several million sufferers world wide (There are no official statistics yet) and it has been known about since the 1950's, it has not been openly discussed very much in the public eye and so few even know "it" exists, let alone we exist, except maybe as some exotic, "extremely rare" condition. But it is neither rare nor exotic and I think you are going to hear a lot more about it in the coming months and years.



It is not curable as yet but with a lot of help and constant vigilance it is somewhat manageable provided one observes a strict and total avoidance of the very large range of triggering chemicals, which for most of us means avoiding the 21st Century altogether. This is because our modern world is awash with these chemicals we must now avoid at all cost if we are to maintain any semblance of health and well-being or to function at all. For most of us exposure to even minute amounts of these chemicals means almost total debilitation and disablement from a plethora of seriously intense, severe, and prolonged reaction symptoms.

However, even when it is properly managed - indeed moreso because of the isolation that such management demands - ,it is still a condition where one of the greatest risks can be suicide from sheer loneliness and isolation and a sense of hopelessness and helplessness. In the black humour that often pervades the MCS community and which helps us to cope and survive it is succinctly expressed in the frequent observation that "the best thing about MCS is that it probably will not kill you. The worst thing about MCS is that - it probably will not kill you".

Geographically, chemical disability breaks your world up into little islands of safety. Special places, though few and far between, where you can survive amid large areas where you, quite literally, cannot. In this aspect chemical disability is rather unique. However ALL disability breaks your world up into islands of ability. In these places you are as able as anybody else in the world - it is the in-between bits where you need the help.

Give a paraplegic a wheelchair and you give him a powerful tool to connect up a lot of his islands of ability. But while with a wheelchair he may run an entire office and staff efficiently and effectively it will still be those five small steps at the front door that will stump him. Blind people can do so many things these days - all it took was a dog! - a few patterns of bumps on a page or a button - a bit of text-to-voice software - a beeper on a traffic light, ... Deaf people can freely converse with deaf and hearing alike by the simple invention of a language spoken with the hands. People without vocal cords can still speak by a small vibrating device. Seemingly simple little things. But little things with a big impact! These are the nuts and bolts of bridges. Bridges that span the otherwise impassable expanses between the islands of their world.

Being the new kid on the block, the chemically disabled still have very few bridges they can use, there being very little developed yet in the way of support infrastructure and specialised equipment available to us. But the bridge that is allowing me to address you right now does exist and there are other bridges between you and me that allow us to traverse the spaces between your world and mine and the worlds of other disabled people - we need only to cross them.

In 1996 much of my world was stripped from me when I acquired MCS. But underneath all that was stripped away I discovered - a writer and poet. What's more it was still something I could do - it was one of my islands. But when it came to publishing my works, especially my first anthology "Life Lines" I found I was still a poet and writer - on an island. Cut off from readers, publishers, distributors and all the other necessities of becoming established in the literary world. A wonderful Christian printing company "Wren Enterprises" in Brisbane built a significant bridge for me by offering to print "Life Lines" on spec and take their costs from sales. Without this bridge my anthology would not exist and I owe them much thanks. Another significant bridge was put in place by the Christian booksellers "Koorong Books" who accepted me as one of the very few Australian Christian poets stocked by them. By doing this Koorong has not only made my book available Australia wide but also world wide via its ecommerce website www.koorong.com.au.

There is another bridge much traveled by me - the Internet. But to get there I had to build a \$2,500.00 plus bridge of my own. A specially shielded and vented desk that allows me to use my computer for a while without it making me ill.

But through the Internet I began to build still other bridges. My Island Place website where I could introduce not only myself but also my works and could invite people in to a little bit of my world as a chemically disabled person. It provided a connection point between me and the world in which I can no longer live.

The Internet also provided a more direct connection - email and chat rooms. I not only joined several overseas MCS email lists I also created one for those in Australia and New Zealand and elsewhere in this region called CDANET (Chemically Disabled Australasia NETwork) which has enabled me, and others like me to establish contact with, or at least become aware of, not only other sufferers but also some of the various MCS and disability support groups and organisations that exist around the world. Groups and organisations that also struggle because they themselves are run by people such as myself on meagre health and meagre resources. And I discovered a world full of island places. ... And on some of those islands were writers and poets just like me.

So with few resources and a lot of determination I am trying to build my biggest bridge yet - "Penned Voices 4 Christ". An international, Internet based, network of linked sites, email lists, chat rooms, even a cybercoffeehouse - The VoicePen Cafe where people can "drop in" and meet with us in an informal and relaxed atmosphere. The idea of Penned Voices 4 Christ is to provide a facility with the purpose of enabling us to overcome our physical isolation and provide a bridge connecting disabled and/or geographically isolated poets and writers not only with each other but with the literary world in general and the world at large.

But we really talk here today about **embracing** and that goes much further than just building bridges. Bridges only GET us to your world - but only YOU can make us a part of it. And sometimes the bridges themselves ARE the meeting place and we need you to be on there with us. And sometimes the bridges aren't for us at all. Sometimes they are for you to get to our worlds to meet with us there. So not only be prepared to build bridges but to step upon them also. To step outside of your world and to visit other worlds and other places, not only other worlds and places of the body - but also of the heart, soul, and spirit. And to welcome in to your world those who come from such places, knowing they begin, feeling like intruders in a strange land, but that you have the power - and the privilege - to make them welcome guests - and friends. Remembering, all the time, that your world is as temporary - and fragile - as ours until the day we all walk that final bridge to the eternal world the Lord has prepared for us.

But an embrace is an intensely intimate experience. You cannot embrace without touching, without feeling - without getting close. So let us get close for a few minutes.

I have been asked what is it like to be disabled by MCS, what does it FEEL like. It is like looking at Christopher Reeves attending the premier of his latest movie in his special wheelchair and wishing you could still go to such places and do such things and in the same breath you give thanks that you can still walk and use your hands. You press your nose against the outside window of a restaurant and watch a blind man having a meal and wish you could join him but are thankful you can at least see him. You watch and deal with MCS because I have to, I have no choice - but you console yourself with the sound of birdsong. You see a one armed man doing things you may never do again and you wonder what an amputated life looks like.

You wonder if your family can handle commuting between two worlds, yours and the 21st Century where everybody else is. You wonder how you can provide them with a future that is not imprisoned by your own. How to be a father from a distance.

You give thanks that you can at least still write and write poetry, create web pages, and create and moderate email lists. Then you wonder how you can take these meager foundations and build a new life on top of them. You wonder if you can shout loud enough from your world to be heard above the hustle and bustle of the 21st Century. And you pray that your foundations are strong enough, for if they crumble - then what do you do?

It is a world of frustration. Not only at your own physical limitations but also at the limited understanding and knowledge of others. A world of insufficient words to explain your situation. To some "allergy" means rashes, sniffles, and sneezes. To those with MSC it may mean irreparable damage to vital organs (including the brain), maybe anaphylactic shock, maybe respiratory failure, maybe coma, - maybe death. Sensitivity, to some, is a weak or over-reactive personality trait. To the severe MCS sufferer it means violent, uncontrollable, bodily reactions to the merest hint of certain substances.

On the screen is an extract from a letter my doctor has given to me to help explain why I cannot do certain things. How do you explain this in ten words or less to a busy, hassled salesperson or office clerk, especially when you have to do it from the footpath outside, where even there you only have limited time? That is assuming you can get their attention in the first place!

It is a world in which many in authority only seem to acknowledge your condition begrudgingly or not at all and even fewer take the time to fully understand the serious implications of your condition. Where sometimes you feel like Public Enemy Number One just because you exist.

Consider for instance the incredibly serious implications in the fact that for most MCS sufferers their mere presence in a hospital, doctor's surgery, or any other normal medical facility means instant, or delayed serious, excruciating, debilitating, and often violent, ill health. Ill health that is not only potentially damaging to them but which will almost certainly interfere with or prohibit regular diagnosis or treatment, particularly as we tend to seriously and unpredictably react to most modern medications. The great advances in modern medicine in the 20th and 21st Centuries in reality do not exist for us and we are quite literally fighting for our lives to obtain environmentally controlled hospital and medical facilities to allow safe access at least.

But you try not to think too hard about needing urgent medical attention- you can only deal with so many nightmares at once.

It is a world in which you become acutely conscious that your existence is precariously balanced on the shoulders of so many. Not only those you know but the man in Far North Queensland who bottles the only water (pure rainwater) you know of that you can drink without getting ill. The faceless people in America who make the only household and personal cleansing product you know of that doesn't make you sick. Those who make 100% cotton clothing. The list goes on for a long way and you are painfully aware that it is only these faceless, nameless people that stand between you and weeks or maybe months of ill health as you struggle to find a replacement by the only means available to you - trial and error.

It is a world in which you come to hate the burden of your special needs. Not the burden you carry, mind you, but the burden you must ask others to carry for you. You soon learn that the "Too Hard" Basket is a sad and lonely place to live, and the "We'll Take Pity On You And Put Ourselves Out For You" Basket isn't much better. You look endlessly for ways you can meet your own needs and are intensely and eternally grateful for those who see no burden in you.

I was going to describe to you what my world looks like, for MCS and chemicals can do strange things to your eyesight. For me it is seeing focused but vertically overlapping double images - from either eye, although the left eye is the most affected. However I can do better than this because I have found a way to show you.

If you look to the screen you will see the world how I use to see it, the way you still see it. There are some days when my particular world almost looks like this again - almost. However it usually looks more like this now, [slide change] and on a really bad day might look more like this. [slide change] But what I can't show you is the way it keeps changing slowly over time like looking through an, ever so slowly revolving glass bottle.

So how am I coping, personally, in this new, strange world of mine? The answer is - surprisingly well! And for that I give thanks to the Lord, for the one bridge that remained firm and unshaken was the one between me and the Lord through Jesus Christ. Indeed, if anything, He has embraced me, and I Him, even more, in a wonderful flesh and the intimate bond. Maybe it is because we spend so much more time together, now - alone. But I must also give much thanks to my wife and children who have worked so hard to keep the family bridges intact through all the turmoil and upheaval of the last few years. You see MCS hits hardest those you love and who love you. I accept and deal with MCS because I have to, I have no choice - but they do. And they must exercise that choice again and again, day after day. Every hour of every day they are torn between life in the 21st Century with everybody else - or life with me. So they commute daily between me and the rest of the world. Each day traversing the narrow bridge of necessary procedures that allows them back into the home whilst keeping me safe from the toxicity of the modern world. And although there is still much we can do together as a family there are many times when they must choose to do things without me.

And whilst I must accept MCS I will fight its constraining hold on my life any way I can - for them. I will push to rebuild as many bridges as I can between me and the rest of the world so that my wife and children do not have to suffer the heartache of choosing between the world and me, and that in the 21st century I CAN be there for them. But underlying that push is the serenity that comes with acceptance of your situation - your limitations. You no longer fight AGAINST them and you start to look for ways to work around them. You come to understand that they may be immovable objects but they are not necessarily insurmountable or impassable. And you learn some other surprising lessons along the way. Like not diminish it or reduce its value. That disability is measured not by what you cannot do but by how much it excludes you from the world of others. By how much the World is unable, or unwilling, to embrace you. After all, consider this, who of you here feels disabled because they cannot fly like even the smallest of birds? Or breathe underwater like the most insignificant fish? They are certainly limitations but they are not disabilities to you because they do not exclude you from the world of others. Not only that but you now have the equipment and facilities to join the world of the birds and the fishes as well, any time you want. Think about it!

There is much I miss including the face-to-face fellowship and worship with other Christians but I have learned why so many of the disabled seem to be the happiest people in the world and why you can learn so much from us. In fact I've even put it on my website. For despite all that I have lost there is still so much that I have. When so much is stripped from you and yet life is still worth the living you come to understand that **the Lord alone is sufficient - everything else is a blessing!**

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