



Photos of Chrissy and DeArthur Johnson by Bart Harris

Caregivers *do far more than* Care

By Laurie Wertich

When Chrissy Johnson’s husband, DeArthur, was diagnosed with stage IV colorectal cancer, she was immediately thrust into the new and unexpected role of caregiver. “Before that I was just his wife,” Chrissy explains. “How do you switch from being a wife to being a caregiver? The title has been given to you without your even requesting it.”

Indeed, Chrissy has joined the ranks of millions of Americans who assume a role they never requested or prepared for. Approximately 65 million (29 percent) American adults have served as unpaid family caregivers (for the ill, elderly, or disabled) in the past 12 months.¹ It’s a full-time job with no application process, no training, and plenty of responsibility. Yet it’s a critical and potentially transformative job—the ultimate act of love and service.

Former First Lady Rosalynn Carter—the inspiration for the Rosalynn Carter Institute for Caregiving—once said, “There are four kinds

of people in this world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers.” In other words, we are all in this together.

Chrissy knows this firsthand. “When my husband and I met, we said, ‘We’re not going to let any person separate us,’” she recalls. “Now we add, ‘nor disease.’”

This determination fuels Chrissy’s energy to serve tirelessly as DeArthur’s caregiver. “I know this is a temporary role,” she says. “Part of my job as a caregiver is to see my husband getting well.”

Caregiving can be an overwhelming juggling act that requires a great deal of adjustment.



WHAT IS A CAREGIVER?

By definition a *caregiver* is anyone helping a loved one navigate a significant illness, such as cancer—but the term doesn't even come close to describing the endless list of roles associated with caregiving. Caregivers are charged with a multitude of tasks. At any given time, a caregiver may do one or all of the following:

- **Patient support.** Provide physical, emotional, and spiritual care for the patient.
- **Medical support.** Manage the disease and navigate the medical system, which may include serving as an advocate for the patient, attending medical appointments, and overseeing paperwork.
- **Life support.** Uphold the ongoing responsibilities associated with daily life, such as grocery shopping, meals, laundry, bill paying, household maintenance, and childcare.
- **Financial support.** Manage the finances, which may include working full-time to maintain income and health insurance.
- **Self-support.** Maintain a self-care routine to manage stress and prevent burnout.

“Caregivers do everything,” explains Michelle Moore, RN, BSN, a care manager at Cancer Treatment Centers of America® (CTCA) in Zion, Illinois. “Their role is endless. They are the note-keepers, the breadwinners, the child-care providers, and so much more.”

The role is all-inclusive and all-important. In fact, Moore insists that caregivers are an integral component

of the team. “It’s a whole,” she says. “Caregiver and patient are one and the same. Both people are going through this.”

While the patient endures the challenges of treatment, the caregiver endures the challenges of juggling a long list of tasks and responsibilities on top of the emotional burden of the cancer. It’s a daunting role—and one that can take a physical and emotional toll.

THE IMPACT OF CAREGIVING

Caregiving can be an overwhelming juggling act that requires a great deal of adjustment. While it can be physically exhausting, it can also test emotional resources, as caregivers may grapple with helplessness, grief, anger, guilt, anxiety, depression, and loneliness—on top of a long list of daily tasks and responsibilities.

“One of the most common things caregivers experience is helplessness,” explains Katherine Puckett, PhD, MS, MSW, LCSW, national director of mind-body medicine at CTCA. “All of a sudden, they’re thrust into this and they don’t know what to do.”

Dr. Puckett suggests that caregivers focus on *being* rather than *doing*. She sees caregiving as a balancing act among three things: being present for the patient, managing practical tasks such as going to doctor appointments, and maintaining an emotional outlet for the stress and the emotions associated with seeing a loved one battling cancer. This emotional outlet could come in the form of counseling, journaling, painting, or whatever helps the caregiver process feelings.

Communication and self-care are critical for navigating the emotional roller coaster of caregiving. “There is a huge need for communication,” Dr. Puckett says. “So often the patient and the caregiver are not communicating because they are afraid of hurting each other’s feelings and neither one wants the other to see them cry.”

Dr. Puckett says that communicating openly and spending time together where the focus is not on cancer can help both patients and caregivers navigate the emotional trauma they are experiencing.

CAREGIVER BURNOUT

Many caregivers develop a sort of superman complex: they want to do it all and do it all by themselves. Ironically, in the midst of doing it all, most caregivers suffer from the fear that they are not doing enough.

“Caregivers face burnout when they feel like they don’t have the right to come first,” Moore explains. “Everything and anything is always about the patient because they don’t want to leave one stone unturned. So, our job is to continually remind them of the consequences if they don’t recognize what they’ve done, how much they’ve done, and that there will need to be downtime.”

CTCA is unique in this approach, providing comprehensive support for caregivers in the form of counseling, massage, reiki, and other mind-body treatments. This caregiver support is critical because a healthy caregiver will be better able to take care of a patient. It’s clichéd for those who fly on airplanes, but true: in case of emergency, secure your own oxygen mask first.

“One of my most important roles is not to let stress take over my life,” Chrissy explains. She knows that taking care of herself allows her to take better care of DeArthur. Chrissy takes at least an hour for herself every night, soaking in the bath and letting the stress and the tension dissolve.

“It’s okay to take care of you,” insists Joanne Ludwig, who served as a caregiver to her friend Wendy Miller when Wendy was diagnosed with stage III colon cancer. “I would strongly encourage caregivers to have massages and reiki treatments.”

CAREGIVING 101:

CRASH COURSE IN CAREGIVING

FOLLOW THE PATIENT’S LEAD. Take your cues from the patient about how much or how little you can be doing to help.

ALLOW THE PATIENT TO DO AS MUCH AS POSSIBLE. Don’t hover. Allow the patient to maintain as much independence as he or she is able.

ASK FOR—AND ACCEPT—HELP. You cannot do it all. Maintain a list of names and numbers of people who can help, including the tasks they can perform.

COMMUNICATE. Be authentic. Maintain two-way communication with the patient, even if it means sharing tears and fears.

FIND HUMOR. Laughter soothes the soul and acts as a release valve for stress.

PRACTICE SELF-CARE. Taking care of yourself enables you to stay healthy and better care for the patient.

GET EMOTIONAL SUPPORT. A counselor or friend can provide an invaluable emotional outlet during this stressful time.

BREATHE. A few deep breaths can have an instant calming effect. Make it a priority to pause and breathe on a regular basis.

CAREGIVING RESOURCES

Family Caregiver Alliance:
caregiver.org

National Family Caregivers Association:
nfcacares.org



Joanne Ludwig
and Wendy Miller

BEING A PATIENT

*Caregiving is a two-way street.
Patients play a role, too.*

► **ASK FOR—AND ACCEPT—HELP.** It's okay to depend on others.

► **USE THE BUDDY SYSTEM FOR APPOINTMENTS.** Always take someone with you to appointments, especially those at which you'll be receiving new information. Two sets of ears are better than one. When we're emotionally involved, it can be hard to keep the facts straight.

► **BE HONEST.** Open communication is critical to a healthy caregiver/patient relationship. Stress levels are high and nerves are frayed. Speak up about what's working and what's not working.

► **LET GO.** Relinquish control where you can. You don't have to do it all. Someone else can mow the lawn or get the groceries. Let go of smaller tasks so that you can focus on what's important: your health and your family.

► **TRUST.** Relinquishing control means placing an immense amount of trust in others.

TEAMWORK

Joanne had significant experience as a caregiver even before she helped care for Wendy; her 22-year-old son has Asperger's syndrome, and she works as both a special needs advocate and a life coach for adults with Asperger's. When Wendy needed a caregiver, Joanne's skill set and flexible schedule made her the perfect candidate for the role.

Joanne and Wendy's was a new and burgeoning friendship. They met through their participation in a spiritual group, and when Wendy was diagnosed with cancer something just clicked. Together Joanne and Wendy learned the nuances of the caregiver/patient relationship—and they both reached the same conclusions:

- The patient needs to relinquish some control and accept help.
- The caregiver needs to follow the lead of the patient.
- There needs to be a team of support because the caregiver cannot do it all alone.

“Let people be who they are,” suggests Wendy. She says that the caregiver really needs to follow the lead of the patient and simply remain observant and know when to step in. She recalls how she stubbornly resisted the need for a wheelchair at the airport—until Joanne insisted one day. “She recognized that sometimes I didn't know my own limits; and when the time came, she didn't ask, she told,” recalls Wendy. And Wendy acquiesced because she trusted Joanne.

That trust was the result of a solid caregiver/patient relationship. Joanne somehow struck the perfect balance between caregiving and allowing for

Wendy's need for independence. “Let the person do as much as they can for as long as they can because they have so little control in their life,” she explains.

Although Joanne was Wendy's primary caregiver, she didn't do it alone; there was a whole team of friends and family providing support, which was critical. Wendy insists that there should be more than one caregiver. “You can't be everything,” she says. “Caregivers need help, too. Keep a list of names and numbers and bring in other people to help.”

PACE YOURSELF

Caregiving is an exhausting, rewarding, and hugely important job. “I think it's important for society to really comprehend that the success and the outcomes of cancer patients are hugely dependent on caregivers,” says Moore.

Caregivers play a vital role in the fight against cancer. It's not easy, which is why the proper support and resources are imperative. “If I could tell caregivers one thing,” says Chrissy, “it would be to pace themselves because this could go on for a long time. You don't know how long you're going to be in the battle, but you have to be ready to fight every day.” **CFThrive**

Reference

1. Caregiving in the US 2009. National Alliance for Caregiving in collaboration with AARP. National Alliance for Caregiving website. Available at: http://immn.org/nac/pdf/research/FINAL_EthnicExSum_formatted_w_toc.pdf. Accessed November 7, 2011.