

Dear Dr. G _____,

March 2, 2009

I write this letter because I am in a very serious situation that requires attention by some compassionate, intelligent and, above all, open and scientific minds.

To this point I feel that I have been inadvertently neglected and improperly treated by the medical system, especially as my condition has worsened in the last four years. Dr. M _____ has recently been working with us and he has been, in contrast to some others, very compassionate and helpful.

If someone were to peruse my file today, he or she would find a somewhat perplexing case, for the simple reason that the information in the file is only partially complete. And this is so, I believe, because my case does not exactly fit the conventional model for lower back injuries, and because the conventional model itself is flawed and incomplete.

Motion, in essence, is the problem. The conventional theoretical model used for diagnosis and treatment of the lower back assumes a more or less static and a relatively simple system, essentially a stack of vertebrae with spacers between. In reality, however, the lumbar spine is a highly complex living system, in motion and designed for motion.

To overlook this is to shut out some knowledge essential to its understanding.

If all injuries are treated alike, regardless of their origin, their progression, and their current stage, this will of course lower success rates, as all complexity and subtlety have been brushed aside, with the loss of much valuable information.

So far, this is what has happened to me, and this is why I appeal to you to take a compassionate, clear eyed and truly scientific view of my case, considering all evidence, even that which does not fit the standard model.

(Though I have an degree in Biology and nineteen years of detailed observations of my own injury, this evidence has been entirely neglected, because I am 'only a patient' and because my observations conflict with, or fall outside of, the standard model.)

What are needed now are open eyes, and men with the courage and honesty to say "I don't know."

We very much look forward to meeting you on our upcoming trip to K _____ and we hope that you will be able to help us.

We have some important concerns that we would like to bring to your attention before we talk, and we have included these here as well as a general account of the symptoms and progression of this injury.

Thank You Very Much for Your Consideration,

Bernard _____

Nicole _____

Our Current Concerns:

As of the present time, a proper diagnosis has not been completed. Based on my long and detailed observation of my own condition and its progression, and on abundant research over the last few years, I have some thoughts on what has gone wrong to this point in terms of diagnostics and treatment, and what might be a profitable direction in which to think as we go forward.

These are our major concerns, stemming from our experiences so far:

1) Motion and diagnosis:

We believe that some very important and central aspects of the situation have been overlooked because of the limitations of available diagnostic tests and because some established modes of thinking involve an oversimplified and therefore incomplete model of the lower back.

It is obvious to me that there is instability or excessive motion of some kind at the L4-L5 level of the spine, the same level at which the nerve symptoms must originate. Inflammation, leg and foot nerve pain, and toe numbness all come after motion at the injured level, and these symptoms always worsen with further motion.

This seems to point to interference of some kind with the nerve roots at that level. (Whether this is direct physical compression during motion, biochemically-triggered inflammation (chemical radiculitis) or some other cause is an open question.) The fact that static scans show no direct pressure on the nerve roots is interesting, but in the end demonstrates only that diagnostic techniques so far are insufficient to the task.

The crux of the matter, I believe, is motion.

Inflammation, nerve pain, and numbness all come with motion, and yet no one has yet addressed this issue. All of the diagnostic techniques available so far have treated the lower back as more or less a static system and have captured views of one single moment in time. None so far has been designed to show changes with motion. Even x-ray views that bend the back slightly ('functional x-rays') have not been done, as they apparently are not known or used here. I feel we must get access to diagnostic scans that show the lumbar spine in motion.

Since nerve symptoms are never present in the legs and feet without prior motion of and inflammation in the lower back, reason strongly suggests that either the motion directly, or the inflammation caused by it, must be affecting the nerve roots in some fashion. And since the pain is bilateral and consistent with nerve root interference at L4 to L5, it also follows logically that the effect is taking place where both nerve roots are present, that is, within the intervertebral space. If nothing is done, it seems sure that this regular and lengthy interference with the nerve roots will begin at some point to cause permanent nerve damage. Avoiding this is my priority.

Aside from occasional episodes springing from sudden, improper motion, the progression of symptoms is always the same: motion at the injured level of the lumbar spine (clearly detectable because of the spondylolisthesis at L4-L5 and the pain there) leads directly to increased pain and, very shortly following, to increased inflammation. This in turn leads directly to increased nerve pain in the hamstrings, calves, feet and toes, and increased numbness in the toes.

This statement reflects many thousands of hours of clear and direct observation by a trained biologist (myself) and yet it has been consistently ignored, because it cannot be directly observed by medical personnel, and the overall process cannot be witnessed in a typical office visit.

Another point of evidence for motion and interference of some kind at the L4-L5 level is the fact that, upon twisting very slightly while lying down, or lying in a slightly non-neutral position, I have often felt a temporary increase in leg nerve pain or sharp pricks in the foot or toes. These excess symptoms then disappear almost immediately upon returning to a neutral position.

The MRI report of three years ago noted damage to the ligamentum flavum at L4-L5. Because of the nature of the injury event itself, and because of subsequent experience with repeated reinjury and healing, I have strong reason to believe that there is deeper ligament damage as well. These injuries, I believe, are contributing to excessive motion at the injured segment.

I have been unable so far to find a physician who will discuss ligaments at all, or even entertain the notion of instability or excess motion at L4-L5.

I am aware that "instability", in the context of the lumbar spine, has been assigned a specific and bone-focused definition, but I feel that this definition is simply incomplete and does not reflect my own experience.

Please consider the following:

- a) The injury took place through extreme twisting and bending motion under heavy load.
- b) All episodes, major to minor, over the years have come after sudden or improper motion.
- c) All pain, inflammation and numbness on a daily basis stem from and increase with motion at the injured level of the spine.
- d) The last few major episodes involved a minute but clear sensation of slippage at the L4-L5 level in the first fraction of a second.
- e) During those major episodes, I perceived an increase in spondylolisthesis at L4-L5 clearly detectable to the touch.
- f) At times during those major episodes, I could clearly feel a sensation of bones grinding at the L4-L5 level.
- g) The MRI report of three years ago indicated some damage to the ligamentum flavum at L4-L5. (I believe there are clear signs of deeper ligament damage as well.)
- h) There is a massive reduction in disc height at L4-L5. How could this not contribute to excess motion of some kind?
- i) I can feel motion at that level.

If the present system lacks the techniques and technology to properly diagnose this problem, we would prefer to be told this directly. We would then be in a position to discuss other diagnostic options and where they might be available.

2) Physiotherapy/movement at this stage of the injury:

It seems illogical and dangerous, in the case of an injury at the spine that is causing substantial nerve pain in the legs and feet and numbness in the toes, and yet remains undiagnosed, to even consider physiotherapy of any kind. And yet, recent experience shows that this is what the system will attempt to do if it cannot find any other immediate avenue. I have no choice but to refuse such ill-advised measures in the interest of basic self-preservation. Motion, at this stage, is harmful for me.

Even if there is no immediate surgical option, I do not want to feel pushed into motion that potentially endangers my nerve function. The notion that movement is always good for the lower back (even at this very late stage of the injury) is, I believe, over-simplified at best.

Unfortunately, because one metastudy has suggested that motion is in general good for back injury sufferers, I have had to fend off constant pressure toward unsafe motion. A metastudy simply clarifies a general direction or trend, but unfortunately, seemingly throughout the medical system, what is at best a rule of thumb is being interpreted as a rigid and all-encompassing truth.

This problem has been exacerbated when medical personnel consistently make false assumptions about my level of strength and fitness, based on the fact that I have been largely restricted to bed for some time. The work, exercise and sport activities I have always engaged in have been very heavy, intense and sustained, and so have built very dense muscle. Just before the major downturn of a few years ago I was extremely strong and fit, and I have remained as active as possible since. The erroneous idea - present throughout the system - that strength always decreases rapidly with bed rest has recently been disproven in the first study to actually examine this question directly. And my own experience has been that strength declines only very slowly and is quickly rebuilt.

It is very important to note that the original injury involved no nerve damage. There is, however, danger of it now, if we are not very careful. There are still occasions, of increasing rarity and decreasing duration (generally first thing in the morning after a good sleep), when I have no leg and foot nerve pain at all, and no numbness in the feet. This occasional absence of pain and toe numbness suggests that there is no permanent nerve damage at this point. Again, my priority is to keep it that way.

3) I have, unfortunately, also sustained a troublesome neck injury in recent years.

About four years ago, at The Calgary Stampede, a safety brace on a carnival ride came down under substantial pressure on top of my head while my head was turned to the left side, forcing my twisted neck very strongly down and to the right and, I think, very nearly breaking it. I felt a strange ache at the base of my neck for hours and an odd sensation there for a few more days. I believe this neck injury has been aggravated by propping and twisting strains on the neck during this enforced period of lying down.

Lying with a pillow behind my head or turning my head to the side to any degree or for any length of time causes substantial burning pain at the base of the neck and often numbness in the face (depending upon degree and duration of strain). This numbness is always the result of twisting, propping or craning the neck. It is more likely to occur on the right side of the face, and is much more substantial on that side when it does occur. Even turning my head approx. 70 degrees to the right for 5 or 10 seconds causes moderate numbness at the top of the right ear, in the scalp above the ear, on the face below the ear and just outside of the right cheekbone. This numbness may last minutes or hours depending primarily upon the degree of twisting, but also upon the time that the head is held in that position. At its worst the numbness has extended to the right cheek, to the center-point of the nose and lower lip, and to the chin.

In a surgical situation, there is no way that I could safely lie on my stomach with my head turned to the side or pushed backwards. Any surgery I would eventually undergo would have to be accomplished with my face set through a hole in the operating table or with thin layers of foam carefully built up into a ramp under my chest. I mention this now for the sake of completeness and to avoid a foreseeable and preventable danger.

4) A cautious approach:

Although time is short in which to act, we have no wish to rush into any decisions. Rather, we would like to proceed in a stepwise fashion, if circumstances allow. We would prefer to avoid a fusion operation if at all possible, as published figures indicate it can be quite destructive and a positive result is very uncertain.

Since nerve symptoms are the most immediate problem, and our primary concern at this point is to avoid permanent nerve damage, we are very much hoping that some minimally invasive techniques could address this.

5) A scientific approach:

It is an absolute necessity to avoid a repeat of past mistakes at this late date, and we feel very strongly that our own observations have been entirely neglected in favour of a standard, one-size-fits-all diagnostic model that fails even to distinguish between a baseline state and acute episodes, or between early and late stages of an injury. And it certainly has failed completely so far to properly diagnose or treat what is clearly a non-standard case. So far the system has been trying to shove a square peg into a round hole, simply dismissing all evidence that doesn't fit the model.

I am a trained biologist and I am offering nineteen years of detailed observation and experience from the perspective of someone who actually has a back injury. I have been continually shocked by the total lack of interest in those observations.

It is also important to note here that the files do not at all reflect the reality of the situation, but rather exclude all evidence that does not result from office visits or fit the standard model.

You may wonder how things have gone this far without my receiving some substantive help. The answer, I believe, is quite simply a lack of imagination and a lack of scientific thinking on the part of some medical personnel on whom we were depending for help. So far it has been a story of people relying entirely on a grossly oversimplified model of the lower back, sticking rigidly to crude rules of thumb and stubbornly trying to apply cookie cutter, one-size-fits-all solutions to complex problems. What is obviously a serious problem, now, in fact, a crisis, has been trivialized and brushed off by a succession of doctors for years now, the injury all the while progressing steadily, and now having reached a critical state.

6) EMG:

Shortly before I was discharged from Nelson, an on-call doctor was in the process of scheduling an EMG. We decided, however that it would be better to obtain it while in Kelowna, due to wait times. This has not yet been scheduled. Nerve symptoms vary widely throughout the day, between days, and depending upon my general condition (normal vs. acute episode). Thus I believe that to obtain a meaningful EMG result, there will have to be some flexibility in scheduling the time to do the scan, to correspond with a period of more acute nerve symptoms.

Bernard ----- - Back Injury History:

Here are some details of my back injury and current situation:

Almost two decades ago, I sustained in my lower back a sport/work injury, which has since worsened at an accelerating rate.

The injury in question resulted from heavy, intense, sustained farm labour, and dates back 19 years, with notable restrictions on physical activity beginning with a major flareup about 14 years ago. It was sustained suddenly (within a period of thirty minutes or less) during work that was extremely heavy, fast-paced and repetitive, with very significant bending, stretching and twisting under heavy loads. This came at a period of physical exhaustion after two weeks of double-shift farm work. Because of the traumatic nature of the original damage, it is surely best to consider it a sports injury rather than a work injury. We can then consider possible deep ligament damage, which I believe is clearly implied by the evidence and which otherwise might well be overlooked.

In terms of healing, the only real help I have gotten was from the University of Guelph (Ontario) sports injury clinic, 14 years ago. In addition to some traction and massage, they taught me a series of stretches and exercises, which I performed daily until they became impossible two years ago.

Over the past two years, I have had greatly increasing symptoms during and after walking or other very minor activity. These symptoms include constant pain and inflammation in the lumbar region, bilateral nerve pain down the backs of the legs, into the calves, feet and toes and, more recently, numbness in all ten toes.

Upon walking more than 50 or so steps, twisting very slightly in a wrong direction, or other 'excessive' activities, the pain is most consistently felt in the lumbar region, hamstring area, calves, left foot (and the big toe and next three toes), and right foot (especially the big toe, but also the middle toes). Especially worrisome is the numbness that has been creeping into my toes over the past six months or so. It occurs only following lower back motion and the resultant inflammation.

Over the last 19 years, I have had a number of sudden 'episodes' (like a hot knife with 10,000 volts to the site of injury in the lower back) upon sudden or excessive bending or twisting. These episodes have come closer together, have been more severe, have taken longer to recover from, and have been recovered from less completely as time has gone on. And the motions that trigger them have become so slight as to be imperceptible. These days, I have become extremely cautious, as even the tiniest false motion can bring a small 'shock' and days or weeks of extra inflammation and leg and foot nerve pain (in other words, a minor episode.).

I have always been very strong and fit and still keep as fit as possible - gentle core abdominal exercises; upper body work lying on a flat, cushioned surface; and slow, gentle standing flexion of legs. Nonetheless, I have gotten to the point where, in the past year, I can move around very little and walk little more than 30 or 40 small steps without substantial lower back pain and inflammation and substantial leg and foot nerve pain and recently, numbness. I can sit less than two minutes without problems and stand ten minutes or less at a time, once or twice in a day. Thus, I spend the vast majority of my time lying down. I exercise great caution in my movements, as experience has taught me firmly that, at this stage, even relatively slight improper motions can lead to major and damaging episodes.

For the seventeen years in which I kept very fit and active, including about thirteen years of daily, physiotherapist-prescribed back stretches and exercises, suitable activity was beneficial and helped me live a relatively normal life. Now, however, movement of the injured level of the lumbar spine (which encompasses most exercises and activities) has, in fact, become destructive and, therefore, counter-productive.

As the L4-L5 disc has deteriorated, the symptoms have become steadily more pronounced. All symptoms worsen progressively with motion - i.e. walking (very slowly), twisting (very slightly), or bending (very slightly) - and slowly subside with inactivity. If I engage in even a little too much motion, it may be hours, days or even weeks before nerve pain and other symptoms return to my baseline level of pain and discomfort. I now cannot work nor do many previously normal daily activities, and I need assistance with many essential tasks of living.

I personally believe that there is a degree of instability at the L4-L5 level, due to a combination of ligament damage (local and possibly deeper ligaments) and the very substantial disc space reduction and its inherent possibility of greater motion. (Additionally, I have always had very loose joints ('double-jointed')). Obviously, for there to be four millimetres of spondylolisthesis, there must have been the possibility of excess motion at some point!

I have been active in athletics my whole life and have done many times my share of heavy and intense activity. I have pulled many muscles, some quite severely, and have had numerous sprains, again, some quite substantial. I have had a knee joint operation, and have a long-standing ligament injury in my right shoulder, as well as carpal tunnel syndrome in both arms. (These all date back to years of weight lifting, running, martial arts training, and the most intense and demanding kinds of physical labour in my late teens and early twenties.) Thus, I can absolutely tell the difference between pulled, strained or spasming muscles and the entirely different sensation of a ligament injury. Unfortunately, the standard medical model of the lower back includes no real recognition of the role of ligaments, and therefore fosters no discussion of them, a situation that, in this circumstance, is very detrimental. I have been unable so far to find a physician who will discuss ligaments at all, or even entertain the notion of instability or excess motion at L4-L5.

As time has gone on, major incidents, followed by permanent worsening, have become more frequent and severe until I have been reduced to lying down the vast majority of the time. Since then (the last 18 months), I have been extremely careful in my motion and thus have suffered no major incidents, though I have had many smaller ones.

The last few major incidents consisted of a minute but clearly perceptible sensation of slippage at the site of damage at the L4-L5 disc, followed a millisecond later by what could best be described as a 'hot knife/lightning bolt' at that location. This intense shock of pain was followed each time by the overwhelming feeling that the lower back could not support the upper body. Thus, the only possibility was to lower the already doubled body to the ground and slowly, with excruciating pain, roll onto the back and pull the knees up. Then followed months of greatly increased lower back pain and inflammation and, with the last few major episodes, very substantial nerve pain in the legs.

These more recent incidents were essentially the same as those I experienced 15 years ago (during the first period of worsening symptoms) and later, but with time the pain has become more severe, the disability which follows more pronounced, the recovery period longer, and the recovery less complete. Also, over time, the inflammation following the initial shock has become more pronounced and longer lasting.

Fifteen years ago, there was no significant leg nerve pain following such an incident, but in the last four years (and especially the last two) all such incidents, major or minor, have been accompanied by proportionate degrees of leg and foot nerve pain, quite severe and long lasting in the case of major episodes. Now, of course, there is almost constant nerve pain in the legs and feet.

When I began to walk again after the last two major incidents, very gingerly, of course, I felt a clear sensation of bones grinding together at the site of the injury (i.e. the L4-L5 disc). This, I can only assume, is osteophytes or vertebral bodies making contact with each other, rather than facet joints, as the sensation clearly came from the center of the spine.

Lower back pain and the attendant inflammation are always directly followed by a proportionate degree of nerve pain through my legs and feet. Over the last year, and in particular the past six months, I have seen the gradually increasing appearance of numbness, occurring in some or all of the toes and ranging from very slight to fairly substantial. As inflammation in the lower back grows with motion (especially improper motion), leg and foot nerve pain increase and this numbness in the toes quickly begins to appear, slight at first, and in roughly the following order: large toe left foot, large toe right foot and middle 3 toes left foot, middle 3 toes right foot. The small toes on both feet also become numb. Nerve pain is always slightly worse in the left leg and foot and the numbness always begins in the toes of the left foot. This numbness in the toes is always preceded and accompanied by nerve pain in the toes. All other symptoms are dependent upon degree of inflammation in the lower back, which precedes them.

As far as moving cautiously to avoid inflammation and nerve symptoms, the issue is not solely one of pain. In the past number of years, all major episodes (of increasing severity, of course) have led to a permanent worsening - more pain, more readily occurring inflammation, and an increased feeling of instability at that specific level of the lumbar spine.

This sense of instability has been clearly borne out by painful experience. Though the musculature of my abdomen was (and largely remains) very strong, harmful episodes from minor to major have become progressively easier to trigger as disc height has been reduced. And they have been more and more clearly preceded by an unmistakable sensation of motion at the site of injury. The risk of sudden episodes, in my long and detailed observation, is greatly exacerbated by the cramping of muscles and the lower back inflammation that accompany walking, sitting, twisting slightly or any other activity that involves motion of the injured portion of the spine. That is to say, essentially all motion is risky.

Here is a typical response to motion: By the time I return from my brief, once-daily trip to the washroom, the pain, cramping, inflammation and feeling of instability will have all risen substantially from their previous level. During the next 20-45 minutes, they will typically rise further. Over the next two to three hours, lying in a carefully neutral position will allow symptoms arising from the motion and inflammation to slowly recede somewhat. This is what happens on a good day.

I currently take 2700mg Gabapentin, 1800mg Ibuprofen, and 2000mg Acetaminophen daily to manage pain.

Two more points that should be noted: Since the effects of motion accumulate through the course of the day, nerve symptoms are generally at their worst in mid to late evening. Also, a degree of tightness in the calves is generally present alongside other symptoms. This tightness is usually in rough proportion to the degree of leg nerve pain, but occasionally seems to be more prominent.

I hope this information helps clarify the background situation.

Thank You for Your Interest and Efforts,

Bernard _____

Nicole _____