

Creating the Caregiver Experience



Giving of Yourself in Support of Others

The Passion of Caregivers

At Relay For Life events, we Celebrate the lives of people who have battled cancer, Remember loved ones lost, and Fight Back against the disease. And for every survivor and loved one celebrated and remembered, there was at least one caregiver beside them through their journey.

Meet Tisha and Sarah. Tisha and Sarah are best friends, co-chairs of the 2011 Relay For Life of Skagit County, WA and caregivers with stories that not only mirror each other, but also mirror those of many Caregivers at Relay.

“At the happiest time of my life I was forced to grieve the loss of an amazing woman who had so much more to do in this world. God proved he had a different plan, and I was going to have to take things one day at a time because that’s what my mom taught me to do.”

Creating an amazing and healing caregiver experience became their call after attending their division Summit the fall of 2011 and connecting with the new RFL Caregiver video (2011 RFL Nationwide Leadership Summit DVD).

Their passion and selfless actions not only created memorable experiences for their caregivers, but also catapulted their event’s Customer Satisfaction Scores (CSS) into the top in the nation for Caregiver Activities.

Throughout this guide you will read more about Tisha and Sarah’s caregiver journey and how they and others like them, set out to recognize and honor their community’s caregivers.

Tisha & Sarah

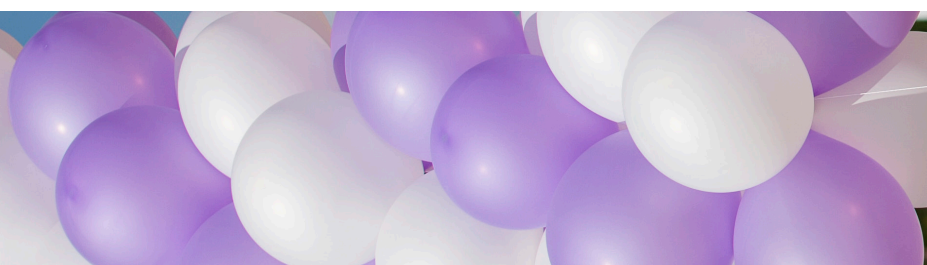
A Caregiver Story



Tisha and Sarah met on the school playground in 4th grade and were immediately inseparable. There are not many of their childhood memories that do not include the other one. One thing that they have always shared throughout their friendship was the strength of their mothers.

In September of 2000, Sarah’s mom was diagnosed with Multiple Myeloma, a cancer of the plasma cells just after she had attended her first Relay For Life event. “I was 22 years old and the idea of losing her was unfathomable.

...Read more of Tisha and Sarah’s story on page 6.



Creating the Caregiver Experience

Creating the Caregiver Experience at Relay

“Celebrate with me, know my journey... and help me with my loss...” unknown caregiver

Relay For Life offers an amazing opportunity to thank and honor those unsung heroes – our Caregivers – who stand or stood by their loved ones during the cancer journey.

How do you create a successful and memorable experience for Caregivers?

1. Special Activities

Identifying and putting into place a passionate individual who understands the importance of recognizing, honoring and engaging caregivers is your first step. Once in place, let their creative minds take your event to the next level of caregiver-ship. Planning special activities and inclusion into event ceremonies is a great place to start.

Caregiver Welcome Area

Providing a special welcome and registration area for your caregivers will help them start their Relay experience off right!

- This could be as simple as a special registration area incorporated into your traditional welcome/ registration area
- or as elaborate as a separate tent or awning
- Either way, consider incorporating special signage like the Caregivers sail banners (7522.65) or Caregiver banner (7543.49)
- Use festive balloons, streamers or even a purple carpet (play off the red carpet).
- When registering absolutely ensure all caregivers are greeted with a welcome smile and an encouragement to participate in any other planned caregiver activities.



“The key to success is putting someone in charge who gets it ~ a Caregiver.”

– Tisha



Celebrate. Remember. Fight Back.®

- Some events have chosen to provide special gift items like the caregiver lapel pin (Turnkey Promotions), sticker ((7549.48) or sash (7547.11).
- Other events have specially made items from local schools or vendors such as Thank You cards, crepe paper flowers or chocolates.

Whatever you provide, your caregivers will be excited and appreciative.

2. Caregiver Reception

Events often encourage survivors to invite one or two caregivers to the survivor reception or festivities onsite. Offering a separate reception for all caregivers provides...

- An opportunity for survivors to spend time with their entire circle of caregivers.
- It also provides an area for caregivers whose loved one is no longer with them to be honored and recognized.
- Simple cake/punch refreshments – at some events served to the caregivers by survivors – is plenty.
- Including a brief program where a survivor speaks and thanks all caregivers would certainly be a welcomed addition.

3. Caregiver’s Handprint Wall

Many events have created hand print walls for survivors where survivors dip their hands in paint, place their handprint on a wall of material or quilt and then sign their name and number of years survived next to it.



- For Caregivers consider having a separate handprint wall/station including their handprint, signature and number of years as a caregiver.
- They could even include the names of loved ones.
- A combined Caregiver/Survivor handprint wall
 - Create a large wall constructed of cotton, muslin or painter’s cloth stretched between poles or pipe.

Creating the Caregiver Experience

3. Caregiver's Handprint Wall (cont'd)

- In the center outline a giant heart.
- Fill in the heart with handprints of caregivers.
- Surround the outside of the heart with the handprints of survivors, their name and number of years survived.

Caregiver's Thank You Garden



Consider creating a special place at your event to recognize caregivers and their journey. A caregiver garden is a simple idea everyone at your event can participate in creating and – once finished – provides a quiet place of honor and reflection for caregivers.

- Provide an area where anyone can create a flower honoring themselves or someone else as a caregiver.
- Supplies can be as simple as ordering or creating pinwheels or paper or foam flowers from craft supply stores.
- Ask individuals to write messages to Caregivers on the pinwheels or flowers
- Have individuals place them into your caregiver garden.
- To create your caregiver garden simply identify a special location at your event
 - Rope or section off the area
 - hang your Caregiver/Survivor banner
 - Include flowers, balloons, or other decorations to make your area special
 - Include some seating so caregivers can stop and reflect within the garden
 - The flowers and pinwheels are your finishing touch – enjoy!

Ceremonies

Ceremonies offer a unique and very public way of recognizing and honoring your caregivers. Whether it is the Opening, Luminaria or other ceremonies, the proper messaging is important to ensure all caregivers – current or past – feel included. Equally important is making sure caregivers whose loved one is no longer with them connect with your messaging.

Messaging

A caregiver is anyone who has provided daily care for someone with cancer, as a family member, friend or essential healthcare professional might. Caregivers are also those who have provided assistance or support for someone with cancer such as emotional support, transportation, helping with chores or meals, spiritual guidance, etc.

No matter the type or extent of support provided, caregivers are “get it done” people who truly understand the magnitude of a cancer diagnosis, the importance of being there and of community. This understanding and the value of the care they provide is never diminished regardless of whether they are currently providing that care, their survivor or loved one is cancer free or their loved one is no longer with them. Each is a caregiver who deserves the opportunity to be thanked and recognized. All caregivers are important!

Opening Ceremony - Special Caregiver Laps

Events offer different caregiver lap opportunities. Here are several different examples you might consider for your event's opening ceremonies:

- Caregivers and survivors are provided different colored balloons for the opening lap.
 - Survivors are given purple
 - Caregivers yellow
 - Caregivers whose loved one is no longer with them are also given a light blue balloon to remember their loved one
 - Caregivers include the name and a message to their remembered loved one on the light blue balloon
 - All walk the lap together.



Creating the Caregiver Experience

- Caregivers are invited to join the Survivors for the second lap
 - Caregivers who do not have their Survivor still with them are given the opportunity to have a volunteer/Survivor walk the lap with them
 - Caregivers who do not have their survivors with them can be asked to lead this lap carrying the caregiver banner (7543.49)
- Caregivers are invited to walk in the opposite direction of the survivors meeting each other half way across the track.
 - Caregivers participating with their survivors meet up and exchange caregiver and survivor pins (Turnkey Promotions)
 - Caregivers whose loved one is no longer with them are greeted by volunteers, other survivors, special guests to be pinned with caregiver pins (Turnkey Promotions)
- This luminaria bag could be in a different color (lavender, yellow, light blue) or could simply say Thank You.
- At Relay place the bags in the shape of a heart in the middle of the Luminaria bags.
- During the Luminaria Ceremony explain the meaning of the special luminaria bags. The bags in the center are in honor of Caregivers, the heart of Relay.

Balloon Luminaria

- Attach helium balloons on strings to luminaria
- The balloon attached to an "In Honor of" luminaria can have a thank you message from the Survivor with the Caregiver name on the balloon
- The balloon attached to an "In Memory of" luminaria can have a message from the Caregiver and the name of the Caregiver on the balloon

Sample Scripts

Two examples of meaningful luminaria scripts for your event can be found at the end of this document.

Luminaria Ceremony

Special Lap

If not during the opening ceremony, events may choose to have a Caregiver lap during their luminaria ceremony. This is particularly appropriate and meaningful for those caregivers whose loved one is no longer with them as the Luminaria ceremony provides individuals an opportunity to reflect, remember and heal.

Guest Speakers

Consider asking a caregiver to share their story as part of your Luminaria ceremony. You may also want to include a speaker who provided care to a loved one who is no longer with us can be particularly moving and healing for them and others.

At your pre event meetings, welcome areas, registration and during your Survivor reception or gathering ask individuals to write messages to a special caregiver on a designated luminaria bag.

Creating the Caregiver Experience Year Round

Captains & Committee Meetings

Captain's and Committee Meetings are an opportunity to highlight and honor your volunteers and captains who are caregivers.

- Consider hosting a special Celebrate Captain or Committee meeting where you recognize and honor all current and former caregivers. Celebrate them with refreshments and a small token of your appreciation. Consider asking one of them to tell their story and introduce you to their survivor loved one.



Creating the Caregiver Experience

Captains & Committee Meetings cont'd

- Your next Captain or Committee meeting could be where you Remember loved ones lost and their special caregiver. Consider asking a caregiver whose loved one is no longer with us to share their story and about their loved one. Honor and celebrate them with a small token of your appreciation and refreshments
- A third Captain or Committee meeting could focus on Fighting Back as caregivers. The meeting could focus on ways caregivers have or could get involved in ACS activities that help them to Fight Back – i.e. volunteering as a Road to Recovery, LGFB, Patient Navigation, ACS CAN, etc.. volunteer. Ask one or more to share their story of fighting back in honor of their loved one.

Kick-off Events & Rallies

These events often focus on bringing new people into the Relay community. This gives you a great opportunity to introduce the messaging of what and who a caregiver is (see messaging on page 3) as well as to recognize and honor those attending your Kick-off event or Rally.

Newsletters & On-line

Local event newsletters, newspapers and your RFL event's on-line page are great places to highlight your event's caregivers. Consider selecting a story that represents all three, Celebrate, Remember and Fight Back story opportunities (highlighted above). Infuse the caregiver messaging and your event will be on its way to educating your community on the many ways of being a caregiver and how your local Relay event is there as a source of recognition, healing and engagement.

- Ask survivors to submit stories about their caregivers and what they mean to them.
- Ask family and friends of caregivers to submit stories about a caregiver they know and would like to have recognized.
- Feature stories could be emailed to all Relay participants, included on your event website or newsletter and in your local paper.

Special Events & Activities

Recognizing and drawing attention to the journey of caregivers can become an integral part of your pre-event planning.

- If you host a booth or table at your local Farmer's Market, Health Fair, Holiday Fair, etc., consider including a Caregiver banner and information about engaging caregivers in the Relay & ACS community
- Plan a special Caregiver reception where all caregivers are invited to attend, have refreshments, learn about ways to get involved with or find support from their American Cancer Society and Relay For Life programs.
- Dedicate an area within your community to survivors and caregivers. The area can be adopted by teams or committee members who attend to decorating the area for the seasons and/or planning special events (holiday luminaria, etc.) .



Creating the Caregiver Experience

Tisha & Sarah's story continued...

"Years of chemotherapy treatments and doctor's appointments followed. The routine was so constant that, at times, I think we both forgot she was fighting for her life."

Sarah's mom celebrated her 62nd birthday in June of 2005- just after Relay.

"By this time, Relay was my family. Being surrounded by a group of people that knew just what I had been going through for the last several years was a comfort that was much needed in my life."

Sarah was pregnant with her 2nd daughter (due in October) and her mom was so excited. "It had been a rough few years and we needed something to look forward to."

Sarah received the call early morning that October. Her mom had taken a turn for the worse and had been rushed to the hospital. Sarah was due to give birth in two weeks.

"I spent the next seven days by her bedside, holding her hand and willing her to live. She took her last breath on the morning of October 24th, 2005. It's a moment I will never forget." Her granddaughter, Lily, was born three days later. "It seems impossible that something like this so tragic happened to me. It is even more unbelievable that Tisha's loss of her mother mirrors my own."

In 2008, Tisha's mom was diagnosed with esophageal cancer, a cancer that had no cure. Tisha swore she would be there for her mom more this time than she was when she had breast cancer several years before.

"I became her caregiver and didn't think twice about it until after her battle was over. You see, the fact that I went to appointments with her, that I sat at chemo with her and that I went to clean her PICC line and feed her through a tube twice a day was nothing to me. That's what you do because she's your mom!"

Tisha's life was rocked upside down, to say the least, when she lost her mom due to complications of cancer on Memorial Day 2009. Her 2nd son was due in just 3 weeks; due on her mom's birthday of all days.

"At the happiest time of my life I was forced to grieve the loss of an amazing woman who had so much more to do in this world. God proved he had a different plan, and I was going to have to take things one day at a time because that's what my mom taught me to do."

"Life is not measured by the number of breaths we take, but the moments that take our breath away." This quote rang true as Tisha and Sarah attended the 2011 Great West Relay For Life Summit in Seattle, WA. It was in the middle of the Caregiver presentation by Jeff Ross that he first read the definition of a Caregiver.

"Caregivers, simply put, are those unsung heroes who care for a cancer patient during their cancer journey. Some might be at Relay with their cancer Survivor. Or maybe some of you are like ME, you have lost that special person you cared for. You are a caregiver!

Jeff Ross - Relay For Life Hall of Fame Member

As is true with many Relayers, this was a difficult subject for both Tisha and Sarah as their loved ones, their mothers, were no longer with them. Following the Great West Relay For Life Summit, we continued to work with our committee and discussed several ways in which we were going to honor the Caregivers of our community.



Creating the Caregiver Experience

While Survivor recognition was vital, it was also important to both of us that we implement Caregiver recognition into our opening ceremony and throughout the event. We followed a similar format of what was presented to us during Summit; recognizing Survivors first followed by a short poem for our Caregivers.

We then asked Survivors to present each Caregiver with a special pin to recognize their contribution. For me, that simple pin is a constant reminder of the gratitude my mom expressed on a regular basis. I have it on my makeup bag and see it every day.

Following our opening ceremony, we asked our Survivors to walk the first lap followed by a 2nd lap with the Caregivers. It meant so much for both Sarah & I to be recognized, as our loved ones were no longer with us. The results of our efforts were immediate. Many participants approached us throughout the event expressing gratitude and mirroring our same feelings. It was an unforgettable experience and we are so happy that we were able to share it together.

“The results of our efforts were immediate. Many participants approached us throughout the event expressing gratitude and mirroring our same feelings.”

Tisha & Sarah

Caregiver Luminaria Script Example #1

Blessing of the Hands

SPEAKER:

You are here tonight because you are a HERO! Whether you think so or not; the small things you did made a big difference to that person who suffered (suffers) with cancer. Yes, you are our HEROES... You made the difference!

Interactive Piece:

SPEAKER: (invites all caregivers up in front of stage)

Please do this exercise with me.

- *Look at your hands – (pause) It was these hands that cared for them. Look at them!*
- *It was these hands that bathed (cleaned) them... Look at them!*
- *It was these hands that fed them*
- *It was these hands that worked tirelessly for them*
- *Now cross your arms (pause) – (Make this very personal)*
- *It was your arms that lifted them*
- *It was your arms that carried them*
- *It was these arms that hugged them... Yes! these arms*
- *Now cross your arms over your heart (pause; do not rush!) – This is the heart that CARED!*
- *This is the heart that shared*
- *Yes! It was your heart that remained strong to help them through the night... Yes, it was your heart!*
- *Even though you grew weary, you remained strong because you had too... just for them*
- *Yes, It was your heart!*

And tonight the American Cancer Society takes this time to honor you...our hero's...our light...OUR CAREGIVERS!

Glow sticks will be available to distribute to all Caregivers participating in the activity. The caregivers will be instructed to lead the lighting of the Luminaries/Luminaria lap and everyone then will follow suit.



Creating the Caregiver Experience

SPEAKER

Because you light the night for our cancer patients we light these honoring you. (Demonstrate by holding up lit glow stick). Please accept this honor by doing what you do best. Lead us in illuminating our Luminaria as we take this special time to honor you and remember family, friends, and loved ones.

(Volunteers distribute glow sticks to caregivers who participated and ask them to begin lighting luminaria)

(Give 1-2 minutes for Caregivers to disperse and begin illuminating luminaria around track)

SPEAKER/PERFORMER -

Announcement: Ladies and gentleman – at this time, we invite everyone to join our caregivers in lighting our luminaria. There are committee members around the track ready to assist you by providing glow sticks.

“Even the smallest forms of gratitude and recognition can mean the world to someone who acts out of love and never needs to be thanked.”

Tisha & Sarah

Caregiver Luminaria Script- Example #2

Supplies:

- Glow sticks in orange, yellow, light blue, pink and purple
- Individual luminaria bags per individual

Good evening, Relayers –

We now come to one of the most special components of Relay – our luminaria ceremony. A time to celebrate and remember the lives of each of our loved ones.

One of my favorite songs, sung by Barry Manilow is called “One Voice”. The words reflect the importance of just one person taking a chance and raising their voice to make a difference. Your one voice leads to another and another. Soon everyone is joining in – making a difference together. Your one voice leads to Hope. Hope for someone who has just begun their cancer journey. Hope for someone struggling with the loss of a friend or loved one. Hope for future generations that they won’t have to face the same fears as many of us have faced.

So tonight, we honor you – survivors who have bravely fought the battle and the caregivers who have courageously stood beside someone during their journey. Caregivers who are currently providing care and those whose loved one is no longer with us. We know your special contribution lives on, even when the battle is over.

You have in your hands glow sticks that represent your role as a survivor, a caregiver or a supporter through Relay .

Each color of glow stick represents something different:

Survivors - over 15+ years – ORANGE

Survivors - 0-15 years – YELLOW

Caregivers - currently or no longer providing care - PINK

Caregivers - loved one no longer with us – BLUE

Relayers – PURPLE

SONG begins to play.....

We would like to ask those who have survived 15+ years to (stand, move forward) and remain standing with your luminaria bag and ORANGE glow stick inside.



Creating the Caregiver Experience

Survivors who have been winning the battle 15+ years. You are HOPE. You are the voice of encouragement to your family, friends and each other and to our newest survivors. You are winning the battle and we need your VOICE to raise money, to raise awareness and to raise up each other in the fight.

Now we would like to ask those who have survived from the present time to 15 years to (stand, move forward) and join your fellow survivors with your luminaria bag and YELLOW glow stick.

Survivors who have been winning the battle from present time to 15 years. You are Hope. You are the voice of encouragement to your family, friends, each other. You are winning the battle and we need your VOICE to raise money, to raise awareness and to raise up each other in the fight.

Caregivers whose loved one is no longer with us, please (stand, move forward) and remain standing while holding your luminaria bag and BLUE glow stick.

Caregivers, You are Hope. You were the strength of your loved one. You were the wind beneath their angel wings. There is still a place of honor for you at Relay. A place where healing begins. A place to celebrate the life and legacy of your loved one. A place to remember the special times you shared. A place where your journey together is not forgotten. Through your voice, your loved one's memory lives on and for that, we honor you.

Caregivers who are currently providing care or are experiencing the joy of celebrating your loved ones survivorship, please (stand, move forward) and remain standing and hold your luminaria bag and PINK glow stick.

Caregivers, You are Hope. You have been there with your loved one every step of the way. Perhaps your journey as a caregiver began at Relay while taking that triumphant lap around the track with your survivor. For the comfort and care you have given, we celebrate you. For the voice you lend to helping conquer this disease, we salute you.

Relayers, please (stand, move forward) and hold your luminaria bag with PURPLE glow stick. Relayers, You are Hope. You are the voice of encouragement to your family, friends, to each other and to all these survivors and caregivers. Your relentless commitment to this battle is needed more than ever before and we need YOUR VOICE to raise money, to raise awareness and to raise up each other in the fight.

As you can see, each of us has a significant voice in the fight against cancer. Whether you have battled this disease yourself, or stood bravely next to someone else during their journey – we all have a voice. A voice to provide comfort. A voice to provide care. A voice to provide Hope.

For all that you do for the American Cancer Society, we honor each one of you. Thank you for letting your voice be heard. Please honor each other by walking the first lap together in appreciation and quiet reflection.

THANK YOU!

Play song again – but loud enough for the audience to hear as they walk the track silently.

