

This letter was written by a family about their remarkable healing journey. The family has provided permission for this letter to be published. They have also requested that their names are to be used. This letter documents their creativity and courage as well as the changes they experienced through therapeutic conversations with a clinician and a clinical team of nurses.

DEAR READER:

N.I.F.T. DAY IS NIFTY

I know right away as you read the title of this letter questions are screaming in your head. Like: What is a N.I.F.T Day? What does N.I.F.T. stand for? Why would anyone want one? Once those questions are answered, the next questions would be “ How do you start and create a N.I.F.T. day? How can it be maintained? How will this help me? How will this help my family? Before we answer these questions, we are going to introduce our selves and give you a brief history of ourselves and how N.I.F.T. day came about.

We are George and Linda Jensen. The present time is December, 2005 and I will be telling our story from my perspective with George adding his perspective and insights. Together we will tell you how we think and cope as a couple. George and I have been together for nearly 11 years and married for nearly six of those years. We are in our early 50's and have been the most fortunate of couples because we have always had a very deep and close connection and very much in love with each other from the start. I don't mean to be bragging but we are so closely connected that other people see and sense our closeness, even our daughter's friends have named us the “The Ultimate” couple. We are also very proud of being able to tell you that in 11 years we have never had an argument or fight. Not to say that we haven't had disagreements or misunderstandings, but we have always been able to talk things out before it came to fighting or yelling. We both had pervious marriages and had experienced the fighting and yelling. As a result, we both knew we wanted something better in our relationship, so right from the start we made the commitment to each other that we would work at communicating and staying committed to each other. We can happily say that we have achieved that goal and still work at it. We are telling you this because we want you understand just how much we had been affected and devastated by the change that stress and anxiety due to illness started to change our relationship.

I have been dealing with multiple health and emotional issues for many years and in mid August 2005 I was experiencing a decline in my health, unfortunately, my health has been progressively getting worse. It has been a long haul, and I have not, as of yet, got all the answers as to what has been going wrong. George has been, and still is a champion at being helpful and is supportive. As, my health declined I experienced much more pain and fatigue. I no longer could drive, do my housework, walk our little dog Teddy and so much more, I wasn't able to keep up with. Shopping became hard work and even simple visits with family and friends became endurance tests for me. Of course, I increasingly spend less and less time with George and more and more time in bed and just resting. I started to become withdrawn and quiet, keeping to myself a lot. George became

frustrated and sometimes angry not knowing what to do to help. It seemed all we had to talk about any more was my health and we started to snip and snap at each other we even had some arguments. We were beginning to experience moments where we were uncomfortable with each other. George had to do more and more by him self.

Yes, as Linda's health declined we were arguing and snapping at each other. I was in a constant state of worry and anxiety the tension was so thick, it was making me increasing unhappy, and so was Linda. I wanted so much to be able to ease her pain and make her feel better and interested in what we used to enjoy together. So much of our focus was Linda's health we were unable to find our joy in each other very often. Living with a spouse who is chronically ill automatically places the healthier partner in the role of caregiver to one degree or another. Having been in the nursing profession for more than 33 years, made it easy for me to take on this role. But, it was too easy and I quickly felt that I was loosing my place as husband, lover, and best friend. One day we had a particularly tense day with moments of snapping and we tipped toed around each other for a couple of days like polite strangers. This was a sure sign that something had gone very, very wrong for us.

I was in counselling at the time learning to deal with and cope with some devastating events and losses in my life. As this tense time George told you about happened a few days before my next session was to take place, we agreed that we needed to bring it up and get some help sorting ourselves out. George has always been very supportive and loving by being involved with my counselling and frequently came with me to offer his insights and observations to my reactions to problems and situations I had been ask to work on. Believe me, when I say his input is extremely important and valuable to me emotionally and practically. His support has allowed me to grow personally and he has encouraged me every step of the way.

What finally came out at the session was all my anxiety over Linda's health, and the thoughts and worries I was having. My main worries about Linda were: What does she need? Is she going to be all right when I am at work? How do we rebuild our connection again? We learned that my thoughts like: Is this really as bad as she says? What is wrong now? Why won't she just try harder to do things? Why can't she just push through the pain? What happens if I can't cope? What do I do with the resentment that I am feeling? I wasn't resenting Linda but the illness and what it was stealing from us. We learned that these were normal thoughts and that I wasn't being insensitive towards Linda. It didn't make me a bad person just human.

What we were forgetting was how all these multiple health concerns of mine were affecting George. Forgetting how worrisome all this was to him. How worried he was about me. Forgetting that George, needed support too, in dealing with a sick wife. All too often, the healthy partner or family members are the ones who are neglected emotionally because the focus is placed on the person with the illness. We forget that the healthy ones feel stressed and anxiety, and sometimes they can feel more stressed than the spouse with the illness. What I was forgetting as well was to really communicate to George exactly what I was experiencing. I hadn't explained very well and mostly it sounded like I was

complaining. George understood the medical emergencies I had but I didn't explain fully what was happening to me and how I felt. Instead of withdrawing and trying not to be a burden (a big fear of mine) I should have been communicating like I was used to doing. I was closing my self off and cheating both of us of comfort from each other.

As a result, we were offered a chance to get some counselling from the Family Nursing Unit at the University of Calgary where they are experienced in offering couples and families practical help in dealing with families in crises because of health issues. And, that was the start of our healing journey.

Before we get into answering the questions mentioned in the beginning, there are a couple important things to recognize, that we had forgotten. The first thing to recognize is that both the person with the illness/ disability and their spouse, in fact the whole family, is that the illness happens not only to the one who has it but indeed to your spouse, your family and yes, your friends. Your illness affects everyone around you not just you. Everyone is impacted to one degree or another. This strangely is something that both George and I forgot. As we have had to deal with (and still are) many medical emergencies and problems while caring for both of our mothers and fathers. We forgot as the healthier people that their health problems stressed us out so much, and was the source of extreme anxiety for the both of us. We didn't learn until almost too late that as caregivers and family members that we needed to take care of ourselves, and de-stress now and again. When it became me that had the urgent health issues we forgot every thing we knew about the impact of a loved ones illness on the spouse, and the rest of the family and friends.

The next important thing to realize is that you are not alone and you do not have to cope with everything on your own. There is help and hope for everyone involved. If you are struggling with the stress, anxiety, and problems surrounding the health issues. Seek professional help it is so worth it to regain control of your life. Help is available in many forms from Mental Health Professionals and the U of C Family Nursing Unit and Support Groups.

Remember everyone needs some kind of support and help to lessen the effects of the stress and anxiety of living with and caring for a loved one. Often we tend to forget that even young children who are too young to really understand what is happening feel the stress and anxiety going on around them, and even they need help and support from someone. Today, there are so many good groups for just about every thing. The right kind of help is there. You just have to ask and search for the right fit for you. Just use every resource you can find. It is well worth the effort to regain control of your lives.

George and I decided try working with the Family Nursing Unit and we decided that this was the right place to get some help with dealing with our concerns about my health and how it was affecting our marriage.

During our first session, George and I spoke of how my illness and chronic problems took up so much of our lives that we did not seem to be enjoying each others company as much as we used to and it was just about all we talked about. Constantly talking about it

robbed us of our security in each other, and our time together just as a husband wife and as best friends. It diminished our connection and closeness to each other. Our family and friends lost out by our not being able to get together with them and when we did the conversation invariably turned to my illness and fatigue. All the questions asked of George and I about my health became the longest topic of conversation by well meaning friends and family. We spoke of how the illness seemed to have a life of its own, and it was causing George more anxiety and worry over my health and I was overwhelmed and not coping well.

Then, we answered many questions about family history and who made up our families and who played major roles in our lives. Questions about our health histories and of our family's health histories also. We were asked to name how this whole health issue made us feel and George called it "The Monster", which fit perfectly for us. "The Monster" took over our lives so quickly and completely and took so much from us. We were then asked to think about creating a time or place to call a "Monster" free zone or time. For us it was easier to create a day when we would not talk about my illness or the fatigue. And that began our search for NIFT DAY.

Now lets answer some of the questions that were mentioned in the beginning.
What is NIFT DAY and what does N.I.F.T. stand for? Why would we want a NIFT Day?

Indeed why a NIFT Day? George and I have found that is has helped enormously to have control over the "Monster" and its effect and control it had over our lives. It has help us to rebuild our connection to each other and made it stronger. It has helped us to realize what is important to us. And most certainly, it has reduced the stress and brought back the laughter to our home and our enjoyment of each others company. We think these are very good reasons to want and use NIFT Day. Don't you?

NIFT Day is simply a day off from talking about health issues and trying to have at least a quiet day and put some fun into your life. It is simply putting the problems on a back burner for a day or at least a few hours.

In keeping with having put a name to our "Monster", we felt it would be appropriate to name the day off from the Monster as well. So, while trying to be a little creative at creating our day off, I came up with the acronym NIFT DAY, which means No Illness or Fatigue Talk Day. You may want to give your day off and Your "Monster" names that fit for you. Be creative and make it fit your needs and personalities. But, yes it is okay to borrow ours, George and I don't mind sharing.

How do we start and maintain a NIFT DAY?

First, we had to have some agreements on what I could do to help lessen George's worry over me. Practical, sensible, and easy things I could do. We made sure the life call system was functionally properly, and I agreed that when I was alone I was to wear the personal alarm button, we also made sure the other "panic" buttons were at low levels so that if I fell I could reach them and they were placed in rooms where there was no phone. We

notified life call of the emergency phone numbers to call if no voice response was received. We gave a house key to a trusted neighbour for emergencies, and let the life call company know who had the key. I agreed to wait until George was home to have a shower. I agree to always use my cane and now the walker when I am out, and in the house when I am not walking well or am weak. George has taken over the household tasks that I can no longer manage, but he offers all the time to help with the things that I can manage but take much longer to do now. We both have agreed to live with a little dust now and again. We learned that letting go of the not so important stuff was so much easier than driving our selves crazy (especially me) trying to be perfect. We agreed that George needed to do things to take care of his self as well.

Next, George and I sat down with our day planner in front of us and picked a day that was normally a day off work for George (I do not work at a job outside of home), and picked a day to not talk about our "Monster". We actually wrote in the planner NIFT Day on Wednesday every week for two months, moving a day ahead or back if something was already scheduled. We planned to do things together that we enjoyed and wanted to do together even if it was just a shopping trip to the grocery store. Often when I was unable to go out or we were financially challenged our day off was still held at home. We watched movies had snacks, cosy meals in front of the TV. Talk about anything but health, read, cuddled, or played games. If I was up to it, we went for walks with our little dog Teddy, played games with him, went visiting, or looked at fancy show homes or motor homes and dreamed. Used your imagination make it fun and relaxing it doesn't have to cost anything or much. Try creating Date Night, ladies fix your hair, put on your makeup and a pretty outfit, men have a shave and put on a shirt and tie or a sport coat, dress up and go out to dinner at your favourite place or if the budget allows some place special or new. George and I try for at least once a month. If dressing up is not your thing then try something else you would do on a date. Try for at least once a month. George and I try for a casual date night twice a month on top of a special date night once a month. If going out is not possible still get dressed up at home and make your favourite meal, set the table nicely and light some candles, and soft music and right before your eyes you got a special date.

Our first day off was not very successful. So we decided we needed to be a little more flexible and a little more creative. We found that if one of us were talking about our "Monster" beyond a couple of minutes we would give the other a signal to get the other to stop talking about it. It could be a code word, phrase, or hand signal. We chose a hand signal that meant something to us, but was still respectful to each other and noticeable to only ourselves. It can help if you make it a funny word, phrase, or signal. We have used an exaggerated clearing of the throat, a time out hand signal and when alone the exaggerated cross as if to ward off evil vampires. If you want, you can let the whole family in on it and friends too. For us, it was just necessary to have the signal for each other. If I was having a bad day with my health, we rescheduled our NIFT Day to the next day or a couple of days later. Having a day off does not mean that you cannot check with each other to see how you are doing. I mean that if you are no better but no worse say something like "I am normal for me thanks and you?" When it is possible use words like I am great, wonderful, terrific, or I'm good. However, when you need to, say

something like: “Sorry, I’m not feeling very well today”. Just be honest with how you are feeling. This helps create breathing space for the both of you, and allows you to go ahead with NIFT day without worry, or anxiety. If necessary, postpone the start of your day off or reschedule your NIFT day. Remember it is extremely important that if your health is not good or something new or scary is happening or your partner is worried or concerned about something just suspend NIFT day to talk about it right away, and for as long as is necessary to address and solve it, or table it (if possible) for further discussion. Never hide it from one another. It just creates more problems later or misunderstandings. You can always continue NIFT day later or reschedule for another day. George and I have found that it is very important to really connect when you need to discuss a problem or issue. We have found that if we sit down together, and facing each other, hold hands, and keep eye contact will help to connect and feel secure. Remember to keep it as simple as possible, and speak and listen to each other in a loving, respectful, and sensitive way. Try not to drag it out and go on and on about it.

Make at least part of your day off for fun, like being silly with each other by make funny faces at each other, tell outrageous stories or jokes, see or rent a comedy, make laughter part of your NIFT Day. Do, do something enjoyable, something you both enjoy as a couple, and when you can include the rest of the family, kids need fun too and family time is precious. When possible, include good friends on one of your days off for at least part of the day.

Linda and I have always had an element of silliness in our relationship. I am a self confessed “teaser” and an avid “pest”. I do like to “pester” Linda. Let me explain a little, I never tease Linda about things she is sensitive about and I am not abusive in any way. I find humour in Linda’s little habits and she in mine and we joke about these little quirks we each have. I have a way with driving her nuts with questions like a kid who wants to know why about everything. It always get a reaction either good or bad which is needed to draw her out when she gets too quiet. I usually say something outrageous and so silly before you know it were both laughing and having a fun time. And, when Linda gets going she can give, as good as, she gets, and I am good at being a “pest”. I understand that this type of humour won’t work for everyone, but it is how our relationship has always been. The point behind this is find a way that works for you to have even just a little bit of laughter every day. After all “laughter is the best medicine”. I must tell you that I always keep in mind how Linda is feeling and just how much” pestering” she is able to tolerate. If Linda is having, a bad day then there is no “pestering” at all. Other times if I come too close to over doing it she will hold up a hand and say something like “oh, be gone little troll” or “ talk to the Hand Stan” and I know it is time to put “Mr. Pester” to bed till another day. And, there is always another day.

If you are spiritual do incorporate this into your life as much as possible in does not matter what religion you are or are not. There are many ways to take care of your sprit. You just have to find what fits for you. Whether it is reading the Bible, going to Church, talking to your Pastor, Priest, Rabbi or whom ever, reading inspirational material or music that lifts your soul, do something comforting together.

In maintaining NIFT day remember to be flexible. We cannot stress it enough. You must remember most chronic/long term health issues vary not only day by day but also sometimes even hour by hour. We found we also have to factor in Doctor appointments, tests, visits to and from health care providers, medications, rests and meals being on time and etc., work, other family issues/problems. Things have a way of coming up and you really need to be willing to be flexible as the saying goes "stuff happens". There really is a lot to think about, but by being flexible, you can work it out. There have been times when we have had to postpone NIFT day as long as two weeks but we do get back to it. Start slow, if need be try for a half day then a full day at least once a week. We started with one day a week. Please do not be hard on your selves and do not beat your selves up if your first few tries at having a NIFT day are not successful. Remember it takes time, practice, patience, and perseverance and yes, I will say it again flexibility. It also takes a high level of commitment not only to each other and your family; we mean commitment to the process of finding your NIFT day. Remember commitment, flexibility, patience, perseverance, time, and practice, practice, practice.

At the end of the day laugh at the mistakes you have made. Congratulate yourself and each other for a very successful day. Even if the day was not completely successful, celebrate each successful moment. Celebrate each other. Do not over analyze the whole day, take a little time to think about it and make suggestions to each other about what each of you may need to do to make it more successful, do not get into a blaming thing it won't help and you just end up frustrated and possibly angry. Not a good thing! Work it out together always be respectful, loving, caring and sensitive to each others needs and issues. In the long- run you will be very happy you did. We certainly are.

It is also very important for the well person to find the time to take care of his/her self, time to do their "own thing" and rejuvenate. As a professional health care provider, this is especially important as that is how I earn a living and I need to care for Linda, as well, I also have the responsibility of helping Linda's father who lives in a nursing home, and helping my mother when she needs help. I take care of my self by having time to do the things I like to do. For example: I go see a friend and meet for coffee, I enjoy my computer so I take time to surf the web and play a few of my favourite games, read and send e-mails to friends and family, instant message by brother and joke around with him. Because I work nights, on a day off and not a NIFT day, I'll take a long soak in a hot tub, take a long cosy nap, watch my favourite programs on TV or put in a favourite movie. I take time to do my own errands then when Linda is ready, I take her where she needs or wants to go. As I get home in the early hours before Linda is up and about, I have time to do my household chores, make plans for things to do if it is our NIFT day or search out things for our next NIFT day. We often discuss the plans I have come up with even on the NIFT day so we can keep on an even keel. I try to surprise Linda with something different now and again because it makes me feel good to see her reactions and her smile. that I do as much for myself as I do it for her.

Take time to do the important little things for each other. I always let Linda know every day, and, sometimes several times a day how much I love her. Linda always makes sure I know how much she loves me. We hug daily and frequently. We always kiss each other

hello, goodbye, good morning, and good night. It's these little intimacies that will lift your spirits and give comfort to each other no matter how bad you are feeling. We are always respectful of each other even when we "tease" and "pester". I try every day not to be insensitive to Linda's needs, and wants and she to mine. Because I work nights and even on my days off from work, I am an early riser, I make coffee for us and I bring Linda her first cup. Linda brings me the second cup. We always use manners, old fashioned please, and thank you-s go a long way. Linda when she is able takes the time to make my favourite meals. Sometimes we will send loving emails to each other. It is a nice thing to open a loving message when you least expect it. Now and again, I will bring her a treat or flowers she makes me cards or gets me a special treat too. We always express our appreciation for each other and the things we do for each other. For me, doing all these things makes me feel complete and it helps keep the worry away. If your partner knows how you feel, it makes things a lot easier. I know that Linda agrees wholeheartedly with me .

We realize that we have been focusing NIFT day primarily on couples but these basic ideas can be applied to your children and other family members as well as friends. We believe, that if a child is old enough to ask the questions concerning the one who has the health issues then they are old enough to be included, at least to some degree in NIFT day. It would help lessen the stress and concerns that they would have. Also, children can add their delightful sense of fun to an outing. Or if you pay attention, they can teach you how to play again. This will lessen the stress for every one and become a win/win situation. And, to Quote "Martha" "It's a good thing".

We know it seems like a lot of work to practice NIFT day, but so worth it. You will all feel empowered by the feeling of having more control over illness and stress, and the effect it has on your lives.

It is now Feb 2006 and as we are wrapping up this letter and coming to the end of our sessions, we are mindful of how far we have progressed. George and I have regained our closeness and are able to communicate even more effectively than before, and the stress while not gone is easier to handle. We have re-established our deep connection to each other and have relearned to "Stop and smell the flowers" and we have found that NIFT day has grown to become part of every day living. We still have to talk about my health issues, appointments and health needs but now with NIFT day as our most valuable and helpful tool, there is no need to talk and talk and talk and over analyze every detail. NIFT Day has saved us as a couple and allowed George and I to be just a husband and wife and best friends again. NIFT day influences many parts of our lives. It helps with more than just the health issues. Life is still not always easy as my health issues progress but we have learned to live with any problems and deal with them as they come up, as gracefully as we can. The stress is easier to handle and not such a burden to either of us. We still have hope, love, laughter, fun, family, and friends among the little thorns of life. We are able to give thanks every day for each other, and our renewed connection and continuing love, and for the resources, we have found. We give thanks daily for all the help from

those resources. We give thanks daily for the coping skills we have learned. We give thanks daily, for though life is not always easy, LIFE IS GOOD!

DEDICATION:

We dedicate our letter in loving memory to George's father Jim Jensen and my mother Phyllis Roffey whose love and encouragement made us want to strive to be the best we could be. We also dedicate our letter to Georges' mother Lavina Jensen and my father Lee Roffey whose continued love, support and encouragement make us feel blessed every day. They all know of the struggle with illness of loved ones from both sides as the healthier spouse and as the one with the illness.

THANK YOU TO:

Patty Brennen whose skills as a therapist, and her advice, and guidance have helped us in countless ways. It was Patty's research and knowledge, which led us to the Family Nursing Unit Team.

Dr. Janice Bell, Dr. Nancy Moules, and all the members of the clinical team of the Family Nursing Unit at the University of Calgary for all their valuable advice, guidance, and feed back. We thank you all from our hearts.

To Aunt June and Uncle Stan thank you with much love for the numerous times you have read and re-read this paper, your advise, suggestions, encouragement and support has been as always outstanding.

Thank you with our love as always to other family and friends for being so caring and supportive.

To all who read this George and I hope you all find this helpful, full of hope and inspiration. We wish you the best of luck in finding your NIFT Day and wish you as much success with it as we have had.

GEORGE AND LINDA JENSEN

February 2006

Calgary, Alberta