

KEVIN MATTHEWS - Kevin's Wilderness Journeys

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Family and Friends Letter #022

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Dear Family and Friends,

Greetings to you all. Unfortunately this letter will not be too big on updates this month given the continuing deterioration of my health and fitness. To be honest I am writing this letter in what is a rare 'window of opportunity' today. I doubt that there will be too much in the way of news concerning other matters - I apologise for that.

HEALTH

In response to a past letter in which I outlined my declining health and attempted to describe what Chronic Fatigue Syndrome (CFS) or Chronic Fatigue/Immune Dysfunction Syndrome (CFIDS) is, I received several replies that were less than 'polite.' In no way was I attempting to be 'self-centred,' 'attention seeking' or other such-like character descriptions. I was however trying to describe my current state for people who had often asked and failed to understand the exact nature of CFIDS - and I must admit I tried to end the frustrations I suffer on an almost daily basis of those who seem to think I'm simply 'tired a lot.'

However, my attempts seem to have largely failed and may have caused more than a few 'fractures' in relationships that were already seemingly intent on being fractured. I am of course disappointed that what had been reasonable intentions on my part have failed to produce the results I had aimed at. Never-the-less, I am hopeful that many more people understand something of the complexities that make up the seemingly endless list of symptoms in such an affliction as CFIDS.

More than one person has pointed out that it would be a great mercy if CFIDS actually took the lives of its victims, for the illness itself often leaves the person suffering it feeling as though they are living in a place somewhere between life and death, and that indeed death would be merciful. It is little wonder (certainly to me) that many sufferers feel the struggle to be too much and seek the way out that suicide brings, feelings that are not entirely unknown to myself. However, a world view that Christianity brings to a person changes the perspective somewhat when contemplating this alleged 'way out' of suffering, not that it delivers the person who is suffering from those moments when the 'way out' seems a very attractive way of ending the torment that endless years of CFIDS brings and promises for the years to come.

For me at this time, I am beginning to fear that the more 'sinister' aspects of CFIDS are making a very real comeback in my own experience and that they may be around for longer than I care to suspect. I have now had this illness for 17 years, with often reasonably lengthy times of 'relative wellness.' The first two years of CFIDS were probably the most difficult and I had times of being stuck in bed and being unable to have

anything like a normal experience of life. Now as I approach the beginning of an 18th year of having CFIDS, I seem to have entered a period of 'resurgence' in the experience of this illness that I have not experienced before. I am experiencing the most severe relapse since I first got sick and find myself becoming increasingly weak and debilitated.

As I wrote earlier I am writing during a rare window of opportunity today. I began the day feeling reasonably well and went to work to complete a hand over of duties so that I could have another 2 weeks off on what is essentially sick leave (though technically annual leave). This seemed to go well, but since leaving an hour after work began I have steadily gone on the down hill spiral. I have already slept for three hours since getting out of bed this morning (it is now 5pm) and feel as though the 12 hours sleep I have had since yesterday evening has not even registered on my 'sleep scale.' I have been unable at times during the last few days to walk even a block or two without feeling incredibly fatigued and unable to continue. Today my mind seems to have been off on holiday from my body as I have experienced this 'shell' moving about barely able to register what it is doing, let alone what is going on around it.

Thankfully the 'brain fog' has lifted a little this afternoon, allowing me to be coherent for the first time in half a day and write this letter. I'm also able to actually sit here and type without sensing that I am about to fall headfirst into the keyboard asleep. Last night I was in bed at 7.30pm, being unable to even force myself to stay upright for any longer.

So the above should give a picture of what life is like for me at the moment and should eliminate the need to ask 'how am I doing (which by the way is just me being tongue in cheek about it all and not saying don't ask).' My stock answer is usually along the lines of 'I'm OK,' 'hanging in,' 'getting by,' or some other type of answer. Though I have gone on in this letter about it I'm not usually in the business of going on about how sick I am (I am very conscious of the poor me syndrome, seeking attention, etc, that can come with being sick).

Some have asked what can they do to help - realistically there isn't a real lot that can be done to relieve the actual symptoms of the illness. So it can be said that nothing can be done in that respect. Having said that, as in every sickness where someone is ill there are things that sincere people can actually do and do do that help to make the daily life of the person a lot easier. Usually it is not the act itself, as the real intention behind the act that helps a lot - certainly that is the case with me. I know when there is a real sincerity to 'be with me' in the difficulty and when there is no such sincerity as often comes with 'token' efforts. I find it better to do nothing than to do token gestures which smack of insincerity - certainly I am far more disappointed with the 'token' than with nothing at all.

Sincere people always seem to find some way of providing real assistance to those who are having difficulties. From such people, even the smallest of gestures seem to carry an incredible amount of 'healing balm' and I am sure that most, if not all of the people reading this letter have experienced this in their own difficulties from time to time.

So what do I need in the way of help - not a lot can be done to remove the difficulties of CFIDS itself. Your thoughts and prayers are always appreciated by me and I know I have a lot of sincere folk out there wishing me well, praying, etc, and I really do appreciate you all. Real friends in times of real difficulties are what we all need and I am finding that to be the real need of the hour for me. So I'm not asking a lot, but then again I am asking a lot :-)

WORK

There have been changes occurring at work, which is nothing unusual I suppose. In the last week we have moved residents from our Nursing Home into the new Banksia House buildings. The old Nursing Home will be renovated and become Grevillea House - then the residents will be moved back. Needless to say this has been a difficult week and having me there dragging the chain with being sick has probably made it the

more difficult.

Anyhow, I certainly have felt it being extremely difficult and taxing. My own limitations because of my current illness have never been so clearly pointed out to me by actually doing the job. It is somewhat embarrassing when you realise that the Ute you are looking for can not possibly be parked inside the Nursing Home where you are looking for it (and other such episodes of CFIDS-inspired dementia). It is also frustrating when you find it impossible to lift items you can usually lift without much effort and others have to take it off you.

So now, having resisted the call for taking more time off to recover from being ill, I am once again on illness inspired annual leave. The great fear here of course is that I may return to work having not made any degree of recovery, or even having got worse. The trend currently seems to be toward a further decline in 'wellness.' Certainly today has shown that I am possibly worse than I was when last on leave (several weeks ago) or even on last week for that matter. Anyhow, that is the risk.

We have also started a new employee in the Maintenance Department this week, who appears to be one of the best recruits we have had in the time I have been in charge of the department - which isn't to give the impression that we have put on a lot of staff during that time. So far Tanya has proven herself as a good selection, though admittedly it has only been just over a day.

OTHER STUFF

I hope no one is feeling that I am having a real go at anyone in this letter and have been offended. I am sometimes accused of standing on a soapbox in my letters and I can see why people would say that. However it is not my intention to write meaningless dribble and so I write about what I believe, what I feel and try to be the real me in them. I don't find a lot of use in letters that contain nothing but meaningless ramblings and that are devoid of any real content - so I suppose I do get on my soapbox. But at the very least you get to see the real me in action and get to understand something of the real 'Kevin.' Now isn't that a charming thought :-)

Well, that will be it for me today and this month. Hopefully next month will see an easing of my health issues and I will have recovered completely from CFIDS, never to be bothered by it again - well, I can dream of such wonders :-)

Regards,

Kevin