“More than 60% of the Cancer Journey Happens at Home; Why No Comprehensive Support?” (Katie Quintas) [#115]

Brad Power and Robert Burleson
October 9, 2024

“Here's the reality that families face once they're outside the doors of the hospital – cancer patients and families are on their own. Less than .001% of all funds raised for cancer actually go to families navigating cancer, which is a scary number. 60% of the cancer journey happens in the home where there's no support for all the things that need to be done. Grant organizations do ***not*** *provide financial help after the journey ends or the patient passes, and bankruptcy then becomes the only choice. 75% of all bankruptcies are the result of medical bills. Today, regrettably, cancer research and treatment have overtaken the care journey in funding those battling cancer.”* – Katie Quintas

“It became very clear to me what cancer families need, which is why I started Here to Serve. They needed a one-stop organization that meets all their needs in the home. They need financial help and practical help in the home so they can focus on their sick family member.” – Katie Quintas

Meeting Summary

Caregivers of patients with children in the home battling cancer are on a journey they never thought possible. They are not trained to navigate cancer, nor know where to go to get help or resources as they try to manage their family’s needs in the home. Most are overwhelmed by treatment and, therefore, unable to seek practical support in the home and financial resources. Many spend their time researching the disease to make sure they are getting the proper medical treatment. They throw caution to the wind when it comes to getting physical, emotional, and financial help in the home. The result can be loss of job, income, home, and emotional stability. Only .001% of all funds raised for cancer go to families who are actually navigating cancer treatments. However, these same families’ stories are leveraged to fund cancer research and hospitals that treat cancer while leaving cancer patients and their families struggling physically, emotionally, and financially to survive this grueling journey. It is important to note that more than 60% of the cancer journey happens in the home, where there is zero support.

Katie Quintas is uniquely qualified to discuss the comprehensive needs of pediatric cancer families. She is Founder and CEO of Here to Serve, a 501(c)(3) charity that collaborates and cooperates with the community, including individuals, businesses, and nonprofit organizations, to reduce the physical, financial, and emotional stress of individuals, families, and caregivers during a family member's cancer journey. Here to Serve combines the services of other nonprofit organizations, corporations, and professional services and mobilizes a network of volunteers to provide targeted non-medical care to families battling a child's cancer or a parent of young children battling cancer. In addition, Here to Serve helps with logistics by identifying resources and provides targeted assistance with child care, finances, meals, household chores, transportation, pet care, and living and home needs. Here to Serve is the only national nonprofit to provide one-stop wraparound support in the home. This gives caregivers more time with their child and family not having to worry about the logistics of home life and financial concerns.

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Katie launched Here to Serve in 2011 after her husband, son, and mother were diagnosed with cancer during a 30-month period; her son and husband within six months of each other. Unfortunately, her mother and husband passed away while her son is in remission today. Her experience gave her the impetus to fulfill an unmet need to coordinate service organizations as well as volunteers to help individuals and families navigate the cancer journey. In doing this, parents and young spouses could avoid losing their jobs, earning ability, homes, as well as sanity and hope. Cancer is a three-legged stool: research, treatment, and journey. Regrettably, cancer research and treatment have overtaken the care journey in the conversation and funding of those battling cancer. Katie is seeking to change that.

What are the comprehensive needs of families of cancer patients?

Once past the shock of diagnosis, finding a cancer doctor and starting a treatment, families with children with cancer need support on many additional fronts:

- Everyday household tasks (meals, laundry, housekeeping, transportation, caring for pets)
- Emotional support, mental health (stress, exhaustion)
- Financial support
- Work issues (quit, go on leave, adjust schedule)
- Family dynamics (social plans, holidays, birthdays and vacations)
- Managing helpers
- Managing the child’s education (tutors?, stop school?)
- Respite for caregivers

What are the services that are available to address these needs?

- Financial aid (requires research and much paperwork to successfully apply for limited amounts of assistance)
- Pro bono tax accountant
- Handymen, plumbers, electricians, carpenters
- Transportation
- Holiday decorations
- Air purifiers
- Adaptive equipment
- Help with packing up, moving, and unpacking a home during relocation
- Accommodations
- Clinical trial transportation and housing
- Family trips
- Help with holidays, birthdays, and memorial services

How can caregivers access needed services, both for the patient and themselves?

- Conduct online research to find available services

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- Same ask friends to help, set up “meal train”
- Some ask friends or family to start a GoFundMe account
- Some join a cancer support group online
- These efforts and others can be splintered and cause more stress on the caregiver as she/he tries to manage not only the cancer patient’s treatment but also the people trying to help. The need for a one-stop solution is clearly evidenced by these splintered resources, but trying to manager the volunteers who wish to help.

How can you learn more?

- Check out the Here to Serve website and contact Katie Quintas at katie@heretoserve.org
- Check out Nancy’s List for a list of support services
- Review the notes from our discussion with Nancy Novack and others on financial support advice for those going through cancer here
- Check out We Are Here, which offers services surrounding cancer

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Meeting Notes

KEYWORDS

prostate cancer, cancer patient lab, nonprofit organization, cancer journey, caregiver challenges, financial distress, emotional support, respite care, insurance issues, patient advocacy, wraparound support, fundraising challenges, community support, cancer research, family needs

SPEAKERS

Katie Quintas (89%), Brad Power (9%), Roger Royse (1%), David Plunkett (0%)

SUMMARY

Katie Quintas shared her journey of founding "Here to Serve" after her husband and son's cancer diagnoses, highlighting the lack of support for cancer patients at home. She detailed the extensive services provided by "Here to Serve," including financial aid, meals, transportation, and emotional support, noting that only 0.001% of cancer funds go to families. Despite their success, funding challenges persist, with 85% of their support going to children and 15% to adults.

OUTLINE

Katie Quintas' Personal Story and Founding of Here to Serve

- Katie Quintas describes the difficulties she faced as a caregiver, including balancing work and caregiving while her husband and son were undergoing cancer treatment.
- She explains her search for a nonprofit to help cancer patients at home and her decision to create Here to Serve when she couldn't find one.
- She outlines the universal experiences of receiving a cancer diagnosis, including panic, searching for information, and finding the right doctor and treatment plan.

Impact of Cancer on Daily Life and Caregivers

- Katie discusses the various challenges cancer patients and their families face, such as work issues, financial impact, and family dynamics.
- She highlights the importance of making choices, including getting second opinions and adjusting to the physical, emotional, and logistical impacts of treatment.
- Katie emphasizes the significant impact on children, including school, social plans, and vacations, using her own family's experiences as examples.
- She describes the emotional and mental toll on caregivers, including stress, exhaustion, and the decision to seek antidepressants.

Long-Term Impact on Caregivers and Families

- Katie explains the long-term impact on caregivers, including the overwhelming nature of offers for help and the eventual feeling of being a burden to those who are helping.

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- She discusses the financial distress and feelings of abandonment that caregivers experience as friends and family move on with their lives.
- Katie highlights the challenges of obtaining resources, including the paperwork required for grants and the frustration of small amounts of funding.
- She emphasizes the importance of wraparound support for cancer families, including meals, childcare, transportation, and emotional support.

Here to Serve's Services and Support

- Katie outlines the services provided by Here to Serve, including updates on CaringBridge, meal calendars, housekeeping, and gift cards.
- She describes the organization's efforts to manage GoFundMe pages and provide respite care, including trips and holiday celebrations.
- Katie shares examples of the support provided, such as tax accountants, handymen, and cars for families traveling to hospitals.
- She emphasizes the importance of a community of support and the need for financial help to focus on the family's needs during the cancer journey.

Challenges and Future Plans for Here to Serve

- Katie discusses the challenges of fundraising and the need for more funding to help more families.
- She explains the decision to focus on children due to the greater appeal and the difficulty of fundraising for adults.
- Katie shares the organization's annual event and the impact of the economy and the election on fundraising efforts.
- She opens the floor for questions and addresses the importance of respite care and the challenges of dealing with insurance companies.

Q&A Session and Closing Remarks

- David Plunkett asks about respite care and its effectiveness, and Katie explains the community-based approach to providing respite care.
- Roger Royse raises questions about dealing with insurance companies and the allocation of funds between children and adults.
- Katie provides insights into the challenges of fundraising and the decision-making process for funding families.
- The meeting concludes with a focus on the need for more support and funding for cancer families and the importance of a community-driven approach.

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TRANSCRIPT

Brad Power
This is the Cancer Patient Lab.

Let me just do some quick introductions, just to give you a sense of the audience:

- Allen Morris is a pathologist in California, and he's a prostate cancer survivor.
- David Plunkett is a prostate cancer survivor in Kansas City.
- Brian McCloskey is a co-founder with me of the Cancer Patient Lab.
- Alexander Lalov is a prostate cancer survivor.
- Ryan Ramanujam is a researcher.
- Rick Davis is with AnCan, which facilitates discussions amongst cancer patients, and is an expert in a number of cancers, especially prostate cancer.

There are a couple of housekeeping things we do at the front. This is for medical information only – it is not advice. We arm people with information to take to their medical team. We are a nonprofit patient-led organization, so would appreciate any donations that people might make.

Let me introduce Katie briefly. Katie is leader of a nonprofit that helps people get access to physical things that surround their cancer. She does very inspirational work. She's been a good advisor to us as we launched our nonprofit and learn about the things you need to do to run a cancer-focused nonprofit. She has many stories to tell, and I'm sure you'll enjoy hearing what her experience has been, the services they provide, and the lessons learned from her many years of experience in doing what she does. She's based in Southern California.

Katie Quintas 2:49
Thank you so much for the wonderful introduction, Brad, and thank you all for being here today.

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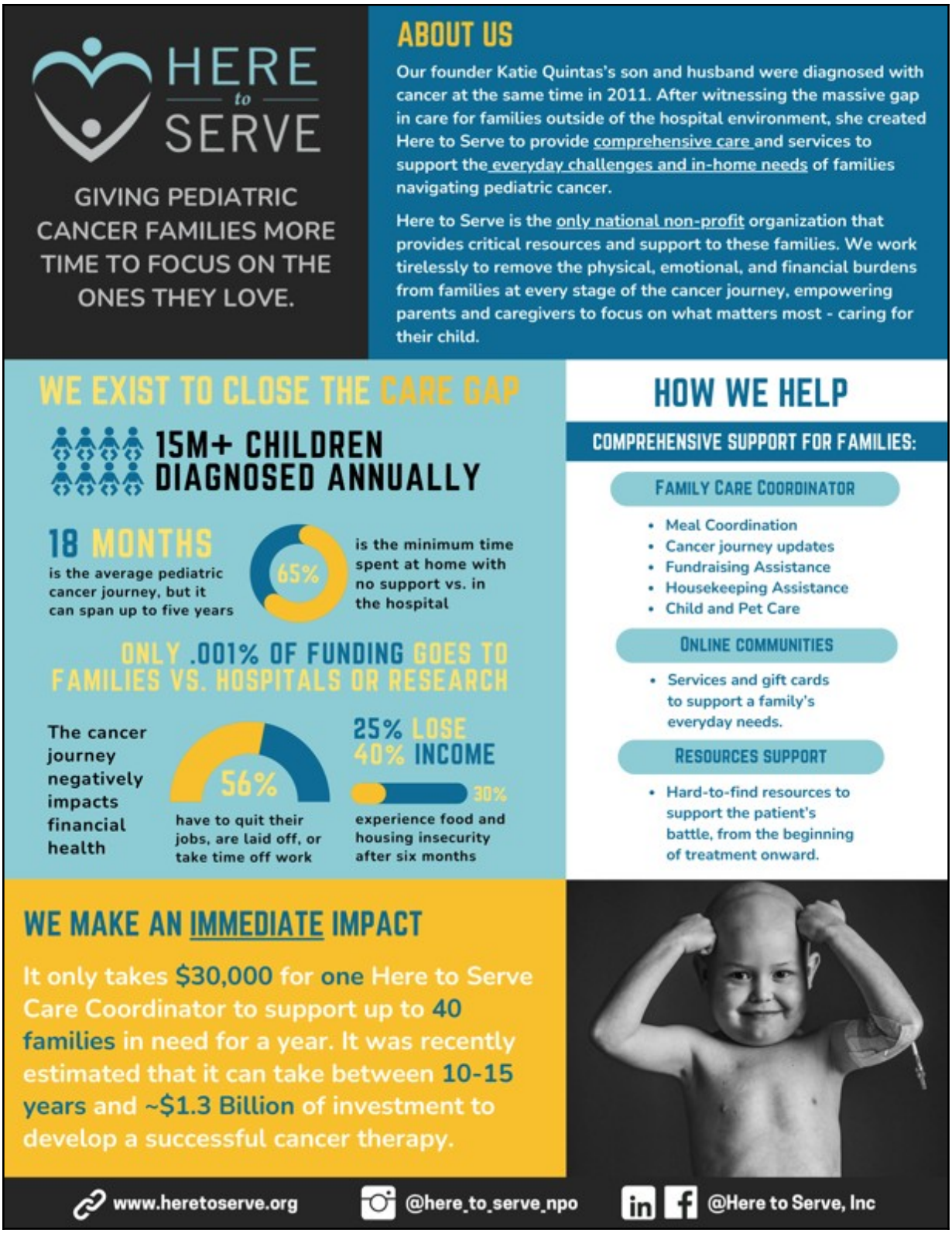


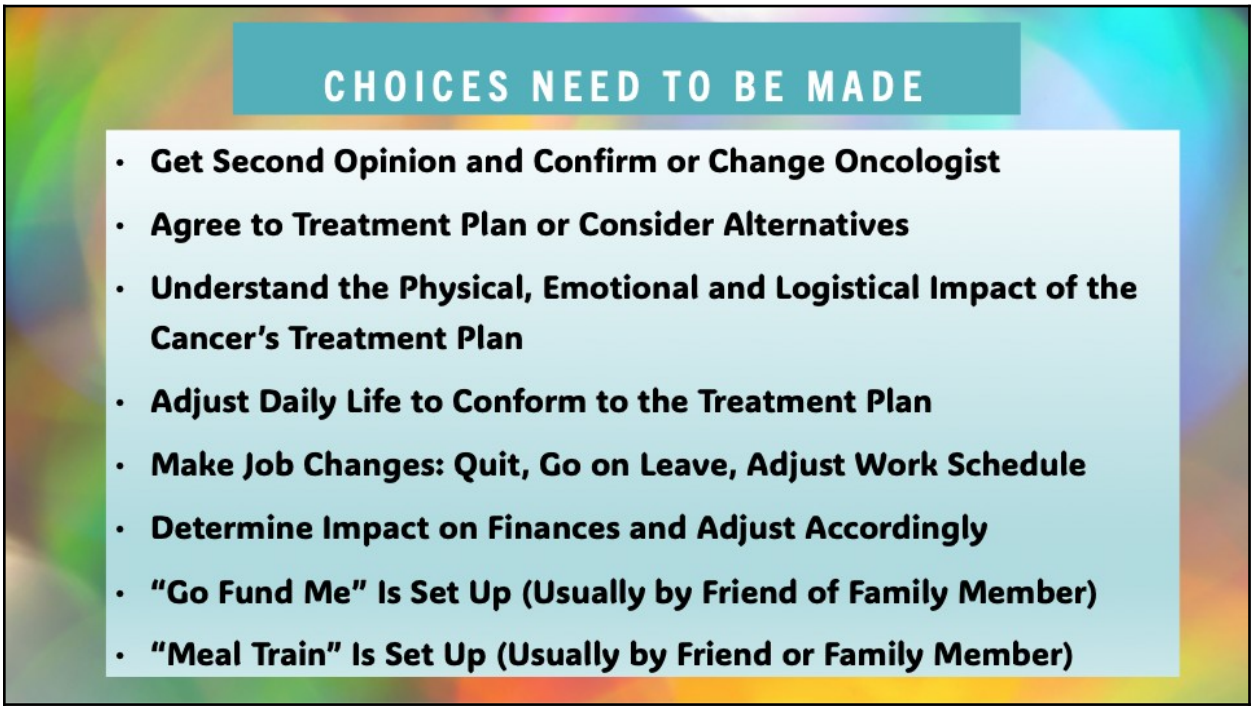
The reason I started Here to Serve is because both my husband and son were diagnosed with cancer at the same time, a few months apart, and I had to be the caregiver while I was holding

down a full time job and trying to work from a hospital room, and also finding ways to get into meetings at work was very challenging. The resources out there at that time and still today, were splintered and varied, and a lot of the things out there required applications and things that I neither had the time nor the desire to do under my circumstances.

So after the cancer journey of my husband and son, I started to look for ideas. I had been working for two of the largest fundraising agencies in North America, and I decided to see if I could find a nonprofit that would help cancer patients in the home. I searched high and low and never could find one. So I ultimately decided to create one, and that was the birth of Here to Serve.

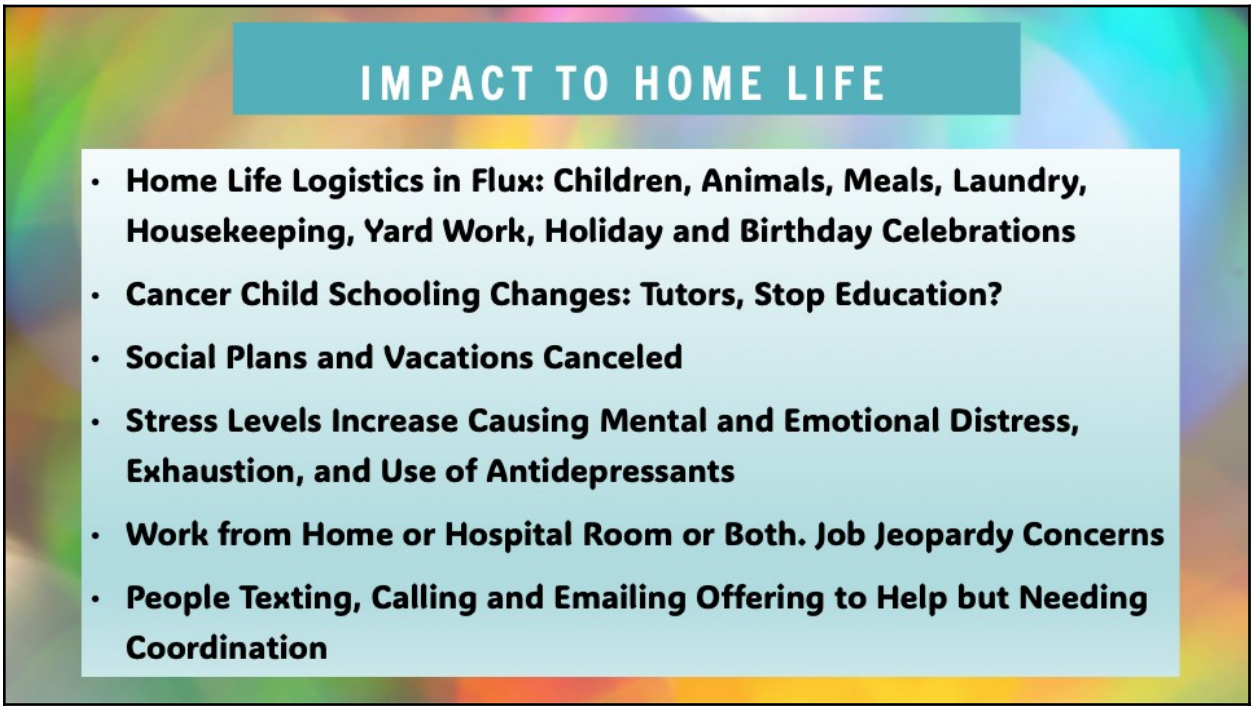
“More than 60% of the Cancer Journey Happens at Home; Why No Comprehensive Support?” (Katie Quintas) [#115]

In the beginning, with a diagnosis of cancer there are a number of things that happen that are nearly universal. I've described them here very briefly – the panic and disbelief, the search for information on your diagnosis, the search for doctors and treatment options. A lot of times you've been given a doctor, but you have questions initially, because you've never been to an oncologist. You ask – is this the right oncologist for you, and is the treatment plan he's giving you the best and only treatment plan for what you're dealing with?



“More than 60% of the Cancer Journey Happens at Home; Why No Comprehensive Support?” (Katie Quintas) [#115]

So you're determining if you're in the right place with the right doctor, and then you begin to weigh the challenges you're about to face. Some of them are work issues. Some of them are the financial impact, some of them – if you have a family– are the children and family issues.. You realize choices need to be made. So most often, people get a second opinion and they confirm or change their oncologist. They agree to a treatment plan or consider alternatives.



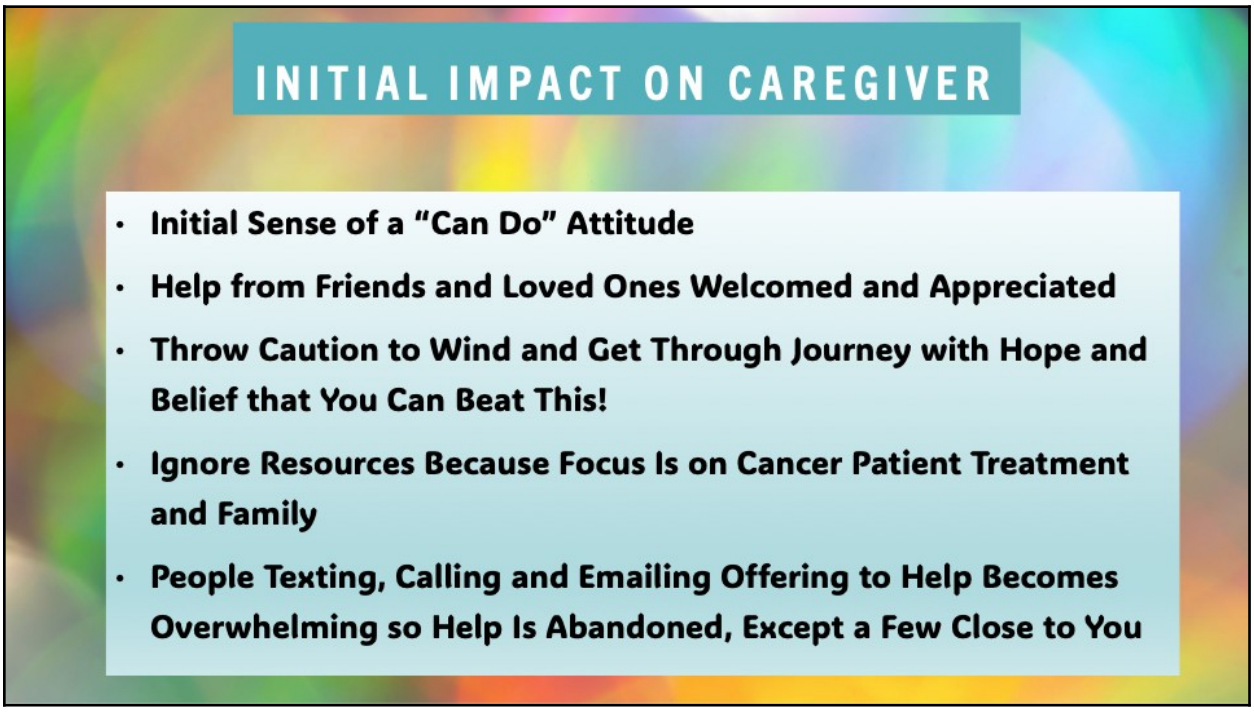
Patients begin to understand the physical, emotional, and logistical impacts of the cancer treatment plan, and they think about what they need to adjust in daily life to conform to that treatment plan. Sometimes, depending on the type of cancer – and I deal with cancers that have children in the home – whether it's the parent diagnosed with cancer or the child diagnosed with cancer.

There are impacts in the home that have to do with the children. Parents may have to decide if they are going to quit their job. Are they going to go on leave, or are they going to adjust their work schedule, which obviously has an impact on finances? A lot of times, they'll have a friend that offers to set up a GoFundMe page, and usually a family member or someone else sets up a meal train. I'll talk about the positives and negatives of these things happening in a little while.

The next thing that happens is you begin to look at the logistics in the home. You have children, and sometimes they have pets. You have to deal with meals, laundry, housekeeping, yard work, holiday and birthday celebrations. Then all those things go in flux, and you begin to realize the impact that cancer is going to have on your life.

“More than 60% of the Cancer Journey Happens at Home; Why No Comprehensive Support?” (Katie Quintas) [#115]

In many cases, we have children that have cancer, and so you start to determine, what's this going to do to the child's school life? Are they going to skip a year? Are they going to need tutors? Do we stop their education? Do we continue it? Social plans and vacations may be canceled. The stress level increases, causing mental and emotional distress and exhaustion. You have to decide if you're going to work from home, the hospital room or both. And then you start to consider, is my job in jeopardy? People are offering to help, but those same people need a coordinated effort to be effective, and that can be overwhelming, too.



The initial impact on the caregiver is you get a “can do” attitude. You begin to realize a lot is resting on you, and you have to meet the challenge. Lots of friends and loved ones have offered to help, and you welcome and appreciate it. A lot of times, you ignore your resources, because you feel like all these people who are going to help you will be an asset, and you don't worry about what the future has to hold. Then as time goes on, the people calling, texting, and emailing you becomes a bit overwhelming, so you may just decide against the help, except for a few close friends.

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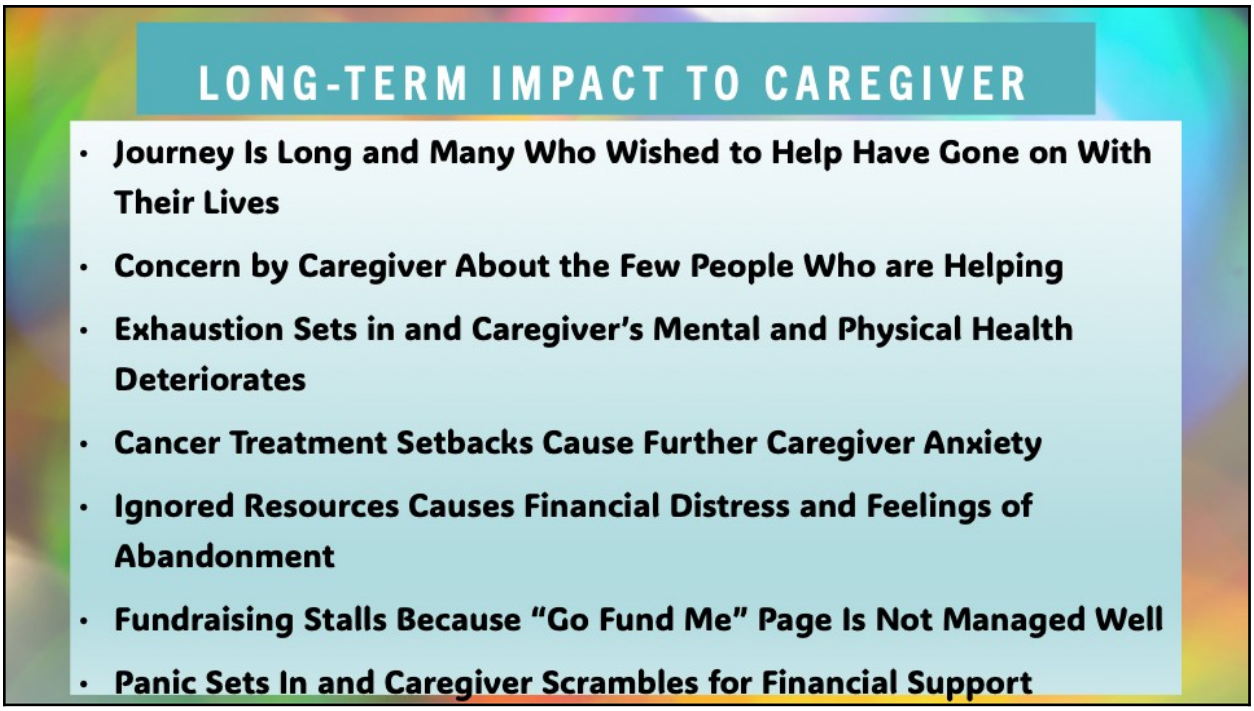

The journey is long, and many who wish to have helped have gone on with their lives. About the few people who are helping you, you begin to feel like you're burdening them, exhaustion sets in, and the caregiver’s mental and physical health begin to deteriorate.

Since we deal with caregivers, these issues about caregivers are very important to us. The caregiver has a lot on his or her shoulders, and we are very much focused on helping the caregiver so they can focus on the family member with cancer.

A lot of times through treatment, there are setbacks. Cancer treatment can be harsh, and you're hoping to get through it. You hear the plan and you think you can get through it in a year, or six months, or nine months – whatever the treatment plan is. But all of a sudden you're in the hospital for infections and sepsis, and a lot of other issues that you hoped wouldn't happen. You realize by this point, the ignored resources are beginning to cause financial distress and feelings of abandonment, because a lot of the friends have moved on with their life, and they're not necessarily there, moment by moment and and you're realizing that you're it as the caregiver. Sometimes, the friend who started the GoFundMe page usually doesn't understand fundraising and what happens is that the GoFundMe page stalls and they don't understand how to continue getting funding from it.

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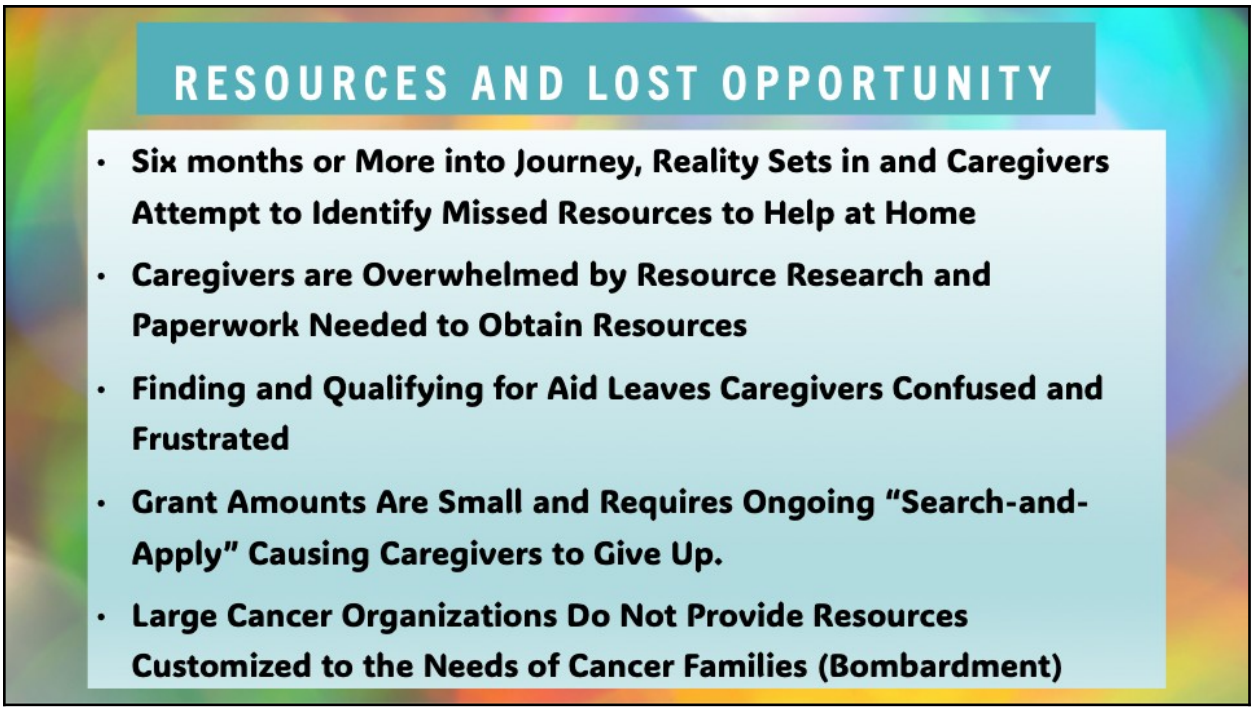

And then the panic sets in and the caregiver scrambles for financial support. At that point, caregivers are overwhelmed by resource research and the paperwork needed to obtain resources. They're realizing that the resources that they're trying to obtain require paperwork, and a lot of times those resources, when it comes to funding, is paperwork, when you're only asking for $500 or $1000 so you have to go to multiple grant makers to get the funding that you need, because your GoFundMe page has stalled at this point and you don't know how to revive it.

Finding qualifying aid leaves the caregivers confused and frustrated. Grants and amounts are small, and the search and application is causing caregivers to give up. Large cancer organizations that do provide resources bombard you with tons of resources without culling through them and determining which ones are best for the family.

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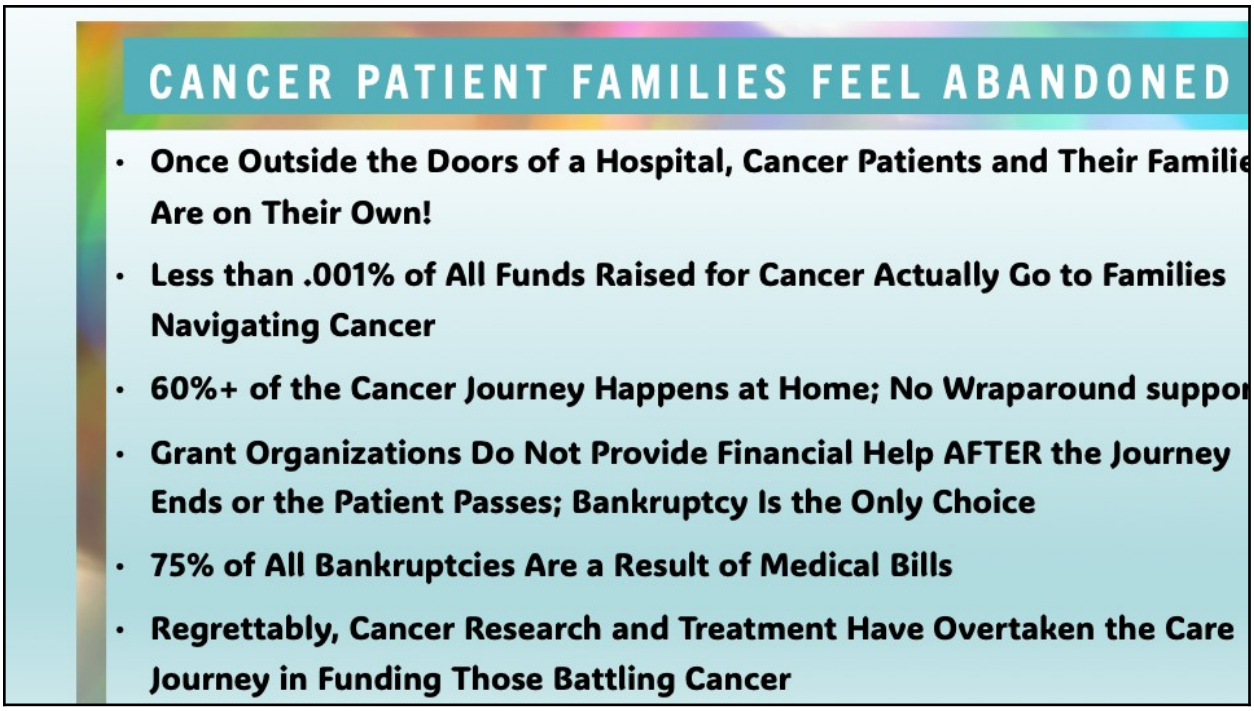

Here's the reality that families face once they're outside the doors of the hospital – cancer patients and families are on their own. Less than .001% of all funds raised for cancer actually go to families navigating cancer, which is a scary number. 60% of the cancer journey happens in the home where there's no support for all the things that need to be done. Grant organizations do not provide financial help after the journey ends or the patient passes, and bankruptcy then becomes the only choice. 75% of all bankruptcies are the result of medical bills. Today, regrettably, cancer research and treatment have overtaken the care journey in funding those battling cancer.

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People's journeys are used to fund cancer research and hospitals that treat cancer, but when it comes to helping that same family in the home or with finances, they are on their own. You have to figure it all out by yourself and they become the recipients of the fundraising, still not what cancer families need.

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It became very clear to me what cancer families need, and this is why I started Here to Serve. They needed a one-stop organization that meets all their needs in the home. They need financial help so they can focus on their sick child, perhaps maybe not in the beginning, and of course, not with wealthy families.

I'm talking about families who are without the kind of aid – basically lower middle class and middle class families – this is where the biggest impact is felt. They need financial help as the bills begin to pile up.. It isn't just the treatment side, and it isn't just meals and childcare and things like that. But they need a place where different types of support happens in one place that means meals, childcare, help with transportation, pet care, housekeeping, laundry and the list goes on. By this point, they need emotional support and respite with people who understand their journey, their fears, their hopes, their faith, their physical and emotional suffering, and financial instability. They need a community of support from family, friends and neighbors and co-workers and businesses.

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This is the need that still exists that has been unmet and we're here to do that. We are struggling, because in the cancer category, the people that own the lion's share of the conversation are the cancer research community and hospitals that treat cancer.

I really want to pause for a minute and say I believe in funding hospitals and cancer research – there is a very important place for these. What I disagree with is that they're the main focus, and that cancer patients should be equally important. with an equal voice and equal funding.

It's a three legged stool with cancer, not two. It's not just cancer research and hospitals that treat cancer, although they're very important, but if not for the patients that actually go through cancer we wouldn't need cancer research or hospitals to treat cancer. So why do we toss aside cancer families and patients and only focus on the funding of cancer research and hospitals? We should focus on meeting the needs of cancer families who are actually going through cancer.

We created a one stop organization for this. Many of you have heard of Caring Bridge and GoFundMe and the meals organizations. We're all those things on steroids and more. We do all the same things as Caring Bridge, and it's only one small part of our platform. We do a calendar of meals (identifying food restrictions). We equip the family with housekeeping. We have gift cards. We manage the GoFundMe page if they haven't set one up, and then we give them respite help.

A lot of times we've sent them on trips – we've fundraised enough to get the families trips! A lot of these families are young families, so while their child is able, we may send them

to Disneyland. The hospital always helps them with Make-a-Wish. So they do get a wish, usually, but these are long journeys for kids. Sometimes I've been with these families for as long as five years. One trip to Disneyland during a five year journey is nearly not enough, and so we work at helping the family enjoy the time when their child or parent is in a portion of the treatment where they're feeling well enough to do things.

We help with respite. We help with a program we call adopt a family for the holidays so the family never has to shop for the holidays. Presents are there, wrapped and under the tree. We do birthday celebrations. We access other vetted nonprofits and grant making organizations who can help them, and when we give them resources, they're vetted resources. We have helped with memorial services and celebrations. We do a Thanksgiving basket program.

During tax season, after these families have received all these gifts, they panic about what the tax implications are and they ask for a tax accountant. So we always find a pro bono tax accountant. We've helped with handymen, plumbers, electricians, carpenters. Families who have a lot of kids need stroller wagons, especially in the hospital so forth. We've given them mattresses pro bono. We've even gotten cars for five families through the years where we've had them refurbished and redone. They're never new cars, but these families are in need of cars because they're traveling back and forth to the hospital, and sometimes their cars are too old or they don't have enough room in them. There's a lot of reasons like this, but we've been able to manage to fundraise to get families cars.

We've done house holiday decorations, air purifiers, and adaptive equipment. All of this is pro bono work. We've helped pack up, move and unpack a home during relocation, and we've even helped during clinical trials with transportation and accommodations.

Katie Quintas 28:10
Families tell us that they don't know how they would have done it without us. Yet many families do as there are 15,000 children a year who are diagnosed with cancer, and that doesn't even account for parents that are diagnosed with cancer, and we can't we can't help nearly that much as you might imagine.

Roger Royse 29:22
We have one question in the chat here about how do you fund your nonprofit? Do you get grants? Do you go out to the general public?

Katie Quintas 29:29
It's from the general public. We don't do many grants. The reason is, when we were brand new, grant writers wanted to wait and see how we survived, and they asked for a mountain of paperwork for a very small grant, and we did not have the resources to put that kind of time into that because we were very focused on our families. But I will say, in hindsight, I should have focused more on fundraising early on than waiting to do it 14 years in when we have a stupendous program and we don't have enough funding to help more people. So that has been

a very big challenge for us. We have an annual event that brings in about a third of our annual budget, and the rest comes from major donors.

And so we still are not doing grants, because when grant writers look at our annual budget, probably the most they'd be willing to give us is $5000, maybe $10,000 and we need $25,000. If you don't know the grant writing organization or have inroads with them, you do a lot of grant writing for no return on investment.