Because You Care

Guidance to help you avoid the Black Hole of Caregiving



Kristine Oller

Hello.

I'm delighted you are giving yourself a moment right now – and I'm honored that you are spending that moment with me. Everyone's time and energy is valuable, but caregiver to caregiver, I know how precious your time and energy is, so I promise that whenever I share something with you – in this download, on Instagram, via email, I promise that what I offer will be brief and clear and worthy of your attention.

Today I'm sharing with you the most important perspective shift that I want every caregiver to know about and, I hope, to embrace. This discovery gave me the ability to sustain my caregiving for over a decade. Learning and making this shift enabled me to stay connected to my self, my life, and my goals, while caregiving for my loved one. And it's a shift that will help you minimize the two most damaging elements that chip away at a caregiver's soul: resentment and exhaustion.

My goal as a coach is to help you remain connected – as much as is possible – to your self, to your life, and to your goals while you give care. But who am I and why listen to me?

Well, I'm **not** Florence Nightingale. I'm Kristine Oller and about ten years ago I became a caregiver for my only sibling, my younger sister who has been ill all of her life and who has suffered for over two decades – starting in her 20's – with intense chronic pain from a few debilitating illnesses that produce a complex network of symptoms which have left her disabled.

I adore my sister, but I was a reluctant care giver for awhile because caregiving was not at all part of my Grand Life Plan. Had this situation not happened with my ***sister*** I think I honestly, at that time, would have done anything to avoid caregiving. My white, able-bodied, neurotypical, cisgendered privilege had allowed me to focus on cultivating my independence which, to me at that time, definitely meant not having anyone dependent on me.

But my sister is also genuinely one of my best friends, and my business consigliere, and my comedic partner and my confidant, so I couldn't **not** care for her. And I knew she would do the same for me were the situation reversed. But I was resistant and unprepared *and* unwilling to give my own life up and allow it to be swallowed by caregiving.

My mind, you see, went immediately to the old cultural paradigm, where a person is described as giving their life over to caregiving – sacrificing everything, selflessly, for the person in need. Or the other old cultural paradigm where you are encouraged to embrace the illusion that somehow you are putting your life on hold during this caregiving experience. No, no, that is a ridiculous notion. This is still your life. All these days when you are giving care, **are** the days of **your** life. There are no extra years that get added to your life once your caregiving comes to an end.

But I didn't want my life to be consumed by caregiving, and financially I couldn't afford to be in that position, I had to work and I am fortunate enough to love my work, so I realized that, for my situation to be at all sustainable over a long-term, I had to figure out a more **modern** approach to caregiving – I had to figure out

how to integrate caregiving for my sister into my life.

Caregiving started for me at the beginning of my 40's and, as I record this, I am weeks away from my 50th birthday. It's been ten of the longest, most excruciating years of my life and I'm still in it, I'm still caring for her. I am here talking with you today not just because I have learned so much from my own experience, but because I'm a person with a background that is particularly useful in the context of caregiving.

I have a unique combination of skills, strengths and experience: I was a professional organizer for seventeen years and I've been a life coach and career strategist for over twenty years… I've worked intimately with clients who were also giving care – some to spouses, some to parents, some to their children – and I've worked with clients who needed care or were receiving care, both in short-term and long-term situations.

I have seen the nuances of caregiving from several different perspectives and I have learned how to become a better caregiver myself – all of that has enabled me to truly wrap my brain around the type of support and guidance that people who are giving care in this modern era need in order to be able to **do** it without loosing themselves **in** it.

With the strains that the global pandemic has put on our already inadequate insurance and healthcare system, the need for friends and family members to integrate caregiving into their lives is only going to increase. I created You First to use my strengths to help strengthen the caregiving community so that we can better support our loved ones without burning ourselves out… and while continuing to keep our own goals and dreams firmly in focus.

Speaking of burnout, as I'm sure you already know, it isn't simply remedied by taking a bath, or taking a walk, or getting a massage or meditating. When I was a newbie caregiver in the thick of all and experiencing my first-ever anxiety attack I was like WHO HAS TIME FOR ALL OF THAT? The concept of "putting my oxygen mask on first" was logical – you get it, I get it – but that was so difficult to do when my schedule had to squeeze in 15 extra unpaid hours each week on top of a full-time job to prepare food from scratch for another experimental diet in another attempt to find something that could help improve my sister's life.

Yeah. Been there. **And that's why, as a coach to caregivers, I am focused on the self-care you can do inside your mind.** The self-care of shifting your perspectives, choosing different stories, changing the tone you use to talk to yourself, and plugging your mental energy leaks. This is the kind of incredibly potent self-care you can do *while* you are doing laundry, or in the waiting room at a doctor's office, or cleaning medical equipment.

Today, as I said, I'm sharing with you the most important perspective shift that I want every caregiver to know about. This shift gives you a whole new awareness of and approach to your **multiple** roles within the caregiving process.

If you are giving care in any way to any one, you are labeled a "caregiver." But within the caregiving process there are actually four distinct roles – and, for you, care **giver** may not even be the most important one.

Let me explain. First I'll list each of the roles and then I'll dive a bit deeper into each of them.

Role number one is **your relationship(s)** to the person needing care. Perhaps you are their child, or their

partner, or their step-parent. In my caregiving situation, I have two relationship roles: I am her sister and her friend.

Role number two is the care **coordinator**. This is the person in charge of the management and organization of the logistics, details, and people involved with your loved one's care.

Role number three is the care **giver**. This applies to anyone who is doing any type of physical action involved with providing care – anything from delivering a casserole once a month or assisting with a daily shower.

And role number four is the care **benefactor**. This is someone who is providing some sort of monetary contribution towards the care.

You likely have two or more of these roles right now.

It is vital for you to know about these four roles because this knowledge, if learned early in the caregiving situation, can prevent you from falling into what I call the Black Hole of Caregiving – or, if you've already tumbled into the Black Hole of Caregiving (as I had), this is the knowledge that helps you get out of it and into a more sustainable situation.

Falling into the Black Hole of Caregiving is, unfortunately, easy and natural – it is so not your fault. Whether your caregiving situation started abruptly or whether you gradually became more and more of a caregiver (as I did), either way, you can find yourself, eventually, elbows-deep in doing, doing, doing all of what is necessary to help this person through their crisis or help them try to heal, or help them rearrange their life to cope with something that's not going away, or help them through the dying process.

In the span of one weekend, my client Sofia, was sucked into the Black Hole of Caregiving very suddenly – as if a trap door just opened up beneath her and in she went. After her mother's stroke, she immediately moved west to become her mom's primary source of care and her to-do list is endless – including repairs and modifications to her mother's home – and her relationships with her parents and two older siblings are combustible, at best. Although she is committed to being, in her words, "a good daughter," she also wants and needs to keep her entrepreneurial and artistic work alive and progressing.

The most important part of the coaching Sophia and I did together was about transitioning her from running a sprint to running a marathon. For eight intense months, Sophia had proven herself to be a powerful sprinter, so powerful, in fact, that she was able to keep adding laps… I just need to keep going until we finish the bathroom stuff… I just need to get my mom through her next round of physical therapy… I just need to hold it together until after her birthday. Getting Sofia out of the Black Hole of Caregiving required adjusting her pace. Adjusting her pace was less about adjusting her to-do list and much more about adjusting her mind.

I fully understand the powerful gravitational pull that keeps you doing, doing, doing inside of the Black Hole of Caregiving, but the strength of that gravitational pull is made up of the stories you are telling yourself. To get out of that hole, you've got to question your stories. Sophia and I spent some time unpacking what being a "good daughter" meant – to her, to her family, within her culture. We discussed the pressures and expectations *she* was putting on *herself* and we identified ways in which she could take some steps back without truly compromising her mother's care.

If your circumstances have changed dramatically (or you know they are about to), why in the world would you

expect that you and your household could or should continue to function in "business as usual" mode? The rules that you or your family have around what's possible, or proper, or expected may no longer apply. I respect that you value your work ethic and you are still able to fit mowing the lawn and trimming the weeds into your schedule, but **sustaining** your mental and physical health throughout this marathon requires adjusting your priorities.

That's a larger conversation than we can have right now, but learning about these four distinct roles in the caregiving process will help you keep burnout at bay. Let's take a closer look at each role:

Role number one, your relationship to the person needing care, is quite often your most important role – especially if it's a role that no one else can fill for this person. I am my sister's only sibling. I am the only person who has had that type of relationship with her. I am also, genuinely her friend. And, unfortunately, all of her other friends basically abandoned her, which seems to be a common experience for folks who get very ill as she did in her 20's, so I am the only person who has had that friendship type of relationship with her over the past two decades.

I'm going to circle back and talk more about this relationship role, after we look at the other three roles.

Role number two is the care coordinator. This is the person in charge of the management and organization of all of the logistics, details, and people involved with your loved one's care. Sometimes, the person receiving the care is able to be their own care coordinator. In my situation, my sister and I were co-coordinators of her care. Other folks in the care coordinator role are managing EVERYTHING for their loved one. If that's you, it's important to realize that this ***is*** a role you are actually filling and it's likely that, because of your proximity or your knowledge, you are the best person to fill this role. Other people can also be their care givers, but there may not be anyone else who can fill the relationship role that you have with them or fill the care coordinator role for them.

You might **also** be one of their care givers – I'm a care giver for my sister, too – but, if you are also in the care coordinator role, getting yourself out of the Black Hole of Caregiving, requires that you start dedicating enough time each week (maybe just thirty minutes or so) to having a little care coordinator meeting with yourself. You need dedicated time where you step away from being down in the daily details as a care giver and pull yourself up to where you can see the Big Picture perspective – up where you can make some plans as the care coordinator.

At this care coordinator meeting with yourself there are three main questions to ask – and too often folks forget to ask the second and third ones.

The **first** question is: *"What does the person I am caring for need this week?"*

The **second** question is: *"What do I need this week?"*

That's right. You. What do you need in order to sustain your ability to provide your loved one with what they need?

That's right – sometimes the outside assistance needed is the type that can take things off of ***your*** plate, so that you can care for your loved one *while* also staying connected to your self and your life and your goals. A service that takes the weekly laundry off your hands to give you two hours to spend on something related to

your life or livelihood may be a very wise investment. In these new, not-business-as-usual circumstances, the fact that you are **capable** of doing the laundry is not the only factor you should include in your decision making process around whether or not you **should** be doing the laundry. And getting help to sustain yourself is a completely legitimate, healthy, and wise use of available caregiving funds.

There are two people that need to make it through this caregiving journey – the person you are caring for AND YOU. It can be so difficult to come to terms with the fact that we really don't have control of how things will eventually resolve for the person we are caring for, but what we **do** have much more influence over is making sure that, once this chapter in our life has come to a close, we are in a place – especially physically and financially where we do not, prematurely, need assistance.

So, at your care coordinator meeting, if the **first** question is: *"What does the person I am caring for need this week?"*

And the **second** question is: *"What do I need this week?"*

The **third** question needs to be: *"Who will be in charge of fulfilling each of these needs?"*

Because the answer doesn't have to automatically be YOU. Delegation is a care coordinator's main tool. And, as with any kind of tool – like a drill or a new printer – it may seem daunting at first, it may take you a minute or two to get comfortable using it, but once you do, it makes your job easier.

The first step in the delegation process is to **re-consider** who – in addition to you or aside from you – who can participate in the roles of care **giver** and/or care **benefactor**.

Role number three, care giver, is someone who is doing physical actions involved with providing care. **Role number four**, care benefactor, is someone who may not want to or may not be able to provide physical care, but who can provide money – even a little. If there is a financial need related to the caregiving situation, ask for and accept the money. As the care coordinator, rather than expending your precious energy trying to get someone to be a care giver because it's what's right or what's fair, instead make a clear and definitive request that they, as a dear friend or family member of this person who now needs financial support, at least become a care benefactor. And, whenever you are dealing with money, it's best to be clear. Get very clear on what they are willing to offer – a one-time contribution? an every-so-often contribution? or a regular, on-going contribution? Maybe they commit to offering a certain amount each month or quarter, or they could pay for one or more specific things like the groceries, or the Netflix subscription or a particular piece of medical equipment.

My client Leo is the eldest of six children and, because he is the closest to his widowed father – both in terms of relationship and location – he has taken on the care coordinator role as his dad gradually requires more and more assistance. As in most families, the dynamics among Leo's siblings are complex – some are living far away, some have families of their own, some have very strong opinions on particular matters, and some don't really want to acknowledge that their Dad's health is likely on the decline. It's so common for someone in Leo's position to conclude that *"ugh, it's just easier to do all the care giving stuff myself so I don't have to deal with my siblings."* I'm not saying that plan won't be somewhat easier in the short-term, but it's not necessarily a sustainable plan for the long-term.

A **better** plan, is the one Leo actually chose – he and I worked together to help him become a more effective

care coordinator. I guided him through strategies about how to conduct planning meetings with his siblings, how to make requests, what to do (and not to do) when someone drops the ball, and, most importantly, how to manage his own expectations and emotions around the fact that his siblings aren't going to do things the same way he would do them ***aaaaaand*** the fact that, despite his best intentions and efforts, in a family as large as this there **will** be times when the poop hits the fan. All of this personal growth was challenging for Leo, but making shifts and adding boundaries gave him back the time and energy he needs to stay connected to him self, his life and his goals **as** he helps his family move through this next chapter.

You might be surprised at how many people are willing to help if they are given clearly defined duties or tasks. More people than you may think will respond well to specific requests and clear directions. Maybe you can find someone who is willing to be the person who picks up all of the prescriptions from the pharmacy. Maybe you can find several people who are each willing to come over for a 5 hour block of time once a month to be in your home so you can have time to yourself elsewhere. Maybe you can find someone willing to keep your freezer stocked with soups.

Now, I realize that, for many people in a caregiving situation, "help" is a loaded word. *"Get some help"* is one of those suggestions that can make you feel defensive or uncomfortable because it's tied to your financial resources, the size of your community, the remoteness of your location, the availability and variety of service providers in your area, and/or the dynamics within your family – among other things. Also, as I record this, we are still in the middle of a pandemic, which has made everything associated with giving care and getting help much more difficult.

Even taking all of those variables into consideration, I still maintain that the majority of caregivers **have** untapped resources within their reach. And those resources have remained untapped because they had not yet taken enough time **away** from their role of care giver to put towards their role of care coordinator.

A care coordinator needs time to coordinate. Time to make plans, time to find people willing to give some care, time to make requests, and time to add those who say "yes" to the team.

Asking for help can feel so uncomfortable, so vulnerable. (Needing help can feel even more uncomfortable and vulnerable.) Even so, keeping resentment and exhaustion to a minimum throughout this chapter of your life will likely require you to endure the discomfort of strengthening your asking muscles AND possibly relaxing your standards. Yes, you care the most so you will likely care the best, but not everything has to be done perfectly. Relaxing your standards can be a powerful form self-care.

I know that when a health crisis hits it's as if ten fires have suddenly spring up around you and all you have is a glass of water. And at first all you can think to do is to dump your water on one of the fires and then refill your glass and then dump it and then refill it as many times as you can. You are responding to what's urgent and right in front of you.

But what I'm encouraging you to do is – as soon as you feel the heat of the flames – to step away and **let the fires burn for a minute** so that you can get the attention of a few firefighters to come and help you put out at least a couple of those fires.

I'm encouraging you to bring in care givers and care benefactors **early**. And I'm saying this emphatically for three significant reasons:

Reason one:
Very few of us are naturally comfortable asking for help and making clear requests, so you are probably going to need some practice to strengthen those muscles and to deal with all of the mindset drama that will likely be stirred up whenever you start to feel uncomfortable. Getting some early practice in on smaller, more minor requests will help prepare you for when you may have to reach out to folks for more major things.

Reason two:
Unless your friends and family have already been in a caregiving situation, most of them are probably not attuned to noticing or thinking about opportunities to give care – but that doesn't necessarily mean that, if asked, they will refuse to participate. Just as you may need to get used to asking for help, they may need to get used to incorporating giving care or providing financial support into their life. And keep in mind that, if your situation worsens, it will be easier to get folks to step up and do **more** if they've already been doing **a little**.

Reason three:
Bringing in care givers and care benefactors early can help the person being cared for soften their edges around accepting care from people other than yourself. And this is especially important if your loved one may eventually need help from others with their more intimate physical needs.

This human you are caring for is in a situation where their life has been upended, they've become (any combination of) vulnerable, dependent, scared, worried and possibly embarrassed because they are loosing a portion of their own agency, identity, and privacy. They are loosing (some degree of) influence over how their days unfold – and that's on top of any loss of mobility, or memory, or any pain they're having to endure. So in the beginning of their care receiving journey, it is understandable if the person being cared for wants to maintain a very small circle of trust, a very small circle of who they want caring for them – especially if physical care is involved. And they may want their circle of direct caregiving to only include YOU – or you and one or two other people.

That size of circle is unsustainable. Yet in the beginning, when all of this is new to you, you're just trying to stay on top of the things that might help make this person's life better so you keep doing and doing and going and going until you burnout. And then you probably do some more beyond that. And by then you've slipped into the Black Hole of Caregiving, where you feel isolated, exhausted and disconnected from your self and your life because **you** do not have enough help to sustain these circumstances – especially over a long-haul.

The person you are caring for may not want "outside help," they may resist it, but please remember that by enlarging their circle of care you are putting them in a much more solid place should something happen to you. And, as awful as it is to contemplate – in the middle of all of this – something could happen to you.

Expanding their circle of care may have to be done gently and gradually which is why I'm suggesting you start early. And still, they might resist or refuse. So part of **your** self-care is to make peace with the fact that your loved one – if they are an autonomous adult – may make some unfortunate decisions that have detrimental consequences for them. Part of **your** self-care is to make peace with the fact that your loved one may reject things that you believe would benefit them. And part of **your** self-care is to remind yourself that it isn't your job to fix them or to save them or to placate them or to protect grown, autonomous adults from the consequences of their choices. I've worked with many clients on coming to terms with the true limits of their influence… on shifting the stories that emerge from their guilt and anxieties… and on staying focused on their core responsibilities: to make sure their loved one is safe and sound and cared for and not harming anybody else.

Now, let's circle back to your most important role – role number one – the **relationship role** (or roles) that you have with the loved one you are caring for… I want to mention one last thing.

In my opinion, the most important reason that you, as a caregiver, must attend to your own self care – mentally, emotionally, and physically – is because, if you do not rejuvenate yourself on a regular basis then you will not have enough bandwidth to fulfill your care giver and/or care coordinator roles **and** your relationship role. If a wrestling match starts between your role as a wife and your role as a care giver, the care giver will win. If you only have enough energy for one role, the care giver role will win. Which means you and your loved one will both miss out on a relationship that each of you need and that only the two of you can fill for one another.

This happened to me for awhile. There was a period of time, when I was in the Black Hole of Caregiving, that I was putting every spare minute and every spare ounce of energy that I had towards the caregiving stuff that I needed to do for my sister. I wasn't reserving any of my time or energy to put towards being her sister or being her friend. Which meant I was ALSO missing out on having the texture of that sister relationship and that friend relationship in MY life as well. Because I hadn't coordinated a support-system and because I was ignoring my self-care, I became a very depleted and slightly resentful Robot Caregiver. I just went through the motions. And we were both miserable. Because even though my sister did need caregiving, she also needed the fun and laughter and affection and gifts and surprises that only a sister and a friend can provide.

I remember checking in with my client Jamie a little over a year after they had begun caregiving for their partner who had received a most unfortunate diagnosis. I sensed immediately that Jamie was in robot caregiver mode – emotionally distant, going through the motions – and, as we started talking, I discovered why. Jamie was protecting themself. They had already been through a lengthy and harrowing caregiving journey with both of their parents and now they were suddenly thrust into what looked to be another long haul. They were furious and grieving and scared and resistant, and being so familiar with caregiving, they just flipped on the auto pilot switch.

One of the things we gently explored was the fact that the experience of caring for a beloved life partner was going to have a very different texture than that of caring for difficult parents – not only because Jamie's general circumstances are simply better this time around but also because this time around they are a totally different person with far more wisdom and resiliency. We also slowed down the spin cycle of scary stories that was constantly going through Jamie's mind. This mindset work allowed them to take off their armor and reconnect with their partner… this mindset work enabled Jamie to keep their focus, more often than not, on the list of things that they both, as loving partners, could still give each other while they were both still here – things that will be missed once one of them has departed: holding hands, taking walks, listening and being listened to.

Your partner may need you to be a care giver but they also need a partner. And so do you. My sister needs me to be a care giver, but she also needs a sister and so do I.

To remedy my own Robot Caregiver situation, I had to start cutting some corners to immediately lessen my care giving load **so that** I could carve out time to put on my care coordinator hat **so that** I could figure out ways to get some help **so that** I could make time for a bit more self care **so that** I could increase my emotional capacity **so that** I felt like spending time with my loved one and do some fun things for us as sisters and as friends.

As rocky as is was for both of us to transition through all of that, we both ultimately benefitted from that time I took – **and** from the time I continue to take – to refill my tanks and renew my emotional bandwidth.

I'm not here as a coach for caregivers because I was the perfect caregiver. I learned so much the hardest ways – but I learned so much. Now that you have this big picture perspective of your multiple roles within the caregiving process I hope that it helps you…

…but here's the thing about guidance. It can sound so tidy. Yet usually what applying guidance and creating new thought patterns looks like and feels like is you having to **drag** your mind over into this new perspective. And then, something happens and your mind freaks out and dives back into the swirl of resentment and exhaustion and frustration, and you have to get up, and go over and kindly yet firmly drag your mind back to the new perspective (again and again) and gently tell yourself the new story (over and over) – the story that calms you down, the story that makes you feel a bit better, the story that enables you to get out of bed and face another day.

And even with all the guidance that's available to you as a caregiver, it can be really difficult to face another day when you are trying to be **your own source** of support and acknowledgement and encouragement. Whether we are sprinting or running a marathon, we humans need **external** sources of support, acknowledgement, and encouragement. We are nurtured when we are witnessed, we are comforted when we are in community, and we are strengthened when we have a strategic plan.

As a modern caregiver, you deserve access to someone whom you can connect to to help you integrate caregiving into your unique circumstances in a healthy and sustainable way. You First is my commitment, as a coach, to helping you learn how to stay connected to your self, to your life, and to your goals while you give care.

All caregiving situations are unique. (As I say: *"You can't compare the care.")* My situation may be easier than what you are facing in some ways and much more difficult than your situation in some ways. Making judgments about caregiving situations is always, always, always comparing apples to oranges.

However, one thing I **do** know about you is that you are here, with me, right now, because you care. You have chosen to say to someone: *"I am putting you first for awhile,"* and that is a remarkable gift you are giving. You are offering part of your life to them so that they do not have to navigate their journey alone. It's a profound offering and one that takes a lot out of you… but there are ways we can make sure that it does not take **all of you** out of you.

If you haven't already, follow me on Instagram – @kristineoller – that's where you can continue to be supported and acknowledged **and** you'll always be the first to learn about opportunities to receive personal coaching from me.

Thank you for being one of the ones who care. I'm wishing you the very best.

An invitation to join You First



If what you've just heard resonates with you, I'd like to invite you to join You First – this is my **group coaching program for caregivers** where you'll have several opportunities each month to coach with me live and you'll be able to listen to recordings of our previous sessions.

Putting yourself in a safe, supportive environment where you can consistently absorb new perspectives and strategies that relate to the specific challenges you, as a caregiver, are dealing with IS THE WAY you can help yourself move through this chapter of your life with as much grace and growth as possible.

The price point for this month-to-month group was chosen to make this kind of unique coaching accessible to you – so I hope you will join You First for a month and see if it helps. You can cancel your membership at anytime.

All of the details are at KristineOller.com/youfirst

About Kristine

As a master coach and strategist, **Kristine Oller** specializes in helping big-hearted achievers who feel confined by the complexity of their current circumstances create new, clear paths towards expansive personal and professional growth. For over two decades, she has been guiding smart, talented adults through ground-breaking chapters of their lives and careers… the big decisions, the tough conversations, the significant shifts, and the inspiring expansions. In addition to her work with private clients, Kristine inhabits two very special corners of the internet:

She is the founder of **You First** where she offers coaching and a community to modern caregivers who wish to stay connected to their life and their goals while they give care.

She is also the creator and coach of the **Creating Cashflow Program** where she guides folks through the process of turning their skills and strengths into income.

There's more info about Kristine and some excellent free guidance for you at:

KristineOller.com/youfirst
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I do not offer professional legal, medical, psychological, or financial advice. But I do bake an amazing chocolate chip cookie (like world-class delicious).