

The CHRONDI Creed: Living Well with a Chronic Disease

By Dr. C. May 1, 2019

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Living a life with a chronic disease is difficult, a battle to live well, obtain a quality of life with experiences of well being despite the disease. The challenges of battle require the mental attitude of a samurai warrior. Like the code of the samurai, the C.H.R.O.N.D.I. Creed is both a guide for battle and for living. C.H.R.O.N.D.I. is an acronym made from the first letters in **chronic disease**. The letters stand for each part of the creed as follows: C – compassion, H – happiness, R – rehabilitation, O – others, N – nature, D – death, and I – individuality. Below is the CHRONDI Creed in its self-affirming dialog. This is followed by a description of each self-affirming statement in this chronic disease warrior's creed.

C – Compassion: (ref2) I will act compassionately toward others and find gentleness toward self.

H – Happiness: (ref3) I will seek the inner bliss of happiness that is not material in nature.

R – Rehabilitation: (ref4) I will apply courage and mindfulness to a total health rehabilitation plan.

O – Others: (ref5) I will genuinely communicate to others my experiences and maintain an attitude of gratitude for their help.

N – Nature: (ref6) I will take time to embrace nature and all its beauty, which may include gardening.

D – Death: (ref7) I will find the courage to face the terror of the “death of self” (loss) and not let it control me.

I – Individuality: (ref8) I will continue to express my individuality, and my purpose, beyond the disease.

These CHRONDI Creed statements are short “I” statement that can not only be self-affirming, they can change how a disease effects one's life. If these statements become an inner dialog, a way of thinking and acting, then they can contribute to quality of life.

The C in the CHRONDI Creed: Compassion

The C in the CHRONDI Creed, a warrior's guide in the battle against chronic disease, is for compassion. It may seem odd labeling a warrior as compassionate. Normally we picture the warrior as fierce, brave, courageous, and strong. Compassion is not often associated with such an image. But, in the battle against a chronic disease being both a warrior and compassionate has important benefits. The compassionate warrior brings a special set of armor and weapons to the battle against a chronic disease.

Compassion is the mindset upon which the strength and courage of the warrior is set in motion. In my research I have defined compassion as empathy plus wisdom (*ref9*): Empathy is the ability to sense, hear, the suffering of others, and wisdom is the ability to do something to reduce that suffering. Compassion is about the reduction of suffering in the world around you. The first step to becoming a compassionate warrior is making a commitment to a life of compassion, a philosophy of compassion (*ref10*). The second step is to realize that you can change your behavior so that you contribute less to the suffering of those around you. The third step is realizing that you can act in a way that helps reduce the suffering of those around you, and without sacrificing your own well-being. In fact, this path of the compassionate warrior promotes personal well-being.

The challenges of living with a chronic disease are many. The most obvious are changes in control of the body, like motor and coordination issues. But there are emotion issues that are equally impactful. Impulse control issues, grief/loss and depression, anxiety, and anger. Also included is a decreased ability to manage these emotions. When the actions connected to these emotions spill out into life the consequences can be costly and add to an already arduous chronic disease battle. The biggest contributor to human suffering is objectification of the other person, which often happens when emotions are overflowing. This is where the practice of compassion plays an important role. Practicing compassion is very much a scenario looping skill (*ref11*), and, as such is good brain training for people with a chronic disease. Without doing so directly, the practice of compassion helps us to moderate those emotions and the decrease the consequences they can have in life.

It may seem odd saying that acting in a compassionate manner has selfish benefits. It is not the goal of compassion nor is it in the mind set of compassion. It is simply a positive side effect. Compassion has its focus on the other person. The skill at which a person can do this depends upon their history with practicing compassion. You don't have to be an expert to have it make a difference. Practicing compassion at any level is good for relationships, and healthy relationships improve the quality of life for anyone with a chronic disease. The compassionate mindset is also one of gentleness, which can be (should be) applied to self in healthy doses. Being a compassionate warrior does not mean we sacrifice our own well being for the sake of another. Two persons in the row boat, one each manning the oars, makes the journey easier.

Compassion, after some time practicing, can move from contemplated action, to the first action taken, to the first thought considered and then to living as a compassionate warrior. I have been training as a compassionate warrior for decades and my chronic disease has set me back. But as a compassionate warrior I continue to work at this, as hard as any warrior would who is preparing for battle. The compassionate warrior does this preparation along with meditation and a calm mind (*ref12*). It is a commitment to a way of living, and it serves as a foundation for the other parts of the CHRONDI Creed. In addition, the other parts of the CHRONDI Creed help to support this foundation to becoming a compassionate warrior to fight for living well with a chronic disease.

The H in the CHRONDI Creed: Happiness

Life, liberty and the pursuit of happiness – the H in the CHRONDI Creed refers to happiness. Happiness can be an elusive thing when battling with a chronic disease like Parkinson's. There are so many things that can get in the way of experiencing happiness: pain (*ref13*), deep fatigue (*ref14*), irritability (*ref15*), the time consumed by the disease (*ref16*) and grief accompanying the losses (*ref17*). Trying to hold on to even small moments of happiness is a challenge. It is possible to experience moments of happiness in the face of a chronic disease if one holds the moment gently – not too tightly.

Happiness is a state of mind and includes a broad range of phenomena, e.g., gratitude, inspiration, accomplishment, beauty, awe, laughter, compassion, tranquility, joy, love, exhilaration, ecstasy, and bliss. The experience of happiness can have a connection to just one (or several) of these phenomena. Before you finish reading this column let's take a mental excursion together. Visualize in your mind the last time you were happy and try to feel how you felt at that time.

Were any of the above phenomena part of your memory? Remembering happiness is helpful in reminding us what it felt like, of what the experience may look like again. It can help us to see it in the smallest of moments throughout our lives. It is not a practice of grasping after happiness. Happiness is like a butterfly flitting from flower to flower. We take in the beauty and the rich sensual experience and hold it gently in our mind. If we were to grasp the butterfly, we would destroy the experience.

Gently holding happiness, without grasping, is tied to a compassionate way of being (*ref18*). So much of our unhappiness is tied to grasping, to misperceptions and to poor communication in relationships. The practice of compassion is about experiencing the needs of others and then moving beyond to a place of well-being. It is a shift out of suffering. Walking the path of the compassionate warrior is filled with happiness experiences accompanied by the knowledge of shifting perception. Scrooge, in Charles Dickens' "A Christmas Carol", wasn't happy until he experienced a shift in perception and became compassionate.

I don't expect of myself to experience happiness all the time. That's just too unrealistic for where I am in my personal development as a compassionate warrior battling a chronic disease. I seek small moments each day, not by grasping for them but by looking for them, like looking at the butterfly, and then gently holding the moment in my mind. Then I am very grateful for that moment and not sad when it naturally fades into the next experience as part of the day. This feeling of happiness is not induced by drugs or alcohol (which bring fake happiness). It is a happiness that comes from the practice of allowing the mind to experience the large and the small moments of happiness. I do my best to begin and end each day with a confirmation (mantra, prayer) of specific gratitude, meaning it is not a statement of general gratitude, but one aimed at something specific in my life. Gratitude is a way of holding the door open for those happiness moments.

The R in the CHRONDI Creed: Rehabilitation

Rehabilitation, the R in the CHRONDI Creed, is about the path to wellbeing. It is an action plan aimed at doing all that is possible to live well with a chronic disease. A well-designed rehab plan can make that journey easier. Think of a rehab plan as an expanded treatment plan that includes not just symptom treatment, but also all those actions which contribute to quality of life – a total health approach.

In the previous columns I have covered a range of topics, reflecting the total health approach of a rehab plan; freezing (body) (*ref19*), deep fatigue (body) (*ref20*), mindfulness (mind) (*ref21*), terror management (heart) (*ref22*), lightness of being (soul) (*ref23*), and the importance of showing compassion and gratitude (support environment) (*ref24*). These columns reflect parts of my personal rehab plan and they illustrate the diversity of domains that need to be addressed when taking the CHRONDI Creed into battle against a chronic disease. My Ph. D. is in rehabilitation counselling with many years of writing rehab plans. Most often a rehab plan is thought of as a “back to work” plan following an injury (or substance abuse). But it can also be thought of as a “back to well-being” plan when facing a chronic disease. A rehab plan includes care for the following: body, mind, heart, soul, and support environment. The well-designed rehab plan includes actions which address each of these care needs in connection with the path to well-being, while also placing emphasis on the strengths of each person (not just symptoms). It is a total health approach.

It has taken me close to a decade to arrive at a rehab plan for this chronic disease. There has been a lot of trial and error, many consults with professionals, support from family and a ton of research. The plan is not a static thing. It is always getting tweaked to keep ahead of the changing demands of the chronic disease. The hardest thing for me has been to keep on the middle path, to not get too serious (intense, righteous) and yet not too flippant (not caring, lost in the clouds). The middle path is also about monitoring actions in all realms (body, mind, heart, soul, environment) to keep an even balance in thought and action. The middle way is about using just the proper amount of action applied to any situation and as a result getting back just the right consequences. The balance of the middle way can be built into the design of a rehab plan and in doing so aid the path toward well-being.

Every rehab plan is individually tailored, and the more closely it can match the needs of the individual the more likely it is to be successful. But this can be a difficult goal to achieve. If you are a strong self-advocate, as I am, then there are hours, days, of self-reflection and examination behind matching the rehab plan to personal needs. But self-examination is not always accurate. There are times when what I want doesn't match with what I need. When that happens it is good to have the ear of a trusted care giver. If you are a caregiver helping to develop a plan, then the question that needs to be continually revisited is, "How well do I know this person and his/her needs?" Walking in another's shoes, and having evidence that this has been accomplished, can reveal a person's true needs. There are varying degrees of empathy and it take skill to understand them and apply them (*ref25*). Not understanding a person's needs is like giving a thousand wool blankets to desert nomads because you thought it was the compassionate thing to do. Misinterpreting another's needs is a major obstacle to designing and delivering a total health rehab plan. It is hard work to design a detailed, individually tailored rehab plan which is focused on total health. It is also challenging to put that plan into action, learn from it, tweak it (over and over again) and come up with an improved version. It takes courage, perseverance, and support

The O in the CHRONDI Creed: Others

The O in the CHRONDI Creed stands for Others – the other people around us that support us, teach us, love us, pray for us, and provide care. Other people can also provide a mirror that helps us see how others perceive our actions. If we can objectively view this reflection, we can gain wisdom about the consequences of our actions, and then make informed choices that will affect how we interact with others. The relationships we have with other people provide a foundation of support and a mirror seen clearly within the compassion space (see diagram below).



Columnist Sherri Woodbridge writes about relationships while dealing with PD saying that we need to consciously put the effort in to keeping that relationship magic alive (*ref26*) and to get help with relationship issues rather than trying to ignore them (*ref27*). It takes work to keep relationships healthy and growth-promoting. We never put our foot in the stream of life the same way twice – our lives constantly change and our relationships need adjusting along with these changes.

Growth-promoting relationships with others happen within what I called the compassion space (*ref28*). It is a shared space between self and the other and the possibility of well-being. There is also movement that takes place within this space. Reaching out to the other and then retreating to self (the “push the person away” and then later “seek to get closer”) is one of the most common relationship dances. A similar dance happens when seeking to help someone toward well-being or to receive help from another with your own well-being. It is a dance of getting closer to well-being and then retreating from the experience. I have termed this compassion space resistance and it is the main source of compassion fatigue (*ref29*). Compassion fatigue does not arise from successful compassion. Successful compassion leaves one with more energy than it takes, whereas compassion space resistance can be very draining and lead to care giver burnout. Imagine that your life long partner has a chronic illness. All you want to do is help move your partner towards a place with less suffering. But every day has arguing, not following the rehab plan, yelling, and a lack of motivation to take personal responsibility for his/her half to the journey toward well-being. Every day is filled with resistance to the compassion space and it can be exhausting.

Successful movement within the compassion space involves a shift toward well-being. When the self and the other are in the compassion space where this shift occurs, they experience a special type of growth-promoting relationship. It is called the healing relationship (*ref30*). The healing relationship is often interpreted as sacred, as a gift, and something which is allowed not pursued (*ref31*). Once the healing relationship is experienced, then the shift toward well-being experience becomes a stepping stone for the other to use in his/her journey toward maintaining a higher quality of life. The self then becomes a witness stepping stone, saying things like “Remember I was there with you.” Then, as witness, asks the other person to recall how much better she/he felt after the event. This witnessing happens within a different type of relationship, one called the support relationship. The support relationship includes discussions on how the person can find his/her personal path to well-being.

Growth-promoting relationships involve entering the compassion space, in the roles of self and other. If we can understand the dance that takes place inside that space (the dance where the relationship changes from healing, to support, to resistance and back again), then we can see our own path to well-being more clearly. Growth-promoting relationships are fundamental to success in the battle against a chronic disease. Healthy relationships with others depend upon the successful communication of our needs to each other. If you are waiting for the other person to read your mind and know what it is you need then you are going to be disappointed. So much suffering in the world happens when people do not enter the compassion space, but instead throw words at each other from inside their personally constructed self-bubbles. We think we are safe inside our self-bubble. But the problem is that we can't

really hear the needs of the other when inside that self-bubble. If we can't hear the needs of the others in our lives then it is very hard to have growth promoting relationships. Care givers in our lives need our attention and compassion (*ref32*). Other people in our lives help us both as mirrors to know ourselves, and as support in our battle against a chronic illness. Use of the compassion space helps individual needs to be expressed and heard more accurately. It takes practice moving around in the compassion space with adept skill. The CHRONDI elements help with this practice.

The N of the CHRONDI Creed: Nature

"Nature", the N of the CHRONDI Creed has always been a part of my life. One doctor said to me, "Your strong history of exercise and nature has kept Parkinson's at bay." I was an avid hiker, cyclist, and rock collector. As I headed into my gray-hair years with PD, I moved from these activities to building and maintaining gardens around my home. I have always felt healthier when gardening, not knowing that there is supportive research (*ref33*). Nature walks and gardening improve total health.

Human beings have been interacting with, and dependent on, nature for millennia. It has only been in recent history that we humans have migrated toward being city dwellers. Returning to our roots (pun intended) can have quite a few benefits. Living next to "green environments" has been shown to have both mental and physical health benefits (*ref34* – two references). Walks in parks (*ref35*), particularly when mindfulness is used, can have positive health benefits (*ref36*). I can attest to the benefits of this practice, both personally and as a teacher of mindfulness. There are people who have trouble meditating while sitting. For many of them a mindful walk in the woods can be very helpful in quieting both mind and body. Reconnecting to nature has total health benefits and it doesn't have to take hours out of a busy life. Just minutes can make a difference (*ref37*), particularly if done with mindfulness.

Humans have built sacred sites on, or near, places of great natural beauty. Experiencing the awe of natural beauty can leave a lasting effect, a change in body and mind. The awe of nature is how our ancestors used the sacred sites to facilitate a doorway to the soul. Such doorways are nearly invisible when surrounded by hordes on the highways, multitudes straining the subway, and a spastic speed of technology stripping away our humanity. It is so easy to get lost in this modern culture, forgetting what a part of being intrinsically human – the nature in human nature. Setting aside time each week to walk mindfully in a green environment is a first step to getting reconnected to our human nature.

Gardening takes more time than a stroll in the park, but there are additional physical benefits. Gardening is good exercise for people with PD, when adjusted for safety and the severity of symptoms (*ref38*). I consider myself a "landscape painter" and gardening is my main form of exercise. Building garden beds and pathways is building a personal green space. I have a relationship with the plants in my garden. So much so, that I have moved hundreds of plants with me when changing homes. Care for the garden and enjoying the beauty of blooms and foliage is a rich back-to-nature experience. For me there is awe in the experience. Gardening has total health benefits that help me to manage the symptoms of a

chronic disease. It's never too late to benefit from exercise (*ref39*) and gardening can be a fun way to get moving again.

The D in the CHRONDI Creed: Death

“Death” – the D in the CHRONDI Creed refers more to the death of our self-identity than it does to physical death. As we battle through the long battle with a chronic disease, dealing with a gradual progression in symptoms, there is a loss of function. The stealing away of bits and pieces of both physical and mental function is touched upon in my column about the “Disease Thief” (*ref40*). The disease thief robs from us of so many of the ways by which we know ourselves. It is a death of the self that is a casualty of chronic disease. The death of self needs to be addressed with as much mindfulness as any other part of the creed for total health to be maintained at the highest level possible.

There is no manual for navigating through the death of self. I was educated in many ways to be prepared for it. And yet when it happened, I was shocked by the severity of its affects. PD gradually took from me those things which I identified as myself, those things I would pull out of my pocket when someone asked, “What do you do?”. Below is the list of things stolen, roughly in chronological order:

- Field mineral specimen collecting (since I was a teenager)
- Professional field geologist
- Hiking and exploring rugged terrain
- Clinical counseling work
- Professor of counseling and geology

The time and money spent on four college degrees is behind all the years of experience expressed in the above list. Now all are casualties of a chronic disease. It is the death of self.

Looking in the mirror, past the gray hair and crevasses of age, deep into multicolored eyes, I found nothing that I remembered as me. The self I was knew was gone – dead! I was sitting in a void, a life without meaning, nothing of familiarity. From my clinical work, I knew that people get lost when this happens. It can be quite difficult to find the way back. I also knew something about this journey from mystical teachings (*ref 41*) but knowing and living through it personally are two different things. Somehow, I had to find my way out. I had to heal from the death of self.

The stages of grief (*ref 42*) can be applied to healing from the death of self. As mentioned in the disease thief column (*ref40* repeat) terror management should be used as needed. And it is important to have a support network through the process, including peers (*ref43*), family (*ref44*), and technology (*ref45*). In addition, the CHRONDI Creed can be used to help with healing, most importantly the I (Identity) of the CHRONDI Creed.

The I in CHRONDI Creed: Identity

Identity - the I in CHRONDI Creed refers to the process of finding a health fostering identity in the face of a chronic disease that has stolen things we loved to do (ref2) and caused the death of self (ref3). When everything I loved to do was taken from me all that was left was the time and energy I was putting into managing the disease. Dealing with a chronic disease consumes a large amount of time (ref4) and conversations about me were now connected to the disease, including my own self talk. Without even knowing how, and thinking I should know better, the disease had filled that void created by the death of self. The disease had become my identity and I hated it. I had to find a healthy new identity to help when battling a chronic disease.

Trying to “find yourself” is tied to one of those great philosophical questions, “What is the nature of human existence?” I have written about this philosophical quest (ref5) and I thought I had a handle on things, a strong identity of scientist, teacher and healer. But when the roles I used to make meaning of my existence were stripped from me I discovered that my intellectual writings provided a thin tether out of the dark void created by the death of self. The actions in my life, the conversations, did not match my identity roles of scientist, teacher and healer. I needed to reconstruct these identity roles - trying on new hats, looking for one that helps me build a new healthy identify. I needed this new healthy identity to succeed in my battle with a chronic disease.

Getting one’s actions in life, the roles we take on, to match the true self is not an easy thing to do in the face of a chronic disease. It takes a commitment of personal resources, courage and persistence to create new healthy roles to fill the void left after the death of self. It also helps to have support from peers, friends and family. But most important – you need a fire in the belly, a passion, a purpose (ref6) that brings meaning from these action roles you will be creating. Then you need to do something every day that will move you one step closer to that purpose driven life and a healthy identity matching the true self.

I started working on creating these new roles in 1999 when I left all that was my life (home, career) to pursue a Ph. D. – the second hardest challenge I have faced in my life. I also retrained myself to use the computer as a way of teaching, and for a tool in aiding scientific inquiry. In 2006 I applied those skills to a science research project which, after 13 years, has yielded new discoveries ready to share with the public (ref7). I have also forced myself to become a writer in the humanities by writing as often as time allowed. I also forced myself to become a computer aided graphic artist and taught myself how to design a website. These skills, web design, writing, and graphic arts helped me to reestablish the multimodal teacher role. In 2018, I became a column writer for BioNews giving me the opportunity to put the multimodal teacher into action more frequently, hopefully as a role model (ref8). Recreating the roles of scientist and teacher, after the death of self, is ongoing for me. Every day is a commitment to these recreated healthy roles as part of building a new identity. It is hard work, but worth it.

The one part of my identify which is still trapped in the void after the death of self is my role of healer. It is a role that is closest to my true nature, my soul. I have received written testimonials from dozens of people who stated that their lives were changed through encounters with this healer role. I miss that contribution to the wellbeing of individuals and to the collective wellbeing of society. I am going to try a different hat. It's a hat where holding the compassion space for others is expected, and in some ways embraced, so I can bring my experience in doing that and use it - hopefully.

The CHRONDI Creed, a plan anyone can put into place when seeking to live better with a chronic disease. The CHRONDI Creed is challenging to put in place as a way of life. It takes courage to face life honestly and to make the changes needed to move toward well being. It takes courage to wake up every day with a chronic disease and to stand tall with the CHRONDI Creed as your action plan.

Life is about choices. Using the CHRONDI Creed is a choice. I could say to myself, "I am tired of having to do all this hard work". And on bad days that voice gets annoyingly loud. That voice was particularly loud while driving to my monthly doctors visit for the other chronic disease I have - histoplasmosis. It's an eye disease and I need chemo treatment injected in the eye every month. This treatment is scary. Imagine watching a needle coming straight for your eyeball and then watching the fluid being injected. Imagine the thoughts, the fears. I sign a waiver every time because of the risks involved with this treatment. Do I want to want to do this? Dumb question, right? But if I don't do it then there is a chance that the disease will eventually take my sight. It's a choice. I could choose not to do this treatment but instead I choose to face this scary treatment every month. Courage is not the absence of fear but rather facing fear and doing what is health promoting.

The CHRONDI Creed is a series of self-affirming statements (for more detailed information about each one click on the link provided). I start each day with these statements and have been doing so for years. They have become my inner dialog – most of the time. A healthy inner dialog to replace all the negative, sometimes nasty, inner noise. Keeping that negative noise numbed down to a level of minimal impact is a very important part of my personal plan for well being.

Choosing to live by the CHRONDI Creed is not quite as intrepid as a needle stuck in your eye, but it is still something which takes a strong dose of courage. I have found that the CHRONDI Creed gives me more strength, helps me to have more courage, and adds to my quality of life while living with a chronic disease.

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