

# CAREGIVER QUICK START GUIDE

Thank you for requesting a copy of this Caregiver Quick Start Guide. My name is Jim Foster and I have put together this guide to help caregivers of other cancer patients as they begin their cancer journey. This Caregiver Quick Start Guide is based on my two different personal experiences as a Hodgkin lymphoma cancer patient (learn more by visiting the About page at [www.cancerinterviews.com](http://www.cancerinterviews.com) for details). It is my hope that every cancer patient has at least one person to be their caregiver. This guide is dedicated to my loving parents and my beautiful wife Suzanne who were wonderful and amazing caregivers during my two cancer experiences. This guide is not intended to be a guide throughout the entire cancer journey, but rather a quick initial guide to getting started in the right direction. It is my sincere hope that the patient you are supporting and caring for will have a successful cancer outcome and I wish you the strength and patience necessary to be a wonderful caregiver.

*-Thank you – Jim Foster*

## WHAT IS A CAREGIVER?

A caregiver is someone, usually a family member or close friend who can oversee and take care of many, if not most of the tasks that need to happen for a patient during their cancer journey and do so in a way that allows the cancer patient to focus on what they need to, in order to get better and not burden the patient with all of the details including everything from cooking, cleaning, dealing with insurance companies, paying the bills, transportation to and from medical facilities and much more. A caregiver is more than just a hired helper, a caregiver is someone who really cares, deep down, about the well being of the cancer patient. It is very hard, tiring and seemingly endless work that somebody has to do and caregivers are very special people. Not everyone has what it takes to be a caregiver. Do you?

## WHO IS A TRADITIONAL CAREGIVER?

A caregiver could be anyone, but typically this role is filled by a family member or close friend. Sometimes there could be more than one caregiver assisting a patient. For example, during my first cancer journey my mom and dad became my caregivers. Without them, I would not have been able to survive. I am forever grateful for their love and commitment to helping me through a very difficult time. Shortly after I went into remission the first time, I met my wife and got married and then five years after my cancer had initially went into remission, we became expectant parents. That is when my cancer returned. My wife Suzanne, was the most incredible caregiver during my second cancer journey and bone marrow transplant. The amount of work she did for me, while pregnant with our daughter Jessi, is simply hard to imagine. I sincerely hope every cancer patient is fortunate enough to have at least one caregiver, because caregivers are truly the most special people on earth.

## WHAT ARE THE DUTIES OF A CAREGIVER AND RESOURCES THAT CAN HELP?

Based on the severity of cancer and treatment plan, the duties of a caregiver can vary drastically between patients. The following list is an attempt to identify many of the tasks that a cancer patient may need assistance with throughout their cancer journey and some

resources that can help manage the workload. From my experience, I have put together a number of caregiver resources that I hope will help you, the caregivers, to help the patient you are caring for, as you both venture through your personal cancer journey.

- **Scheduling appointments**

There will be lots of appointments for everything from doctor visits to treatments and a myriad of other things. Both times that I was dealing with cancer, my caregivers used paper wall calendars to keep track of my appointments. That worked well for us, but only we had access to the calendar. There was no easy way to spread the word to concerned extended family and friends who wanted to help out in some way. With the changes in technology, software, smart phones and the internet, it is now very easy to have an online caregiver calendar that you can see and you can give certain people different levels of access to your calendar so they can stay informed and volunteer to help out with certain caregiver tasks like driving you to an appointment or cooking a meal. The free service that I recommend the most is a non-profit organization known as Lotsa Helping Hands, which was founded by a caregiver, who had been through the caregiving process when his wife was battling cancer. To learn more, visit [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com) or view the resources page at [www.cancerinterviews.com](http://www.cancerinterviews.com).

- **Transportation to appointments**

During both of my cancer ordeals, I was too ill to drive on my own, so I relied on my caregivers, whom were my mom, dad and the second time, my wife to drive me to and from doctor appointments, treatments and anywhere else that I needed to go. It was a huge burden, as sometimes I would be at a treatment center for hours and they would have to wait or come all the way back later. Again, with the free online caregiver calendar service, Lotsa Helping Hands you can give certain people different levels of access to your calendar so they can stay informed and volunteer to help out with certain caregiver tasks like transportation to appointments.

- **Meal preparation**

Somebody has to do the cooking and meal prep. Often times, as a patient, your appetite can fluctuate greatly in a matter of minutes. What sounded good 5 minutes ago, may not seem pleasing now. It can be very difficult to cook for a cancer patient and they may be hungry at very odd hours, which don't coincide with traditional meal times. You may also be surprised at how many people want to cook a meal, or pick up or deliver food from a restaurant for you. Sometimes more than one person may do so on the same day, resulting in too much food for you and your family and it may not even be something that the patient is hungry for.

By having a caregiver calendar, such as Lotsa Helping Hands, you can enter in food requests for each specific meal on each specific day, if you want and include dietary restrictions and food preferences so that volunteers can commit to a meal

and prepare at least what the patient has requested in advance and you won't have multiple people bringing food for the same meal. There will be many days in which nobody brings in food, but it can reduce the workload for you, the caregiver.

- **House cleaning**

With or without an ill member in the household, house cleaning is an ongoing task that has to be done. When a cancer patient is living in your home it is even more important to keep the house extremely clean, especially the bathrooms and kitchen. In some instances it is required by doctors to live in a "clean environment" but to say the least, you may have to have the heating and cooling ductwork cleaned and use special type of air filters on the heating and cooling systems. The amount of house cleaning will most likely increase from normal daily living prior to having cancer. Again, utilizing a caregiver calendar can allow ready and willing volunteers to help out with these types of tasks.

- **Laundry**

Most likely the amount of laundry will increase for a cancer patient due to the need to keep one's surroundings as germ free as possible. It can be a good idea to wash clothing after each outing to doctor appointments, treatments, clinics and other public places. Laundry can be overwhelming and you might be surprised but there are people that you know that care about you who would probably be willing to volunteer to help with your laundry. There may even be commercial laundry businesses in your area who will pick up your laundry and return with everything professionally cleaned, folded or on hangers.

- **Bathing assistance, if needed**

Based on the physical condition of the patient, assistance with bathing may become necessary. The safety of the patient as well as the caregiver is paramount. It may be as simple as utilizing a shower chair, or installing a non-slip mat in the bottom of the tub or shower. However, it may be much more involved, requiring lifting of the patient, transferring in and out of the bath or shower from a wheelchair, etc. not to mention assistance with the bathing process itself. Most bathrooms are not designed and built to accommodate a patient with these types of needs, however, there are many resources available that can enhance the usability or modify most bathrooms. You may want to consider visiting a medical equipment and supply store near you, if there is one, or visit our resources page at [www.cancerinterviews.com](http://www.cancerinterviews.com) for online businesses that offer these types of products and services.

- **Corresponding with insurance company or governmental program**

Depending on the patient's health insurance coverage or governmental assistance program, there will most likely be a great deal of paperwork, correspondence and interaction with whatever entities are involved. Many of us have never had to deal with this type of work and are instantly involved and often overwhelmed by it. Very often, the patient is too ill, too young or incapable for whatever reason, of taking

on the responsibility of this extremely critical, ongoing workload. In many cases, this process falls in the lap of the caregiver.

- **Paying bills**

Some bills will be covered by insurance or government assistance programs, however, many things may not be covered and billed to the patient. Often, even things that might be covered by insurance are first sent to the patient and then it is the patient's responsibility to submit proper documentation to insurance companies for payment or reimbursement. In addition to medical related bills, the patient's normal bills still have to be paid, such as housing payments, utility bills, possible car payments, other loan payments, clothing and essentials, groceries and normal living costs. Not paying these bills could result in foreclosure, eviction, repossession, reduced credit ratings, etc.

- **Lawn care**

Depending on the type of housing you and the patient may have, there may be a lawn or gardens to care for that can consume both time and energy. IN some cases, you or the patient may be a farmer or rancher and have a substantial amount of agricultural land to maintain. Although this may seem totally unrelated to caring for a cancer patient, in the overall picture it is still work that probably has to be done. Getting help from volunteers to do this type of work can be a big help when your time is stretched so thin as a caregiver.

- **Home maintenance**

This falls into a similar category such as lawn care, laundry or house cleaning, but things around the home do need fixed or repaired from time to time, such as plumbing or electrical issues, or trouble with appliances, windows or doors. In some cases, it may be beneficial to the patient to make some physical modifications to the home to make it more accessible and comfortable for them. Having some help with these types of home maintenance tasks can be a huge help and delegating some of these projects to volunteers is strongly recommended, if possible.

- **Updating friends and family who are calling with questions & well wishes**

Friends and family members will be curious about the condition and progress of the patient. They have the best intentions at heart and want to offer well wishes, but the sheer volume of their calls, emails or personal visits can be totally overwhelming. During my first cancer experience, my parents were my caregivers and they would be on the phone for hours and hours during any given week and I would hear them repeat the same progress reports over and over and over. They became totally burned out, however, each individual who was calling was truly concerned about my condition and they just wanted to share that concern for me and they didn't realize the burden these calls put on my parents.

This was prior to Facebook and many other online communication tools, but now there are some great options to keep everyone up to date and more. A lot of

people use Facebook for this purpose, however, it has some drawbacks including a lack of privacy, unless you create a private page and it doesn't have a great way for you to post a calendar of asks that you could use help with from volunteers.

Again, with the free online caregiver calendar service, Lotsa Helping Hands you can give certain people different levels of access to your calendar so they can stay informed and volunteer to help out with certain caregiver tasks. You can also update everyone in your network that you want to be updated by posting regular updates, posting visitation hours and restrictions and posting requests for help with a variety of daily tasks.

This platform also allows people in the network to post comments and well wishes, avoiding the need for hours of repetitive phone conversations or individual email reading or replies.

- **Earning an income to cover household bills**

Depending on the patient's individual situation, they may or may not be able to work during all or part of their cancer journey. In many cases the caregiver is an immediate family member, living in the same household. Unfortunately, normal living expenses continue, with or without cancer in your life. As a caregiver, you may be torn between providing the care for the patient around the home and the necessity of going to work full or part time to keep up financially.

Depending on where you live, you may be able to take time off to care for a family member, while still being paid during your absence from work. In the United States you may be eligible for the Family and Medical Leave Act (<https://www.dol.gov/general/topic/benefits-leave/fmla>), which is a federal law that guarantees most employees up to 12 weeks of paid leave, without threat of job loss, or losing one's health insurance benefits. Some other countries have similar programs available to families.

Perhaps you or the patient have the type of job where your employer may allow you to work from home, or modify your job description to include duties that could be done from the computer or telephone while in the comfort of your own home. There may also be some online opportunities to do some work from a computer through online websites such as [fiverr.com](https://www.fiverr.com), [upwork.com](https://www.upwork.com) and [freelancer.com](https://www.freelancer.com).

Another great tool to help cover household bills and medical expenses is to create an online fundraising campaign. The online crowdfunding organization that I recommend the most is [GoGetFunding.com](https://www.gofunding.com). They charge a lower administration fee than some of their competitors. This is a free tool to you and the patient that allows you to create a free, simple online webpage with zero technical skills required. You can spread the word to people that you know who may want to make an easy, secure, online financial contribution directly to you.

With the power of the internet, your fundraiser page could spread to people you don't even know who may want to gift you some money through your GoGetFunding.com page to help you during this time of need. This type of online fundraising web page is something that I feel very strongly that every cancer patient and their family should have, to allow people, if they so choose to simply, safely and securely donate funds to help.

- **Taking notes at doctor appointments**

Quite often, one on one time with a doctor can be quite rare and when you are fortunate enough to meet with them in person, the appointment can often be very brief. Doctors are used to speaking a different language of medical terms and words that many of us have never even heard before. It is strongly recommended that you and the patient write down a list of questions ahead of time that both of you would like to get answered by the doctor. Don't be afraid to ask them to explain something in more simple terms, if you don't understand the medical terminology. Most doctors aren't comfortable being recorded electronically via audio or video during appointments, however, they are not opposed to you taking notes about the conversation and writing down answers to your questions.

It is very common that a cancer patient is either too ill, or physically unable or mentally exhausted to clearly communicate and remember what gets said during a doctor appointment. This is one of the most important responsibilities of a caregiver. Getting the facts straight, the questions answered and the recommendations of the doctor and keeping all of that information available for the patient for future reference is best done by taking clear and legible notes.

- **Picking up prescriptions and supplies from the pharmacy**

Depending on the individual treatment plan for a patient, there could be prescriptions and over the counter medical supplies that will need to be purchased and picked up from the pharmacy. As a cancer patient, it is not a good idea to be exposed to a lot of sick people, due to your own weakened immune system. If possible, having someone other than the patient assist with visits to the pharmacy would be wise. Depending on the patient's prescription needs and physical location, there are even online pharmacies that can ship products directly to your home. Some pharmacies offer drive through service where you don't even have to get out of the car, minimizing exposure to germs.

- **Helping remind the patient when to take medication and assisting with dosages, based on the doctor's instructions**

Different treatment plans may require medication to be taken at home and throughout the day. Keeping track of these medications, dosages and times they are to be taken can be quite overwhelming, especially for a cancer patient who may not be feeling well, who may have trouble remembering things due to medications and who may be sleeping a lot at irregular times.

Having a caregiver keep a clear schedule for all of the patient's medications is a huge and important responsibility. Some medications will be in pill form, while others may be shots via a syringe and others may even be intravenous or IV. Some prescriptions may require the patient to be awakened in the middle of the night and at odd hours.

- **Coordinating with in home care professionals such as nurses, physical & occupational therapists, dieticians and nutritionists**

Depending on the patient's treatment plan, some or most of the treatment may be administered on an outpatient basis, at home. In addition to medications, some of the treatment plan may include physical or occupational therapy and assistance from a dietician or nutritionist. These medical support professionals often provide in-home appointments and may come out at any time of day or evening. Having a caregiver who can answer the door if the patient is in bed or otherwise indisposed is extremely helpful. Also, a caregiver can communicate with the service provider

- **Shopping for groceries and everything else the patient may need**

In addition to going to the pharmacy for prescriptions and medical supplies, someone will have to do the grocery shopping for all the things we need on a daily basis from food to household supplies to clothing and the list goes on and on. Depending on the condition of the patient, leaving them alone, even for a short period of time may not be an option.

There are several resources that can assist you if this is the case, such as Lotsa Helping Hands which, as mentioned above is a free online service that allows you to coordinate with volunteers in your network for help with shopping or staying with the patient, while you go shopping. There are also a variety of ways to shop for products and groceries through online resources, to reduce or eliminate your need to leave home in order to shop for the products you need.

- **Running normal errands**

This is similar to some of the duties already mentioned, such as going to the pharmacy and grocery store, but in our daily lives, there are tons of other errands that we have to run throughout a normal week. Perhaps that is going to the bank, the gas station, the dry cleaners or anything else that might come up. In some cases, it is not possible to leave the cancer patient alone while you go run these errands. Having a volunteer support system is highly recommended, which could allow for a volunteer to come and stay with the patient while you go run the errands, or possibly even the volunteer could go run the errands for you.

- **Assistance with exercise**

Depending on what the patient's doctor recommends, physical exercise may be a very important part of the patient's treatment plan. This may include exercise appointments with a physical therapist and it may also include instructions from the doctor for the patient to exercise on their own. Perhaps the physical therapist that comes out to your house shows you how to do certain exercises and then

instructs the patient to do them on their own based on a daily schedule that they provide. The patient may need the assistance of a caregiver to carry out these exercises safely at home. It may be recommended by the doctor to go walking on a regular schedule. In areas where the weather may not cooperate outside, due to cold, heat or precipitation, it may be necessary to go somewhere that has indoor space adequate to go walking. Some places may include a gymnasium or recreation center, however, there other options may be shopping malls or other large indoor, public facilities. Based on recommendations from the patient's doctor, it may be advisable to wear a medical mask to minimize exposure to germs while out in public places.

- **Conducting fundraisers for the patient's medical and living expenses**

There are tons of different types of fundraisers that can be organized to raise money for living and medical expenses, ranging from bake sales to bowling tournaments, to walk-a-thons and anything else you can think of that would allow people to donate money to help out. One of the easiest and most successful ways to raise large amounts of money quickly is through crowdfunding.

Crowdfunding is a way to raise money online from your friends, family, loved ones and anyone else who wants to contribute to you in a safe, secure and user friendly way online. Most online crowdfunding organizations are free to set up for the patient or person who needs the donations. Most of these crowdfunding organizations charge a fee in the range of 4 to 6 percent of the amount donated. This administration and processing fee is deducted from the total amount donated by the donor. There is no additional fee charged. These donations are not tax deductible for the in the United States, unless they are made to a qualified non-profit organization and income taxes may be applicable to the amounts you receive.

Please visit the Resources page at [CancerInterviews.com](http://CancerInterviews.com) for more information about the crowdfunding organization that I recommend the most, which is, [GoGetFunding.com](http://GoGetFunding.com) since they only charge a 4 percent administration fee compared to their competitors who charge 5 or 6 percent. However, you and the patient may decide to fundraise, I highly recommend starting a fundraising campaign early on in the cancer journey to help with the increased financial obligations and perhaps loss of income for both you and the patient.

- **Making sure the patient is comfortable and has what they need 24/7**

Caring for someone who doesn't feel good can be a very difficult job. Depending on their illness and physical ability, cancer patients may need help with things all throughout the day and even at odd hours during the night. Perhaps they might need assistance getting to and from the bathroom, or need more blankets at night, or if they are confined to their bed, they may need their water refilled, or some food prepared and so on. It can literally be 24 hour round the clock care necessary to ensure the comfort of the patient. Again, having some assistance from volunteers



can be a huge burden off your shoulders, while still giving the patient the care and support that they need in this very difficult time.

- **Taking the patient on personal fun outings, like going to the park, a weekend getaway, etc.**

Depending on the patient's illness and physical condition, there may hopefully be days when they would love to get outside. This could be as simple as going out and sitting on the porch for awhile, or going to a park or taking a stroll around the neighborhood. It may entail going away for an overnight trip or a long day trip to a fun destination or event. Getting outside of one's living quarters and getting some fresh air can be extremely beneficial for the patient, as well as the caregiver.

It can also, potentially be a lot of work for the caregiver. Before leaving home you will need to make sure you have any medications with you that will need to be taken prior to your return. You will also need to consider taking extra clothing or a jacket, gloves, etc. as well as any adaptive equipment such as a stroller, cane or wheelchair. If you are going to be out in the sun, it would probably be a good idea to have sunscreen, lip balm and sunglasses along. If you are going to a public place, you may want to have a medical mask for the patient to wear to prevent being exposed to germs. It's always a good idea to carry bio-degradable hand sanitizer with you so that you and the patient can clean your hands regularly.

- **Keep a list of all key contact information for doctors, support providers, family members, friends, pharmacy, volunteers, etc. including phone numbers, emails, addresses, etc.**

Throughout the cancer journey, you will come in contact with tons of new people and accumulate a very large amount of names, phone numbers, emails, addresses, websites, account numbers, login names, passwords, pin numbers and so forth. You may be tempted to keep all of this information in your phone, or on your computer, however, it is recommended that you keep a hard copy of this information in an easy to read format in a safe place and provide at least one other person a copy of it, in the event that you, as the primary caregiver became incapacitated for a period of time for some reason.

This information needs to be easy for someone who may have to come in and take over temporarily or permanently as the caregiver for the cancer patient. Having a hard copy of all of this information could be a lifesaver for the patient and the next caregiver who may find themselves in the caregiver role. Either way, it is a very easy way for you, the patient or anyone else who may become involved to have immediate access to all of the key contact information necessary.

- **Pet and animal care.**

Depending if the patient or the caregiver has pets, animals or livestock, someone will have to take care of those animals including everything from feeding watering, letting them out to the bathroom, cleaning up after them in the yard, or litter box or

cage and making sure they get groomed, if necessary, to veterinarian appointments when needed and more. In the event you or the patient are farmers or ranchers, the amount of work related to the livestock and farm or ranch in general is much like a full-time business.

- **And the list goes on and on...**

### **CARING FOR THE CAREGIVER:**

As mentioned above, caregivers are some of the most wonderful people on the planet. They take on tasks and responsibilities that would be almost impossible for a cancer patient to do on their own. Taking care of a cancer patient is a wonderful thing, but who takes care of the caregiver?

- **Taking care of yourself.**

As a caregiver, taking care of yourself throughout the cancer journey is in its own way, just as important as taking care of the cancer patient. If you get worn down and burned out, you won't be able to take care of the patient and both of you can suffer as a result. Make sure you get adequate sleep, nutrition, exercise and free time to do the things you want and need to do, or just to be alone.

- **Understanding your feelings.**

Just as the news of cancer can be life changing to a patient, so can becoming a caregiver. Taking time to consult with a counselor about your feelings, help you deal with the magnitude of the situation and better prepare you to be the caregiver for your loved one.

- **Asking for help.**

Don't be afraid to ask for help. Many people who care about you and the patient will naturally want to help, so don't be afraid to ask. It does not demonstrate weakness or selfishness to ask for help in this type of situation. You may be very surprised how many people you know and even some that you don't know yet, who will be very excited to be able to help you and the patient in your time of need.

- **How to make time for yourself.**

Depending on the severity of the illness of the patient you are caring for, their care could require assistance 24 hours a day, 7 days a week. You owe it to yourself and the patient to get some help from volunteers, including friends, family members and other volunteers. Delegate some of the work load so that you can take care of yourself and have some free time to do the things you want and need to do.

- **Going with your loved one to medical visits.**

Again, depending on your relationship with the patient and the physical condition of the patient, it is if possible to attend doctor appointments with the patient, so that you and the patient can be assured to accurately document the information provided by the doctor and ask all of the questions that you both may have. If the patient feels that it is not necessary for you to stay with them during treatment sessions at the

treatment facility, this could give you a break for a few hours in which you may want to go run some errands, enjoy some free time or even take a nap.

- **Talking with friends and family members about cancer.**

Don't be afraid to talk with your friends, family and loved ones about cancer in general and the cancer journey that you and the patient are currently on. You may be amazed to find out that some of these people have either had cancer themselves or have a loved one who has and they may be someone you can benefit from by hearing their story and sharing your hopes, dreams, fears and concerns with.

- **Don't be afraid to say no.**

Not everyone is physically, mentally and emotionally able to be a caregiver for a cancer patient. Perhaps you were able in the beginning, but you have worn yourself down to a point where no matter how much you want to, you can't provide the level of support care needed to effectively care for the cancer patient. Don't be afraid to speak up and say no. Ask for help from friends, family and volunteers to either help out or to completely take over the responsibilities as the caregiver. It will be in the best interest of both you and the patient.

Hopefully, you will find some information in this guide that will help you and the patient you are caring for have a successful cancer journey. Thank you for reading!

*With sincerest, best wishes for a full and speedy recovery - Jim Foster*

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## **OTHER ONLINE PATIENT AND CAREGIVER RESOURCES**

(Please note: CancerInterviews.com is not endorsed by any of these organizations)

[www.cancer.gov](http://www.cancer.gov) National Cancer Institute at the National Institute of Health (United States of America)

[www.cancer.org](http://www.cancer.org) American Cancer Society – Charitable organization with resources for cancer patients, caregivers and families.

[www.cancercare.org](http://www.cancercare.org) Charitable organization with resources for cancer patients, caregivers and families.

[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org) Charitable organization with resources for cancer patients, caregivers and families.

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## **FOR MORE HELPFUL TIPS AND INFORMATION...**

To learn more, please tune in to the [Cancer Interviews podcast](#) where we interview survivors, patients, caregivers, doctors, medical professionals, cancer support

professionals and more. Our hope is that you can learn helpful information based on other experiences of people who are also on the front lines of the daily fight against cancer.

Here are some places to get more information:

Web: [www.cancerinterviews.com](http://www.cancerinterviews.com)

YouTube: [www.youtube.com/cancerinterviews](http://www.youtube.com/cancerinterviews)

iTunes: The Cancer Interviews Podcast

Stitcher: The Cancer Interviews Podcast

Google Play: The Cancer Interviews Podcast

Facebook: [www.facebook.com/cancerinterviews](http://www.facebook.com/cancerinterviews)

Twitter: [@CancerInterview](http://www.twitter.com)

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