

## Journey as a Spouse

Having a spouse or parent with Parkinson's is a big experience, and can be obscured by the intense experience of the person with Parkinson's. Sometimes we lose ourselves in daily business, and concern for others. This can work for a while, but eventually we need to get back in touch with SELF, and when that urge comes, it can be very overwhelming. Concerns often mentioned focus on one's own emotions and thoughts: impatience, worry, judgments regarding one's own behavior, anticipation and anxiety. How can a difficult situation lead to anything but difficult thoughts and feelings? There are many coping strategies, many tips, and tools to adopt, but having them available when most needed is a tricky feat. We learn by observation and practice. Humans are masters at mimicking. But when do we have the time to rehearse our notes, and how do we know which note is appropriate now? Wouldn't it be great to have a little role model in our pocket? We could pull it out and get direct and personal coaching in the moment we are confronted with a sticky situation. Fantasy aside, I propose that we *can* use a map – a very personal map that we can each create and use to guide ourselves through life's difficult times. The following description comes from my M.Ed. final project: Integrating the Arts and Art Education as a Health Practice. Much of what I learned came from Gabriel Roth's teachings of the 5 Rhythms®, and my personal experience as a close relative of two people with severe illnesses. I hope that sharing this perspective will trigger in others a health practice that is personal, perpetually available, and practical.

Each area of the map presents a terrain that calls for a type of behavior. For example water calls for swimming, extreme temperatures call for seeking shelter, etc. So it is in life that certain situations call for certain types of behavior. Sometimes we are compelled to hold on to our emotions. Other times we seek privacy and allow ourselves to cry. And at times we cry when least expected. If we are unsure about where we are “on the map” our behaviour can trigger doubt, confusion, anxiety, shame, remorse and so on. For each of the five areas on the map (West, North, South, East and Centre) I've associated a prominent task to guide behaviours: Identify, Act, Let Go, Commune, and Witness. I've used this map to guide me in art, leadership, learning, friendship, healing, marriage, life. Caring for 'relationship' is caring for our partner, for self, and just as importantly it is acknowledging our own journey's impact on our partner's and vice-versa.

Identify – Let’s just say we are starting in the West. This is a place where we strengthen our sense of self. How do we do this? We attend to the information that is most personal and subjective. We may ask, “Where am I... in this moment...perhaps in a chair, in the garden, in the city, on an island. Am I safe and comfortable... Am I unsure? How do I feel physically and emotionally?” Eventually we ask, “What do I need? What do I want?” The task is to continue the exploration of senses, thoughts, and emotions without interruption; allow thoughts and feelings to come and go and come and go and the answers come clear.

Act – In the North, now that we have identified what we want and need, it’s time to fulfill these wants and needs. It might be simple or complex depending on one’s stability. If we are feeling disrupted, fragile or scattered the wants and needs are likely simple, such as needing rest, nutrition, organization, routine. The more stable we are with these fundamental needs, the more complex our wants and needs will be and also our plans for attaining them. We look to others with experience, and learn strategies. In this place we gain knowledge by repetition of these strategies, making them routine and increasing skills. We then use knowledge to act with sureness of direction and impact, like swinging a hammer to a nail. Time in the North becomes a time of clarity, precision and purpose. The actions might be nurturing like establishing a weekly visit with a friend or the actions might be adventuresome such as facilitating a support group or taking a new class or practical and calming like reorganizing the garage. These are the actions that when repeated, strengthen skills and build a sense of security; these structures we rely upon for predictability and protection are our own constructs. It is easy to get stuck here. Holding the fort, stressing over getting tasks done or keeping the appointment, sensing that if the routine is not executed, everything will fall apart. Then it’s time to move South.

Let Go – As we move South we feel the burden of our efforts, the responsibility of maintenance, and the struggle of keeping pace with others; we notice our strain. A sense of danger develops when the winds of change beat against the structures that we believe provide stability. Eventually, as we arrive South, comes the realization that no matter what action is taken, and beyond all control, we are in the throes of transformation. If we cling with desperation to the ways of the past, we risk more than if we let go of those ways. It’s as if a storm has struck and we must surrender the structures that cannot withstand such force. A solid footing may be impossible to find, and so letting go of knowing, and letting go of *wanting* to know is the only

way to survive this torrential place. Cancel that date with the lawnmower, turn up the music and dance; get out the bicycle and ride; have a mid-day shower and wash away the concerns of the day. Whatever is chosen the intention is to slough off all that no longer serves its purpose.

Commune – Arriving in the East where the good storm has washed away everything superfluous there is no more need of “letting go”. The experience of “not knowing” comes with ease rather than fear. We are released from the illusion of stability, the illusion of opposites and the illusion of separateness. The meeting place is clear of obstacles; it is visible and attainable. So with a lightness of being comes union. Relationships are evident, renewed and celebrated.

Witness – In the Centre of the map we find a broad and deep perspective of self, of relationship, of other. We hold position; quieten judgements, plans, and subjective experiences. In stillness we can witness wholeness. As Franz Kafka wrote “You don’t need to leave your room. Remain sitting at your table and listen. Don’t even listen, simply wait. Don’t even wait, be quite still and solitary. The world will freely offer itself to you to be unmasked. It has no choice. It will roll in ecstasy at your feet.”

Though the journey appears complete we are at the brink of another beginning, another cycle of creation – cycles upon cycles that are ever expanding.

Relationships go through phases as they develop and change, undulating intimacy with estrangement in varying degrees and according to internal and external influences. Recognizing one’s own process can lead to ways of coping and understanding our partner. I tend to ask myself questions as a way of finding my task. Do I crave time by myself to relax, to follow the current of the day, to move from one thing to another without decision and without interruption? Do I long to be in the moment? This is the phase of Identity. Perhaps I am in the place of Action. I will be compelled to declare what I want and to establish some routine and order. And when I am holding on tight to everything I know to the point of pain and angst, then I need to Let Go.

Living with a serious and prolonged illness in the family is complicated and often overwhelming. This little essay attempts to offer a simple practice to tease apart complexity. Identify, Act, Let Go, Commune, Witness. By understanding where we are on our journeys – even during times of confusion and doubt, we are better able to cope, to allow inevitable change, and to become equipped with compassion and patience for self and other.