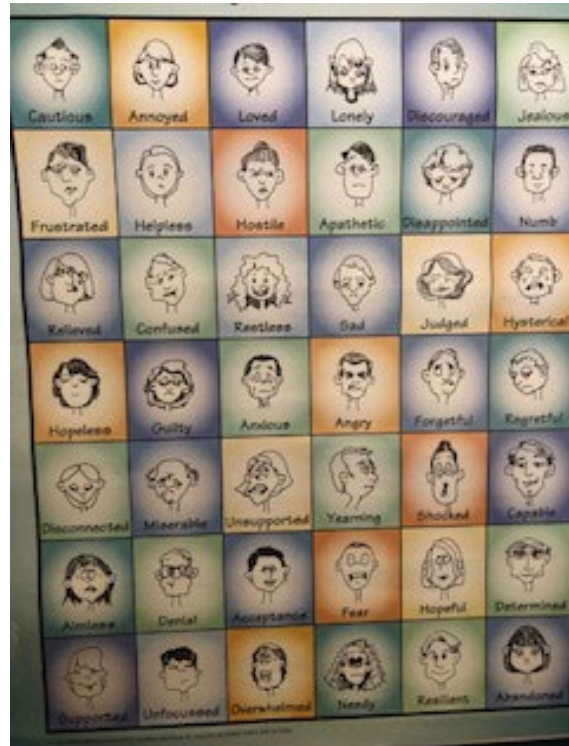


Creating Hope While Living with Grief and Loss



Three main aspects that are a part of living with chronic illness:

1. **Grief**, the thoughts and feelings that result from major loss.
2. **Hope**, adding an attitude of gratitude to difficult thoughts and feelings.
3. **Resilience**, caring for yourself and others in times of difficult changes.



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Grief

The chart is a reminder that the many emotions of grief include everything from sad, helpless, numb, and miserable to determined, loved, acceptance, and hopeful. And the good thing about emotions is they change from one moment to the next, they move, even the most sticky, icky feelings.

Think about emotions as energy-in-motion. This means if you keep them in your head, they'll roll around and gather more of the same. You may get stuck in a bad mood. But if you can express them, either out loud, or on paper, it's possible to change your thinking, what you're feeling, and even get to something you're thankful for.

Grief is the normal and natural reaction to loss of any kind. It consists of the thoughts and feelings we experience as a result of loss, the end or change in familiar ways of doing things. Think of all the changes in what you can and can't do, of how your relationships change, the roles you play. Think of the loss of energy, fun, and care-free time.

The process of grief can be complex because so many emotions accompany the multitude of thoughts that can change from one moment to the next. These thoughts and feelings that well up within your heart and mind, can be overwhelming, leaving you in a state of numbness.

There are some universal thoughts and feelings of grief—denial, anger, bargaining, depression, and acceptance. Sometimes these are labeled stages. However, it's more accurate and helpful to understand them as an unpredictable process and a wave of emotions.

Unlike stages, which imply a linear process with a start and finish, a right way and wrong way to grieve, the reality of grieving is more like a wave that inundates us and can make us feel like we're drowning in sorrow, pain, and sadness. It leaves us feeling tossed about by a feeling of being out of control.

One day we're drowning in sorrow or pulled by riptides of guilt, and then, out of the blue, we're back in denial and then angry that we just can't move on.

Let's delve into each of these aspects of the grief process:

Denial is a state of shock that results in thinking or making an assertion that something said, believed, or alleged is untrue. Denial comes from experiencing that what has



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happened is just too much to process, just too hard to live with. Denial shoves down the pain-filled emotions that come flooding up, thoughts of “this can’t be happening to me.”

The powerful emotion of anger can serve to cover up the pain of loss for periods of time. It keeps a person in motion, doing what needs to be done while suppressing the wave of sadness, shock and denial. Thoughts go toward who or what is to blame for what happened.

Bargaining is a strategy the mind uses to try to gain some kind of control over what has happened. “I promise to do this if only you bring back my healthy partner.” Then reality hits and we sink into a state of depression, believing nothing will ever be good again.

Depression involves withdrawing and isolating, experiencing a lack of hope, and having low motivation and difficulty going on as usual.

Acceptance is being willing to tolerate a difficult or unpleasant situation, to be in the embrace of what is, without resistance. It comes with understanding you can’t change what happened. But you can change how you’re thinking and feeling right now so you can keep going.

The most useful thing you can do for someone going through grief is to listen with an open heart and a blank mind. I call listening, the silent healer.

Listening:

1. Takes no particular expertise and with awareness and practice you can get good at it
2. It’s not hard to do, except when you’re thinking about something (which is most of the time)!
3. We love it when someone really listens to us.

Listening is the gift we give to each other. Listening is the healing power within each of us. It’s a natural part of our everyday communications. And the more we use it, become aware of it, and perfect it, the more power it has to make a difference in our life.

When we listen with a blank mind, no agenda, no judgmental thoughts, just focused listening, we can hear all of what a person is saying. There is clarity and wholeness of the message, not just the words. We hear the feelings beneath what is spoken.



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Think of a person in your life that you can tell almost anything to. Isn't part of the reason you feel that way because you don't feel judged by them?

A couple of things we need to remember in supporting those who are having a hard time:

- Be a safe person for them to talk to...ask if they want to talk
- Listen with compassion, without an agenda or judgments
- Give your presence, not your advice
- Suggest a couple of actions you could do that might be helpful to them
- Follow up as they might not reach out
- Do your own grief work as the more we heal our own wounds, the more we're able to listen to the pain of others.

The experience of grief becomes a seemingly interminable, ever-changing time of being thrown around in the waves of denial, anger, bargaining, and depression, with peaceful moments of acceptance.

As you tell the truth about what you're feeling, your thoughts and other emotions show up. In a calmer state of mind, you can remind yourself of what you love, what you're grateful for, something that is going OK in your life.

A powerful antidote for some of the most painful thoughts is the serenity prayer: accept the things you cannot change, the courage to change the things you can, and the wisdom to know the difference.

You can't change the body you're in; you may not want to change the relationship you're committed to; but you can change how you're thinking and feeling and going forward to create each day with more calm and moments of happiness.

There are things we each can do in addition to prayers, mantras, and meditations to create more resilience and give some hope in living with progressive health loss.



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Hope

Think of who you are and what you do in life. You are not your illness. You might have PD or you might be someone who needs to do a bunch of activities that we call caregiving. But you are not *Parkinsons Disease*. And unless you are a professional caregiver or you volunteer for an organization that does caregiving, you are not a caregiver.

You are a husband or wife, parent, a son or daughter. Maybe you're a professional caregiver or just a really good friend.

I'm a mother, a wife, a friend and colleague, a coach and speaker and writer. I play different roles based on who I'm with. And in all moments, I'm a caring person and giving a lot of care when someone I love is challenged. I'm a person deeply committed to making a difference in every conversation I have. I use this intention to keep going when I'm exhausted, when I don't want to listen to one more person. When I'm tired of waiting on whomever is in most need.

The roles we play and shifting how we think about them can serve everyone. I'm talking about being yourself and enjoying daily moments even as you deal with a life that becomes more limited in what you can or can't do. You stop asking for help because you're sick and tired of feeling like an invalid. As the partner doing more and more in serving the needs of others, you can become depleted from all the giving.

If you stuff your pain and pretend like you're OK, the suppressed thoughts and feelings will grow. The result will be less aliveness, honesty, and love.

If you don't shift something within you and think differently, you'll use the distractions to keep going, but you'll still end up overwhelmed, depleted, and miserable. The chatter inside your head might play over and over, oh *poor pitiful me*. It gets really loud and you just might become negative, unhappy, a real bore to be with.

You'll say, "I want to be happy and light. I want to feel joy, but find it harder and harder to put on my happy face." I grumble and groan, and stop seeing or calling friends and family. I see less friends, ending up isolated and resenting friends who are happy.

Oh, I do my gratitude journal and think about doing a couple of exercises and meditation in ZOOM rooms and then say: "it's all x@#" ...excuse me, but I'm in a depleted mood! This is my signal that I need to take a time out and to schedule something fun on my calendar.



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Resilience



Resilience is the capacity to prepare for, recover from, adapt to, learn from and transform effectively from the stress of adversity. Coping and bouncing back is usually how we think of being resilient.

I am thankful for all the useful, practical, and relaxing activities people come up with. It's important to keep a list of these so you can remind yourself when you are depleted or just feeling a bit grumpy. Add ones that you particularly like for your list.

For a quick turnaround, my three favorites are:

- Take a drive around the block and have a scream (if not driving, scream into a pillow)
- Walk – alone (even if just in your mind)
- Write the terrible things going on in your head and then rip it up and toss it away (or just think them and then delete, delete)

Habits to maintain Mental/Emotional/Physical Well-Being

- Sit to eat your meals, even if it's just a snack
 - Buy healthy foods
- Take yourself for a walk, even if it's just in the house
 - Moving the body also moves your thoughts
- Rest between heavy activities
 - Take time to ask what you are feeling
- Stop and do mindful practices
 - This allows for listening to your inner knowing
- Talk to your friends



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- Being social is a key for being healthy
- Have at least one safe person to tell your innermost thoughts and feelings

Remind yourself

- a. You are a good person and that you do a lot of good things, you love deeply, and it's OK that you're not always at your best.
- b. You are human which means you'll say and do things that are not useful, sometimes hurtful.

Apologize and forgive yourself and others.

Find joy in the small moments and create fun in hidden places, like the garden, a book, a quiet walk (even if it's just to the kitchen), do a jig of joy (even if it's only in your head).

Dance with whatever shows up because you've got a plan (even if it's just for today) and remember that you can change it.

Write down projects and put actions on your calendar. Schedule important things like: *lunch for me, take a walk, reading time and friend time.*

In summary: Living with chronic progressive illness comes with ongoing grief and loss. Staying resilient is not easy, but it is possible to remain hopeful, even if just for moments of clarity and calm.

Some reminders:

- Express your thoughts and feelings of the ongoing losses and the wave of grief emotions that come with them
- Keep in mind there are things you can change
- With good support you can accept those you can't change.

Support in good times and bad is one of the greatest gifts we have. Ask for it with kindness and patience, and ...

Keep an attitude of gratitude, because no matter what, there is always plenty to be thankful for!



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Questions to ask yourself and talk about with someone you trust.

When chronic illness progressively limits your ability to care for yourself, someone else has to do more and more. How does that make you feel?

How do you get control over yourself when you're feeling out of control?

Who are people in your life you can talk with? What is it about them that has you feel safe?



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What was your latest loss that you now accept? How did you get to a place of acceptance?

How would you describe yourself?

How do you not get swallowed up by the disease, or by serving the other? Name some distractions that keep you going.

What do you do when you feel tired, mad, and sad? Talking with a trusted friend is a way to let off some steam before you get depleted.



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