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Extreme Caregiving and the Problem with "Self-Care"

By Mel Berwin

"How are you taking care of yourself? What do you need?" Just about every friend I have has asked me these questions during the several years I have been in and out of crises with my daughter. They started when she was 11 years old and suddenly diagnosed with a severe chronic illness.

Over the next two years, she was in excruciating pain. She saw one doctor after another and spent time in the hospital more than once. She had to go on a restrictive diet and get immunotherapy infusions, leaving her severely fatigued and still trying to fit in at her new middle school. She didn't know how to manage it all. She started restricting her eating, then self-harming. On top of her physical illness, she was diagnosed with an eating disorder, anxiety, and depression.

Then one day, a particularly despairing one, because the therapy program she had just started didn't feel like it would help, she attempted suicide. Fortunately, she survived and landed in a residential treatment program for the next few months. During that time, I visited her every day.

Ever since her physical and mental health crisis started, I have felt hope and despair and anger and confusion and constant worry as well as pressure to figure out what she needed and how to show up for her. I also have felt shame and isolation. I've struggled to figure out how to cope while being the sole support for my child.





I am a single parent with three kids and a very full-time job in education. Fortunately, my work allows for some flexibility in my time during the day, and I have very supportive colleagues as well as decent health care and a steadfast village of close friends. And while I have never lost sight of my gratitude for each of those essentials, through much of my daughter's ongoing crisis, I have felt existentially alone.

Despite the many therapists, psychiatrists, and nurses caring for her, the residential treatment centers felt very "one size fits all" with their rules and their zones and their clinical notes. None of these people really knew my kid or saw her for the beautiful, creative soul she is. When she was most depressed, she went numb, blank. This wasn't the bright, sassy, creative, or even irreverent, quirky, and darkly humorous child I knew. I felt I had to persuade her to keep going, to survive this time because it would — I promised, I prayed, I couldn't quite imagine how — get better. Plus, I alone was navigating the health care system, communicating with her providers, receiving the midnight phone calls with yet another staff member on the line reporting my kid had made yet another attempt at suicide. As much as my family and friends cared, it was my body holding the constant grief and worry, supporting my other two kids in their normal daily needs plus the extra stress of their sister's crisis while trying to keep my household running, let alone keeping up at work to keep the roof over our heads.

So when well-intentioned friends would ask, "How are you taking care of yourself?" I felt furious. What does that even mean? Can't you imagine just how much I am taking care of right now? Do you think a bubble bath or massage would help when my daughter is on the brink of life and death? If I am still standing, if I am going to work, if I am eating and sleeping, if I am not abusing alcohol or drugs to deal with this stress — isn't that enough?

"What do you need?" felt equally challenging to answer. My instinctive response: "I need my daughter to live." That was what felt true. And yes, I appreciated help with meals or laundry or other tasks, but when your nervous system is set on constant alert, trying to answer a question about mundane needs honestly just feels baffling.



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My daughter is now 19. She graduated high school. She is enrolled in university part time and has a job she loves. She has good friends and several pets and is a talented artist. In addition to her original diagnoses of chronic illness, depression, and anxiety, she has been diagnosed with epileptic and nonepileptic seizures and bipolar depression with psychotic symptoms. In the past eight years, she hasn't gone a few months in a row without a hospitalization or debilitating challenges. We are in constant consultation about medications and symptoms. Indeed, it's been an incredibly rocky road for her.

And from all of my years in this position of what I call "extreme parenting," I have learned much about my own coping strategies. I know I have physiological and emotional "armor" that allows me to stay calm in a crisis and manage the challenges at hand as well as any triage nurse. I know to alert my inner group of friends about what's happening, so they can be on call to support me and my other kids as necessary. I've gotten better at asking for and accepting help from friends and community members. I have determined the most helpful tasks or gift cards we can use when we're in the hospital or when I'm on 24-hour safety watch, and I know when to designate one or two friends to field those questions for me from other folks in my community who want to know how they can help. I know fresh air and walks and nature are always healing for my nervous system, even in small doses. I know when the crisis ends, I will experience a wave of exhaustion and emotion that can last up to a week, and I have found a somatic therapist whose practice helps me heal my nervous system from the constant hypervigilance of having a kid who has these life-threatening and unpredictable conditions.

And now that I have these strategies in place, I feel less aggravated at the well-meaning questions folks ask about self-care. I focus on gratitude for the good care we receive from friends, family, colleagues, and community. I also really appreciate when friends offer something specific, because I know they've thought about what they are able and willing to provide: "I'm stopping at Trader Joe's. Want me to drop anything off?" or "I'm free this weekend and would be happy to give you a break at the hospital for a few hours." When I'm exhausted or stressed, I can say yes or no to those specific offers more easily than trying to answer a general question like, "What do you need?"



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I am quite open about our family's experiences (my two sons have also experienced significant depression and anxiety). My daughter has spoken publicly about her experiences with mental illness, and I facilitate workshops on supporting kids with mental health challenges. This too is a form of self-care: receiving and offering support from and to others in similar circumstances. We have both found communities of support and connection that have been vital for us. I have joined Facebook groups for parents of kids with the specific illnesses she faces, and I have created a network of friends and acquaintances near and far who know what it's like to have a kid with extreme physical or mental health challenges. For me, being able to share support, resources, or just a few words of true "I get it" empathy with other parents is a direct way to turn our suffering into a blessing of connection.

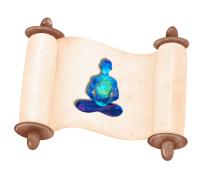
As much as I've learned, though, I still question the timing and use of the term "self-care." Caregiving through a short-term crisis or providing long-term care to a loved one is often an isolating experience. The question or expectation of "self-care" at precisely that time feels like an added burden, investigation, or judgment lobbed at us during the moments in our lives when we actually need the most communal care. Instead of asking a friend or relative what they are doing for self-care, consider offering a specific helpful act, whether it's providing goods or time on the phone or in person or a task you can help them with. Or validate how many things your loved one is doing well, despite the challenges, and ask what they are worried might be falling through the cracks. In a quieter moment, ask what they are learning about the type of care they are providing and how it feels physically, emotionally, or spiritually.

As someone who has experienced the extreme stress of critical and long-term care-giving to a loved one, I understand intrinsically I have to take care of myself as much as I'm able to in order to take care of my child. But having family, friends, and a community who are willing to show up in so many forms and remind me I'm not alone — that is a true gift of care.





What Does Judaism Say about the Soul?



The soul, or neshamah in Jewish thought, is the self, the "I" that inhabits the body and acts through it. There are many words for the soul in Hebrew, but the most commonly used are nefesh and neshamah — both of which mean "breath." - Rabbi Yanki Tauber

God formed the human from the soil's humus, blowing into their nostrils the breath of life: The human became a living being. (Genesis 2:7)

In this final section, we bring together the concrete information presented in the previous sections while going deeper. The word neshamah means "breath." This act is not only essential to life but also to us maintaining our connection with our mental health. The act of breathing is at the core of just about every aspect of maintaining our mental health. It is the way we connect with our body, in order to notice what is going on with us internally, so we can assess what we need. It is the primary aspect of our emotional experience we can control.

This section seeks out the gaps. Now that you have practical information and a sense of what "to do," what is missing? When you take a step back and look at yourself, your child, and your family, what do you still need? As stated in the beginning of this section, being this type of caregiver requires an immense store of mental, physical, and emotional energy. Where does it come from? How do you replenish it? And where, or to whom, can you turn when you just don't have it? Finding ways to nourish and maintain the spiritual parts of ourselves can help to hold the rest together.





What is well-being anyway????

Well-being is one of those terms that have many vague definitions, which actually leads to a lack of true understanding of what it means. According to Psychology Today, it is the experience of health, happiness, and prosperity. It includes having good mental health, high life satisfaction, a sense of meaning or purpose, and the ability to manage stress.(1) Online and in other media, one can find countless articles, surveys, and experts telling us how to achieve it — by purchasing things, changing our diet, activity, medical status, relationship status, job, you name it. There have been hundreds of studies (likely more) that have come up with different ways to measure it and then share the "data."(2)(3) For our purposes, I think it makes the most sense to make your own working definition of what YOUR well-being currently looks like and what direction you would like to go in — knowing there are some aspects of your life you feel you can control and others you can't. Start by asking yourself the following questions:

- On a scale of 1-20, how am I feeling mentally, physically?
- Are my social needs being met?
 - Do I have the energy/time to make that a priority?
- Can I find satisfaction in my daily activities?
- Do I feel confident in my ability to complete tasks?
- What makes me feel happy? Connected? Fulfilled?
- Am I spending enough time doing things that interest me?
- Can I ask for help when I need it?
 Set expectations in my relationships?
- What else matters to me?
- (insert your own questions here)



⁽¹⁾ What is well-being?

⁽²⁾ What is well-being?

^{(3) &}lt;u>Definition, Types, & Psychology - The Berkeley Well-Being Institute</u>





What is Self-Care(4)

The National Institute of Mental Health (NIMH) defines self-care as "taking the time to do things that help you live well and improve both your physical and mental health."(5) How we do this looks different for everyone. For most of us, it's more than manicures and bubble baths.

Self-care is preventative and interventional. If you regularly take time to practice it, you're acting to prevent stress. If you have a high stress level, it's important to begin self-care practices as intervention.



Intention

If you don't know where to begin, ask yourself this: "If I had free time with zero obligations for a day, what would I do? How would I spend my time?"

Everyone is going to have a different answer. The key is to be intentional about how you spend your time. You choose to do something because of how it makes you feel. Recognizing the effect of the experience, and knowing the feeling came from your self-care practice, solidifies the intention and sets you up for success.





Time

A little self-care is better than none at all. Starting small will create momentum that results in progress. It may mean taking just ten minutes a day to begin creating your self-care practice. It can be hard to find the time. Life is busy, and individuals are pulled in a hundred ways. The key here is to make the time and change your mindset to include self-care in your daily (or weekly) routine. When you use time and intention in your self-care practice, you'll find your mind will be clearer, and you'll feel more relaxed and re-energized.

As your self-care practice deepens and becomes more routine, the next step is to encourage others in your community to create their own self-care practices. By helping them make positive changes in their lives, you can make a real impact on the world. That's what tikkun olam is all about, and there is no better feeling.

Find REAL Self-Care

We need different types of self-care as we respond to the world around us. We can think of self-care in different ways to help it feel more approachable.

Reactive vs. Proactive

As you think about caring for yourself, consider how you might support yourself in these different scenarios:

- What do you do after a stressful experience or in a time of crisis?
 - This is reactive self-care what we do in the moment to help ourselves feel grounded, re-regulate our bodies, and be able to continue on with the tasks ahead.
- What are you doing long term, on a daily, weekly or monthly basis?
 - This is proactive self-care the habits we are building to care for ourselves, so we have the bandwidth to navigate the daily challenges of life and the more stressful moments.





It helps to distinguish between reactive and proactive self-care. You might do very similar things in these scenarios, because you have found something that really works for you. Your reactive care might be something you can engage in quickly and get back to the day ahead of you. Your proactive care might require more scheduling — time you've set aside to connect with others, move your body, engage your brain. This distinction might not resonate with you, however, and that's OK!

Wellness Dimensions (6)

Society often refers to self-care as a "one-stop shop" — the one thing you can do to make yourself feel better. But in reality, we are complex beings with different needs. As we navigate challenging situations, we might need different support based on the situation at hand. The Wellness Initiative through SAMHSA breaks wellness down into eight dimensions.(7)

- 1. Emotional: Coping effectively with life and creating satisfying relationships
- 2. **Environmental**: Enjoying good health by occupying pleasant, stimulating environments that support well-being
- 3. Financial: Satisfaction with current and future financial situations
- 4. Intellectual: Recognizing creative abilities and finding ways to expand knowledge and skills
- 5. Occupational: Personal satisfaction and enrichment from one's work
- 6. Physical: Recognizing the need for physical activity, healthy foods, and sleep
- 7. Social: Developing a sense of connection and belonging; and having a [good] support system
- 8. Spiritual: Expanding one's sense of purpose and meaning in life

As a caregiver, we are often so in tune to the needs of those around us. These wellness dimensions invite us to tune into our own needs. These dimensions can be a great tool to help us better identify what would be supportive for us. If you are struggling spiritually, you might reach out to a religious leader or attend services. If you are struggling emotionally, you might connect with friends or a mental health professional.



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These different approaches and tactics to engaging in self-care might feel really helpful for you. We would be remiss, though, if we didn't acknowledge just how hard it can be to engage in self-care practices. There are real barriers despite our best efforts. As caregivers, we do not always have time and energy to dedicate to ourselves. It can feel selfish to prioritize something for yourself.

During airplane safety instructions as the plane is getting ready for takeoff, the flight attendant says to put your oxygen mask on before assisting anyone around you in the event pressure changes in the cabin. If you don't have enough oxygen to stay alert, you cannot help those around you. Self-care can be an oxygen mask as we navigate crises and daily life.

Caring for ourselves does not have to look the same every day. Some days it may be a small moment, while other days we have more bandwidth to do something that rejuvenates us. It can be challenging to find the energy to care as deeply for ourselves as we do for those around us. As you navigate this day in and day out, offer yourself the same patience you would offer those around you.

Find Your People

While it may seem like common sense, it is still worth saying: We all need our village, and different people provide different kinds of support. You need your professional team but also your family and friends — the one you call in the middle of the night, the one to come stay at your house when you need a break, the one who will listen when you need to vent and anything in between.







It can be very easy to isolate yourself when your child is struggling. For many of us, being with other people takes energy, and it may seem like there is little to spare. Others isolate because of a sense of fear, guilt, and/or shame. We would like to really encourage you to fight this urge to hide what is "wrong" in your family and reach out — both to people you have existing relationships with as well as other caregivers who have navigated similar experiences to yours. Most higher level of care (IOP, PHP, inpatient or residential) treatment facilities have parent support groups, and parents can find online resources to connect with each other. While that type of support is not a substitute for clinical expertise, it is so powerful to get that kind of validation.

Getting Started with Self-Care(8)

The following is not a fully encompassing list of self-care practices but rather some suggestions for starting off. Always begin with time and intention. As a caregiver, we might not have a lot of time to dedicate to ourselves, so think about the small things you can do. Small actions add up over time and create a great impact.

Connection

- Reach out to someone to share the positive things happening in your life.
- Reach out to someone when you need support.
- Make plans with friends or family to feel connected to someone you care about.
- Attend a community event to feel connected to the greater community.

Get organized

- Create an achievable to-do list each day that will help you feel accomplished and not overwhelmed or lost. Keep it simple and realistic.
- Plan your meals for the week to reduce stress around what you're going to eat and to ensure you're eating a healthy diet. Consider asking for help with meals if you need it.
- Say no. If you're swamped or don't want to go to something, then don't. You have limited time each day and week. It's OK to say no.





Move Your Body

- Open your mind, and increase your health through physical activity. Set aside even five minutes to move your body.
- Go on a walk with a loved one.
- Visit a local park for a picnic.

Reflect

- Write in a journal. This will help you reflect on how you are spending your time and what is happening in your day.
- Compose a list of the most important things and people in your life. Reference this list weekly to remind yourself to spend time on these things or with these people.
- Watch YouTube videos, read books, or research the topic of mindfulness.
- Challenge your mind with Sudoku or other brain puzzles.

Relax

- Meditate.
- Get adequate sleep.
- Try cooking or baking.
- Find a creative outlet. Try coloring, listening to music, writing, reading.

This S*^t is Hard - So Try Not to Take Yourself too Seriously

Doing this work, taking care of a child with mental illness, is a thankless job. It is unpredictable, drains energy and often does not make logical sense. It can be easy to get caught up in the moment, feel overwhelmed, and not know the way out or how to move forward. Humor can be a reminder to take a step back and find what matters in the moment. Laughter gets the air moving in our bodies and gets feel-good chemicals moving.





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Humor has long been a part of Jewish culture; officially since the 19th century, but likely has been with us all along. There are many theories and opinions about what "Jewish" humor is and where it came from. For our purposes, we can look at it as a tried-and-true coping strategy, combining humility, intellect, resilience, and creativity. From a mental-health perspective, it can be an effective strategy to help reconcile things in our lives that are out of our control or do not make sense. Cognitive dissonance happens when we are unable to reconcile contradictory information. This leads to mental discomfort and anxiety. Humor is a way to remind ourselves things will not always add up, and we are capable of stepping back and moving ahead. It also helps us experience conflicting emotions in a safer way. And perhaps most important, humor can communicate things that are difficult to say otherwise and create connections between people who care about each other.

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"Inevitably, in our lifetime, we will face countless moments so frustrating and so confusing that we will be unsure whether to laugh or cry. Jewish tradition suggests we do both, preferably at the same time."(9)

Tamar Bendror

Humor can be a very powerful coping tool, both for an individual and the family. It can be helpful to give a mental illness a name, e.g., "that annoying guy ED (my eating disorder)," as a way to separate the problem from the person and to take the pressure off when things are intense and words and actions may be taken personally. As a family, find the rhythm and boundaries around the humor that works and doesn't work for you.







Gratitude

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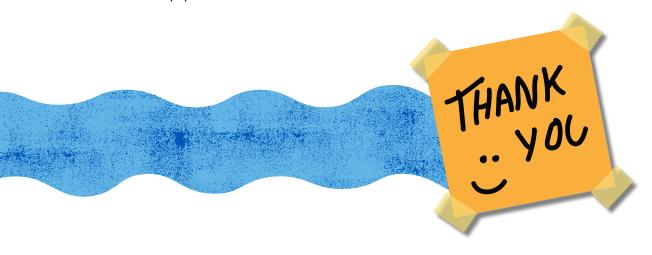
Feeling gratitude and not expressing it is like wrapping a present and not giving it.

- William Arthur Ward

Gratitude is more than just a feeling; it is the way we express our appreciation. This feeling is magnified with intention and awareness. Hakarat hatov, the Hebrew phrase for gratitude, translates to "recognizing the good." The active nature of gratitude can be a powerful way to feed our soul and engage in self-care.

Research finds that practicing gratitude helps people feel more positive emotions, relish in good experiences, improve their physical and mental health, enhance their ability to deal with adversity, and develop stronger relationships. When we practice gratitude, we strengthen our mindset to engage more easily in joy.(10)

Joy comes from adding something pleasurable or removing something uncomfortable. The feeling of Joy is the release of dopamine, the chemical that allows you to experience pleasure. It helps regulate movement, attention, learning, and emotional responses. It also enables us not only to see rewards but to take action to move toward them.(11)







How can you incorporate gratitude into your daily life? There isn't one way to practice gratitude. It can vary from engaging with others to individual practice. Here are some places you could start:

- Share your gratitude with others: Tell someone in person, write a letter, pick up the phone and call.
- Write your gratitude down: Journal daily, weekly, monthly. Write about the big and/or small things you are grateful for or the things that feel challenging.
- Quiet time: Spend a quiet moment with yourself. Meditate to reflect on your day or think about what is to come.
- Connect your mind and body: Engage in the five senses activity from the "Body" section.
- Ignite your creative side: Draw, paint, write, dance, or do anything else that allows you to get your creative juices flowing.

Using "SMART goals" to engage in gratitude

SMART goals allow us to think about how we can actuate our goals by making them specific, measurable, attainable, relevant, and time-bound. The way we choose to practice gratitude may change depending on our circumstances. For example, if we have had a long day talking to medical and mental health professionals, we may not want to pick up the phone to call our friend like we normally do. That is OK. Think about the type of gratitude you need on a particular day. Here is a SMART goal template you can use:

Specific: My goal is to,,, (week, month, etc.)	times per
Measurable: I will measure my progress by	
Attainable: I will	to build in time for this practice.
Relevant: This goal is realistic for me right now because	·
Time-bound: I will evaluate in (# of days, weeks, etc.) to s	ee if this goal is still working for me.





Routines are Routine...Until They're Not

It would be challenging, if not impossible, to fully encapsulate the laws and regulations of the Shabbat experience for the diversity of this publication's intended audience. Between the various denominations, each with different definitions of Jewish legal texts and terms, and different methods of interpretation and application. Generally speaking, if there is a life-threatening emergency or even the chance of a life-threatening emergency, you do what needs to be done to get the help you or your loved one needs. The Torah teaches, "That a person shall perform in order to live by them." (Leviticus 18:5) 15th-century scholar from Safed, Rabbi Josef Karo wrote:

"For someone who has a dangerous illness, it is a commandment to break Shabbat for him. One who hurries to do this is praised. One who [hesitates and] asks [a question about the permissibility of an action] is a murderer. (Shulchan Arukh, Orach Chayim, 328)

Maimonides also wrote: Shabbat prohibitions are suspended in the case of a danger to life, the same as other mitzvot. Therefore, we may perform anything necessary for a sick person whose life is in danger, as determined by a doctor. If there is a doubt as to whether Shabbat must be violated for a sick person, it should be violated, because Shabbat laws are suspended even in a doubtful case of danger to human life. This is also the case when one doctor says to violate Shabbat and another doctor says that doing so is unnecessary. (12)



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Depending on your denominational affiliation, there may be more detailed questions you'll have about Shabbat or holiday observance in your hospital setting. It is best to contact your hospital chaplain or the synagogue nearest you to ask what you need to know to support your Shabbat practice. Regardless of affiliation or denomination, one thing is pretty certain: the Shabbat experience is going to be hard no matter what.

Routines keep us grounded. They keep us moving, give us purpose and give us direction. For Jews, Shabbat practices provide observers with a sense of routine and regularity; the day is an immovable anchor in an otherwise unstoppable world. "Six days a week, we wrestle with the world, wringing profit from the earth; on the Sabbath, we especially care for the seed of eternity planted in the soul. The world has our hands, but our soul belongs to Someone Else. Six days a week, we seek to dominate the world; on the seventh day, we try to dominate the self." More poignantly, early twentieth-century Hebrew essayist Ahad Ha'am wrote, "More than Jews have kept Shabbat, Shabbat has kept the Jews." But when you or a loved one is hospitalized or you're a caregiver, that anchor begins to disappear. And a day or holiday usually spent with family and community can be isolating and deeply disheartening when observed alone.









Shabbat is Waiting for You

By Max Hollander

When my father was sick, I spent almost every Shabbat and holiday in the hospital. On days that would otherwise have been spent in a brightly lit synagogue among friends and community, I was sitting in a dark hospital room greeting nurses coming in and out. Instead of listening to the melodies of a prayer service, I listened to the beeping of hospital equipment and the shuffle of emergency room personnel. This went on for months. At one point, I was spending more time away from my community than I was being a part of it, and I felt my connection to my religious practice eroding.



I was still adhering to most of my religious practices — praying three times a day and studying Torah when I had the chance — but I was doing it on an irregular schedule and I was doing it alone. Similarly on Shabbat and Jewish holidays, I adhered to the religious norms of traditional orthodox observance I am accustomed to, despite often having to change the way Shabbat looked for me when medical needs came up. To be clear, I don't regret anything I did or any changes I made to my religious practice. Still, that doesn't change the fact that I'd had a major part of my life, in a sense, taken away from me. But strangely, I hadn't realized that I'd lost it until it was almost gone.

As the months dragged on, and my father's medical situation worsened, he needed me more and more. I visited my father countless times on Fridays and had to call my wife to let her know I'd probably be in the hospital for Shabbat because his condition had suddenly taken a turn for the worse, and wouldn't be coming home to be with her and our baby. But with each passing week, something inside me began to hurt. I thought it was just the experience of caring for my dying father, but one Passover morning, I sat down to pray *shacharit*, the Jewish morning prayer service, and I looked down at my *siddur* and began to tear up, barely recognizing the book I was holding. I had been using it every day but not with any intentionality or regularity, and all those months of distance between me and my regular practice finally set in, leaving me feeling adrift and alone.





It reminded me of a story told by the Ba'al Shem Tov, a 17th-century mystic:

A King had an only son, the apple of his eye. The King wanted his son to master different fields of knowledge and to experience various cultures, so he sent him to a far-off country, supplied with a generous quantity of silver and gold. Far away from home, the son squandered all the money until he was left completely destitute. In his distress he resolved to return to his father's house and after much difficulty, he managed to arrive at the gate of the courtyard to his father's palace.

In the passage of time, he had actually forgotten the language of his native country, and he was unable to identify himself to the guards...

In the parable, the prince is sent on a mission that doesn't go as planned, and he subsequently loses himself in the new life he is forced to make for himself. Regardless, the story ends with the King (God, Jewish tradition, his foundational beliefs) hearing the prince's cries, running past the guards, and welcoming him back home.

I had that epiphany about the status of my relationship with my religious practice in April before my father passed in June of that year. But even after identifying what had been pulling at my subconscious for so long, I didn't and couldn't change anything about my practice.

Since he passed, I've been able to reacclimate to the life I once had. I've learned the Judaism and life I'd stepped away from weren't gone; they were just waiting for me to return. And they will be waiting for you, too.



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When our routines and rituals are shaken, situations that are challenging already can become so much more difficult. Be kind to yourself if you have to make adjustments unexpectedly to support your child. Think about who you can turn to when you feel overwhelmed by these changes, even if they are short term. Know that even in the most difficult moments, you are not alone.

