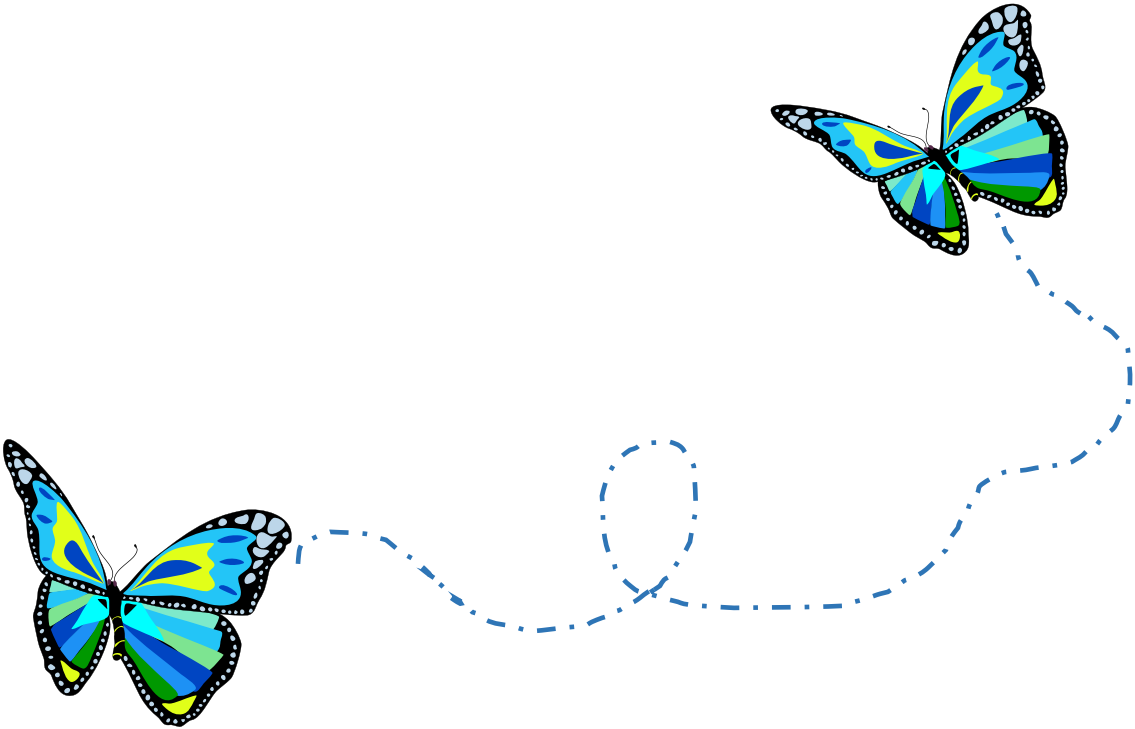




# Stay in Touch Program Manual



St. Jude Children's Research Hospital  
Bereavement Program

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## Stay in Touch Program Training Manual

### Part 1: Basics of the program

Introduction: The *Stay in Touch* program began as a pilot program to reach parents of every St. Jude family that has experienced the death of a child. Maintaining communication with bereaved parents and providing support is essential during the early months of their grief journey. Many studies have shown that having a bereavement care program is an integral part of an institution's overall success and has largely been beneficial for bereaved parents. To learn more about this topic, please see *Empowering Bereaved Parents Through the Development of a Comprehensive Bereavement Program*. The weblink is located on the resources page of this manual under *Part 5: Quick References*.

The mission of the Stay in Touch program is to provide newly bereaved parents of St. Jude Children's Research Hospital with the unique understanding and support which only another parent who has walked a similar path can provide. More specifically, the *Stay in Touch* program's goal is to reach out to parents and provide them with bereavement support and resources in the first year of their grief journey.

Purpose: As a component of a comprehensive institution-wide bereavement program, trained bereaved parent advisers provide bereavement support and information about St. Jude bereavement resources to newly bereaved parents or caregivers via phone calls, texts and emails. Parent advisers also communicate concerns or needs identified to the bereavement coordinator for follow-up.

Program Description: St. Jude bereaved parent advisers complete Level 2 volunteer training through Patient Family-Centered Care. They then receive specific training focused on making a series of bereavement contacts with newly bereaved parents or caregivers. Beginning approximately 2-3 months following a patient's death, bereaved parent advisers contact parents or caregivers who have not been identified by their psychosocial team to be "high risk" for complications in bereavement. Parent advisers, following a loose script, offer support to bereaved parents or caregivers and provide information about grief resources available through the bereavement program at St. Jude. Physical, mental, emotional, spiritual adjustment or other identified needs are communicated to the bereavement coordinator for follow-up. If the parent or caregiver agrees to be contacted again, the parent adviser calls, texts, or emails, as requested, on a monthly basis up to 3 more times, or as agreed upon with the bereaved parent.

Parent advisers are provided information forms through encrypted email. Each form includes the name of the patient and pertinent family information: patient's date of birth and death, names and contact information of parents or caregivers, known risk factors for complicated bereavement, siblings, diagnosis and a brief summary of the patient's illness, treatment and death circumstances. Parent advisers complete a Bereavement Encounter Form after each successful contact or series of attempted monthly contacts. The content of the contact is summarized and identified concerns and resource needs are explained. The form is accessed by a web link and, when submitted, is emailed to the bereavement coordinator and then

permanently stored on a secure site. When a form is successfully submitted, the sender receives a message and a copy of the submission.

Parent advisers participate in debriefing telephone sessions with the bereavement coordinator or parent supervisor if either a parent caller, parent supervisor or bereavement coordinator deem it necessary.

## Part 2: Important Information

### Role Distinction

*Stay in Touch* Parent Volunteer vs. QoL Parent Mentor: It is important to make a clear distinction between the roles of the bereaved parent adviser in the *Stay in Touch Program* and the QoL Parent Mentor Program. The role of the parent mentor is to provide support to another parent by establishing an ongoing, ever-deepening relationship through support, encouragement and availability. In contrast, the role of the *Stay in Touch* bereaved parent adviser is to attempt to establish contact with newly bereaved families to:

- express condolences on behalf of St. Jude and as someone who knows the pain and loss of losing a child,
- offer the caregiver an opportunity to share their story with a compassionate listener,
- inquire about the family's bereavement needs and communicate them to the bereavement coordinator, and
- provide information to caregivers about resources available through the St. Jude bereavement program.

A strength shared by the Parent Mentor and *Stay in Touch* programs is that the bereaved parent adviser's personal experiences offer a common ground for connecting with other St. Jude parents.

Similar to the role of a parent mentor, as a *Stay in Touch* parent adviser, you will use parts of your personal story in your conversations with newly bereaved parents. For example, you might talk about what you needed when you were first bereaved. You may also share briefly some of the struggles you had in your early grief and follow it with a question such as "Have you had any worries about how you are coping?" You might share what you've learned about "normal" grief. For example, "you're not crazy, you're grieving" and "it's normal to have sleep and appetite changes."

### Complicated Grief

Complicated grief is considered when an individual's ability to resume normal activities and responsibilities is continually disrupted well beyond six months of bereavement. Six months is the minimally appropriate point to begin considering Complicated Grief Disorder, since studies show that most people integrate bereavement into their lives by this time and resume functioning for the most part.

While you will be contacting caregivers who will generally not be far enough out from their loss to meet the criteria for the disorder (at least 7 months), it is important to know the predictors

and symptoms. Over the course of your contacts, you will generally see some improved functioning in most caregivers. This does not imply that the grief should be resolved--it means that most parents are able to begin to function in their daily tasks of living and most are able to return to work. When this is not the case, or when you see deterioration in functioning, there should be red or pink flag concerns.

### Predictors of Complicated Grief

- Multiple losses
- Traumatic death
- Knowledge of prognosis of the illness
- Previously diagnosed with a mood disorder
- Previous fragile physical health
- Low self-reported social support
- Insecure attachment with the deceased
- Child loss
- Difficulty expressing emotions
- Inability to handle stress
- Emotional reactions of anger, bitterness or intense guilt
- Low frustration tolerance
- Lack of religious affiliation or spiritual connection

If you identify one or more of the predictors listed above in a conversation, please make sure to indicate it on the Encounter Form (see pg. 18) and describe details in the “Brief Summary of Call” section. Indicate a pink flag or red flag concern.

### Pink Flag & Red Flag Concerns

Pink flag concerns arise when a parent tells you something that is worrisome. These do not immediately affect the physical or mental safety of the caregiver or another person but are of concern and need attention. Red flags concerns are extreme or urgent situations that require immediate action.

#### Pink Flags

- Excessive parental worry
- Family or spousal conflict
- Health concerns regarding the parents
- Concerns regarding the siblings
- Extreme financial concerns

Displaying behaviors that might prove to be harmful over time (increased risk taking) such as:

- Drinking more than usual
- Using more prescription or non-prescription drugs
- Engaging in sexual activities that are unsafe or unwise
- Driving in an unsafe or reckless manner

### Red Flags

- Depressed mood
- Suicidal thoughts or actions
- Suspected child or elder abuse/neglect
- Suspected domestic abuse
- Alcohol/substance abuse
- Significant complaints about staff

For any red flag concerns, take the following actions immediately:

1. Tell the person: *“It sounds like the last days/weeks have been really hard for you. Given what you have been telling me, I am going to ask Dr. Lisa Clark, who is a psychologist and the bereavement coordinator, to call and check in with you as well. She may be able to locate some resources close by to you that can help you get through this.”*
2. Call Dr. Lisa Clark, Bereavement Coordinator, (901)595-2658-office, (901)848-8392-cell, to discuss the situation. If not available,
3. Call the Parent Mentor Program Coordinator, Brittany Barnett, 901-595-7560. If not available, social worker Traci Adams at (901) 595-3667 or psychologist Kristin Canavera at (901) 595-6053
4. Call 911 for all concerns about immediate safety.

### Grievances

You may occasionally speak to an angry parent. There are many reasons why a parent can be angry or frustrated, including grief. When you encounter an angry parent, it is important to utilize compassionate listening. Listen to the parent and validate their emotion (e.g., “I can hear how angry you are about that” or “I hear how upset you are.”) Do not give advice, argue with the parent, or try and talk them out of their feeling, even if you feel compelled to. Most people who are angry want to be heard and to have their feelings acknowledged. You don’t have to agree with their thinking. Once you have finished your call, inform Lisa Clark about the situation. She will determine the appropriate course of action to take. In some situations, the St. Jude patient relations coordinator may contact the family to help resolve a problem.

### Boundaries

This work requires great capacity to maintain balance. You are being asked to journey with another to a place you have already experienced intensely and help them find their own way and their own strengths to live in the new normal. This work can provide tremendous benefit to others, personal satisfaction and, at the same time, can take an emotional toll. Boundaries are essential to maintaining balance, supporting good self-care and avoiding burnout.

Boundaries are with us always as a natural part of our journey through life. They serve to protect and to define us individually and in our relationships with others.

A first step toward good boundaries in this type of relationship is to clearly define your role. Having clarity regarding the limits of your role helps the bereaved parent you are contacting understand your purpose and your limits. When you are mindful of role boundaries you are helping the newly bereaved parent by supporting them as they find their way in this new world without their child. While you can provide support, each newly bereaved parent must find their own way through grief. Recognizing that will be very helpful. What worked for you may not work for them. You can only make suggestions. Don't take responsibility for making sure they take your suggestions.

Most people come to this work of helping others in difficult times out of great compassion, with a desire to ease suffering, to support, inspire, encourage and to assist. It can be these very motivations that also provide the impulse to cross or violate boundaries.

### Boundary Violations

To better understand a boundary violation, the nature of the action, the intent, the impact, the frequency, and the motivation are all points to consider. Boundary violations are serious and can damage autonomy and trust. Some examples can include using or sharing confidential information for your benefit, attempting to influence a parent's decisions based on your beliefs and/or forcing your influence in any way. An example of a boundary violation would be accepting or initiating a friend request with a parent or joining a Facebook group with that parent in it. There should be no continued contact with the parent after you complete the four-month contact program.

Boundary violations usually occur because:

- We try to please others at our expense and possibly the expense of others
- We desire to solve problems rather than empower
- We act as super-caregivers and deny our needs
- We begin to feel more special than others
- We think we know better than others
- We don't recognize our own secondary pain and suffering and take refuge in activity

In summary, good boundaries are essential for this type of relationship. Developing them requires self-awareness which enables you to monitor your own emotional reactions and listen to your intuition. Establishing trust, while avoiding over involvement is crucial. Sharing with the parent that you will be sending a summary of each contact to the bereavement coordinator fully informs the parent from the beginning. Transparency helps to build trust. If you are ever in a situation and in doubt, proceed with caution and call Lisa to discuss.

### Emotional Impact

You become an active participant in a newly bereaved family's grief journey by providing resources and bereavement support. Devoting energy and focus to this can be emotionally, physically, and spiritually draining. As a parent who has gone through similar events, the families you serve will touch the depths of your heart and soul. Because of your personal experience, chances are slim that you can avoid the stress of emotional involvement. Working

within appropriate boundaries, having self-awareness, and implementing a deliberate plan for self-care will enable you to provide these necessary resources to families and lead your own healthy and separate life.

### Self-Awareness

As a *Stay in Touch* program parent adviser, you will be in a role that requires personal awareness and evaluation. Why? Because talking with families who are grieving will cause you to grieve. It may even bring up unresolved grief from your own experience that may catch you by surprise. If you feel grief, it will not mean that you are “weak” or that you “can’t handle” being a parent adviser. It simply means that you are human and experiencing emotions are normal when caring for others. The task is being able to identify self-concerns, evaluate the severity, and to take steps to address them. Some things to be aware of:

- Exhaustion and loss of energy
- Irritability and impatience
- Cynicism and detachment
- Physical complaints and depression
- Inability to stop thinking about a conversation or bereaved parent
- Ongoing need to check in with a parent before the next scheduled contact time

### Self-Care

To embrace the deep appreciation for the role you have assumed, you must stay grounded. To do so means caring for yourself as well as for others. Here are a few suggestions which seem to be common among caregivers:

- Embrace supervision/support—share any concerns about your reactions
- Associate and celebrate with people who are not connected to St. Jude
- Engage in a hobby that is not connected to St. Jude

Think of ways to care for yourself in the moment should you have a difficult or upsetting interaction with a grieving parent and find yourself sad, stressed, anxious or angry. Some suggestions are: go for a walk, go to the gym, meditate or pray, listen to calming music, take a bath, call a friend. List some things here that you can choose from when you need self-care in the moment: \_\_\_\_\_

### Sharing Your Story

Personal stories, when shared well and at the right time, can serve as a powerful tool to encourage and share hope with another person. It is important to clearly understand the purpose and intent of your message. Each circumstance requires a special understanding and sensitivity to know whether it is appropriate to share your story or not and which part of your story might be helpful to share.

When effectively sharing your story, you can expect that some people who hear it may be deeply moved. You may also feel emotional at times. Remember that emotions are an honest



response to the reality of life circumstances. Vulnerability and openness make your story more powerful and make you more approachable.

### Sharing a Negative Experience

Sharing a negative experience can validate another person's feelings. Sharing negative experiences can be appropriate if you make it a constructive learning opportunity by emphasizing the positives.

Briefly describe a negative experience you have had in your grief journey. What positives came from that negative experience? \_\_\_\_\_

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### The Value of a Story

Our stories are what define us as human beings and allow us to connect with each other. Your story is a gift. Take some time to think about your story, you can even write it down if that helps you. Some things to consider including in your story: what you felt when your child died; what you felt in those first days, weeks, months; what helped you cope; what gave you peace; what caused you stress, etc.

### Time

Before you get started talking with parents, it is important to understand the time commitment you are about to enter into. While it is important to listen to parent's stories, concerns, and worries, you should attempt to limit your conversations to under an hour. While the length of each conversation may vary, it is important that you share the appropriate resources with parents. If you find yourself having difficulty keeping your conversations under an hour, try one or more of the following suggestions:

- Suggest the Quality of Life Parent Mentor program by commenting "I can tell that it's helpful for you to talk to another bereaved parent, so I'd like to refer you to our Quality of Life Parent Mentor program. Would that be okay?" This is an excellent program to refer parents to, especially if you think they would benefit from it.
- Suggest a call from Lisa Clark, the bereavement coordinator.
- Gently say, "I wanted to let you know that I have about (give amount of time) minutes and then will have to end our conversation. I wanted to let you know now so that I won't have to just cut you off later."

Although this program requires a time commitment, it also offers a lot of flexibility to you, the parent adviser. While you may need to coordinate with a parent a convenient time to talk, there is not a specific time of day that you must call. Let this program work around your schedule. You can be flexible. If you find that the only time a parent can speak with you is a time that you aren't available, let Lisa know. She may reassign the parent to another parent adviser who is available at that time. More often, you may find that you get no response from the parent you are attempting to contact. It's easy to get discouraged by this but please

remember the early days of your grief. You may have not wanted to talk to anyone at that time either. However, each parent you text, email or leave a voicemail for knows that they are not forgotten or abandoned. They know someone cared enough to reach out to them and that means a lot. You may find it helpful to get tips from some of the seasoned parent advisers who have developed messages that get more responses than others.

### Confidentiality

You may be wondering how you are to keep the patient's protected health information (PHI) safe and confidential when you are sending in encounter forms. As a parent adviser, you are considered a "workforce member;" therefore, you have access to "need to know" information. This allows us to send you information about the patient and the family in our information forms. It also allows you to send us information through the encounter form. Through your St. Jude email, information will be secure. Do not send any patient or family information through your personal email.

Do not share patient information with your friends, family, St. Jude staff members or other volunteers that do not need to know information about the family you are calling. You are not to talk with your own care team regarding another patient and should never give out information about one of your parents or their families to another parent.

Any information that you might gain from being a parent adviser at St. Jude is considered confidential. You have probably heard of HIPPA at some point prior to this training. HIPPA stands for the Health Insurance Portability and Accountability Act of 1996. This act requires that everyone, including volunteers, safeguard and protect patient health information. This information can be oral, written, or electronic. It includes medical records, conversations, emails, and texts. To safeguard patient information, shred any notes regarding the calls you make when you are finished. Lock your cell phone with a 6-digit passcode and do not discuss private information regarding the patient or their medical status via text unless the parent brings it up first. Only use your St. Jude email when discussing patient information and type [Encrypt] in the subject line to ensure the utmost security.

Do not "friend" a parent you have contacted on social media, such as Facebook. Do not post any comment on a parent's Facebook page if you have contacted them through this program.

## Part 3: Making Contact

Listed below are the steps to contact a family. A visual representation is provided on page 13. Once you make contact, we have provided a guide of talking points that may be helpful during specific calls. This is just a guide and does not have to be strictly followed. One parent texts and if no response sends out an email and calls the next day. Another parent calls first and leaves a message stating that she will be texting and sending an email. You might want to try a several approaches and see what works best for you.

### Initiating a Contact

Month #1

### Step 1: Text

- Send a text message to the number listed on the Bereavement Information Form
  - Your message should include who you are, what your purpose of the call is/why you want to call, when would be a good time to talk to the parent
  - Here is a sample text:

*“Hello [insert parent’s name]. I was so sorry to hear about your dear child [insert [insert child’s name]. My name is [insert your name] and I’m a St. Jude mom. My (daughter/son) died of [insert diagnosis] in [insert year]. I’m also a parent volunteer working with St. Jude to better support you through your grief journey. I was wondering if there is a time that I might give you a call to let you know what grief resources are available to you through St. Jude. Texting or emailing is also fine if you’d rather not talk on the phone.”*
  - If you receive a response within 48 hours, schedule a call
  - Following the call, submit an encounter form under “Encounter 1”
- If the parent doesn’t respond in 48 hours, then go to Step 2

### Step 2: Email

- Parents may not respond to a number that they do not recognize. Send an email if one is provided to you. If an email is NOT provided, send a second text message that is very similar to your first one.
- Always send emails from your St. Jude email address explaining who you are, your purpose, why you want to set up a call, and when would be a good time to speak or text, etc.
  - Here is a sample email:

*Hi [insert parent’s name],  
My name is [insert your name] and I am a St. Jude parent volunteer who lost a son/daughter to cancer. I am so sorry to hear about [insert child’s name] passing.  
I sent you a text message on [enter date/time of text]. If you are willing, I would like to speak with you to let you know about the grief resources St. Jude provides to families. If you are willing to speak with me, please text me or respond to this email with a good time to reach you.  
Thank you,  
[Your name and phone number]*
- If the parent responds within 48 hours, schedule a call
  - Following the call, submit an encounter form under “Encounter 1”
- If the parent does not respond to your email within 48 hours and has not responded to your text, move to Step 3

### Step 3: Call

As mentioned before, some parents do not answer calls when they do not recognize the number. Although you may have previously sent a text, they might not recognize the number or have saved your number.

Call the number provided to you.

- If the parent answers, say who you are, why you are calling, and ask if it is a good time to speak with them
  - If it is a good time for the parent to speak with you, continue your conversation with them, and submit an encounter form under “Encounter 1”
  - If it is not a good time for them, ask to schedule another time to call.
    - Call back at the scheduled time you discussed. If the parent answers, re-explain your purpose and continue your conversation with them. Once this is done, submit an encounter form under “Encounter 1”
    - If the parent does not answer, leave a voicemail explaining that you will call again in a month, acknowledging that they are going through an extremely difficult time now.
      - Submit an encounter form as “No Contact Made” for “Encounter 1”
      - Try calling the next month
- If your first call goes straight to voicemail, leave a message explaining who you are, why you are calling, etc. and that you will call again in a month, acknowledging that they are going through an extremely difficult time.
  - Wait 48 hours in case they do call back and submit an encounter form under “Encounter 1” as “No Contact Made”

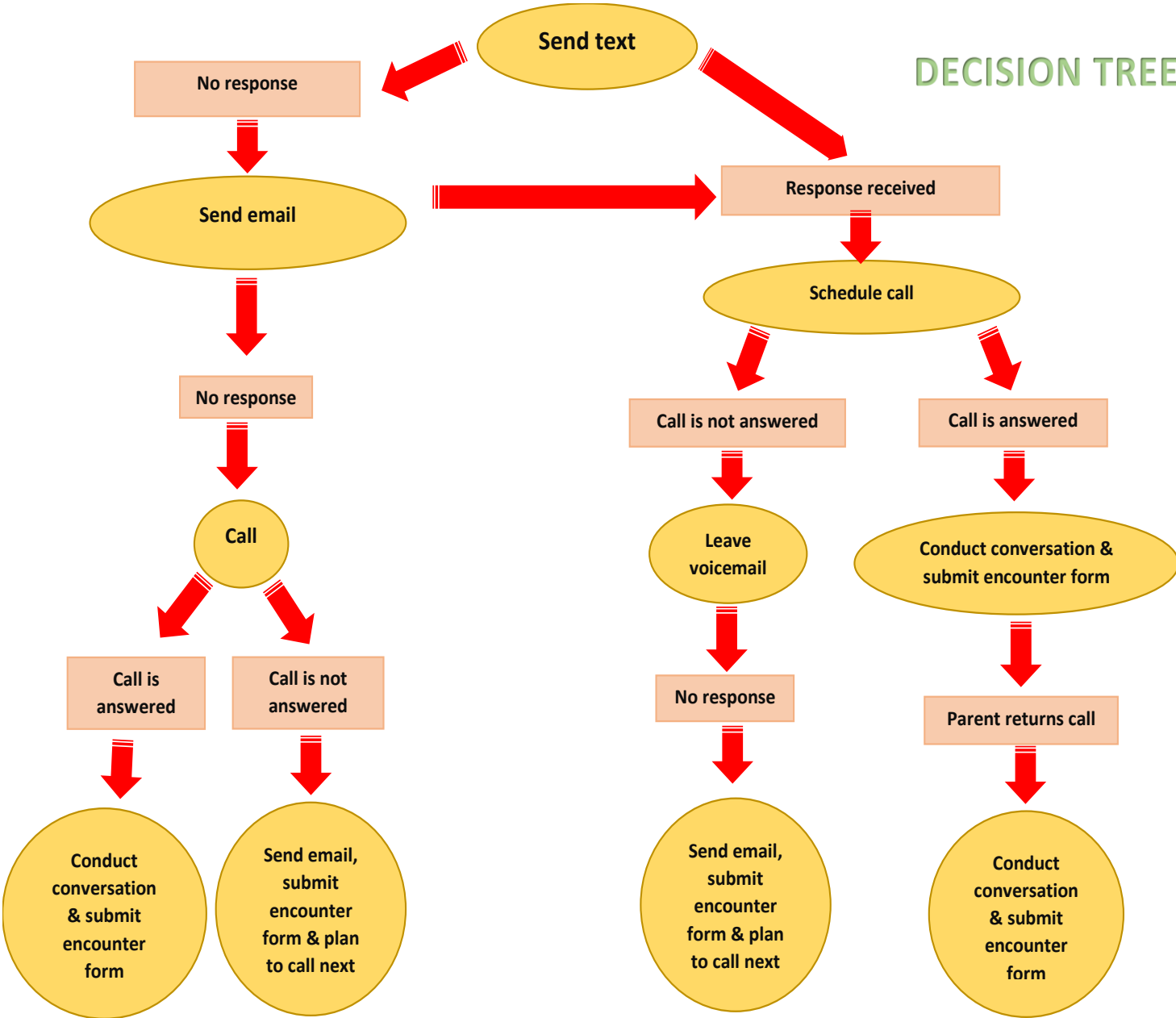
Months #2-4

Repeat steps 1-3 above.

- Review previous encounter form and notes before calling. Ask follow-up questions based on those. Example: “Were you able to connect with your parent mentor since we last talked?” “Were you able to check out the bereavement website?” I also sent you an email last month about other programs created by St. Jude bereaved parents for bereaved parents. Did you see it? If not, I can send it again.”
- Ask about mailings. For example, “Did you receive the Seasons of Change book? It’s the size of a magazine. The stories were written by St. Jude bereaved parents.”
- Submit an encounter form within 48 hours after a successful contact. For example, if you texted or called the second month and the parent answers, within 48 hours submit an encounter form under “Encounter 2.”
- Submit an encounter form each month after completing steps 1-3, even if you do not get a response. For example, if you got no response the first month and now it is the second month, attempt steps 1-3. If you get no response after attempting each step, submit one encounter form under “Encounter 2” and mark it as “No Contact Made.”
- Final contact (month 4)—let the parent know this will be your last contact. If you want, you can encourage them to keep your contact information in case they need to reach you in the future. This may give them a lifeline to hold on to. Remind them that St. Jude is still here for them and they can reach out to the bereavement coordinator at any time.

Decision Tree

DECISION TREE



### Length of Call

Your initial call to a caregiver should last about 20-30 minutes and not more than 60 minutes. If a call lasts longer than 60 minutes, you have likely moved into the role of a mentor. If you find that the caregiver is asking you a lot of questions about your St. Jude experience or your own grief journey, or is disclosing a lot of personal details, it is important to utilize that opportunity to tell them about the Parent Mentor Program or to offer to have the bereavement coordinator contact them. Subsequent calls should typically be shorter than the initial call.

### Emails

When available, you will be provided with a caregiver email. You will find that some parents will respond to an email but will not answer a phone call or text. Please remember to encrypt emails [Encrypt] and to always use your St. Jude email when emailing a caregiver.

### When to Stop Attempting Contact

Do not make further attempts to contact a caregiver when any of the following conditions apply:

- the caregiver requests that you make no further contact
- the bereavement coordinator instructs you to make no further contact
- you complete the 4 calls
- you have made **3** consecutive attempts at contacting the caregiver following steps 1-3 outlined above with no response for that month

### Documentation of Contact

To document your contacts with each family, you will be given access to an Encounter Form (see page 18) and will briefly summarize your call or attempts to contact parents. You can access the form and complete the form online by clicking this link:

<https://hospital.stjude.org/apps/forms/fb/bereaved-encounter-call/>.

Successful contacts: Following a response from a caregiver, you will complete and submit **one** Encounter Form within 48 hours, unless there is a red flag concern. ***If you have a red flag concern, follow the instructions on pg. 6 and complete an Encounter Form immediately.*** If you identify any concerns during your conversation, please give details in the summary section of the encounter form and be sure to indicate any pink or red flag concerns.

Unsuccessful contacts: Complete **one** encounter form per month after you have made 3 attempts to contact a parent with no response. For example, you text on Monday, email on Wednesday, and call on Friday without a response. You then submit one encounter form within 48 hours of your last attempt detailing your 3 attempts to contact the parent.

In addition to submitting a monthly encounter form for each patient family, we strongly recommend that you keep track of contacts you've made and due dates for next contacts. See pages 25-26. Please use whatever method of tracking works best for you.

## Preparing for a Call

Before you make a call, take a few moments beforehand to review the information sheet regarding specific information about the family. After reviewing the information sheet, look over the St. Jude resources listed below and familiarize yourself with them. For example, if the family is local to Memphis, make sure that you make the family aware of the local monthly St. Jude bereaved parent support group. Taking notes during your calls and reviewing them before the next call will allow you to follow up with the parents about concerns or resources they might need or want. We have created a tracking worksheet for you to track your phone calls if you find this to be a helpful resource.

Before calling, go to a quiet area and take a deep breath. You are playing an important role in assisting newly bereaved parents in finding resources and supports that work for them on their grief journey.

The guide below may help you navigate your conversations with caregivers. It is meant to serve as a guide only. Allow your conversations to flow naturally.

## Conversation Guide

### Call/Contact #1

- Newly bereaved parents will most likely want to tell their story
  - You will hear things about disease, progression, death
- Ask parents how they are/what today is like

**Tip:** You may want to use part of your story here. One parent said, *“I feel invasive asking direct questions to someone I do not know. I approach questions by sharing my own experience first. I may say, “When my child died, I struggled with crying all the time. How are you doing with that?” Or, “I struggled with sleeping because each morning I’d wake up and have to relive it. Are you sleeping?”*
- Ask about any immediate concerns
- “ Did you receive the Bereavement Resource Guide?”
  - Think about which resources this parent might benefit from. Mention the St. Jude resources to them
- Verify the mailing and email addresses
- *NOTE: This call may last longer than others, as it is your first conversation, and most parents share their story during this call.*

### Call/Contact #2

- “Since our last conversation, have you noticed any differences in your grief?”
- Refer back to topics you discussed in your first conversation
- Any new concerns? How are they managing their concerns?
- “Have you utilized any supports or resources?” Are there needs for specific resources?
  - Counseling centers, books, grief camps, support groups
- Discuss the St. Jude resources they might be interested in
- “How are you remembering your child?” “How are you keeping him/her present? One way I keep \_\_\_\_\_ present is by saying his/her name.”

### Call/Contact #3

- “Compared to the first two months, how has this month in your grief journey been similar or different?”
  - Perhaps talk about sleep, appetite, attention. “Has it gotten better or worse since the death of your child?”
- “Are you receiving our mailings? Specifically, have you received the *Seasons of Change* booklet?” They may remember it if you describe it as the size of a magazine with pastel colors that came in a big white envelope. Let them know that the book contains stories which were written by St. Jude parents.
  - If parents are not receiving bereavement mailings, please let the Bereavement coordinator know
- “What can we do for you in terms of providing support and resources?”
  - Remind them of the St. Jude resources and note which ones might benefit them

### Call/Contact #4

- This is the last contact, so let the parents know this
  - “From this point, you will need to reach out to us for help in connecting to supports and resources.
- Are there any lingering needs or concerns regarding resources?
- Remind the parent of the resources they can tap into
  - “You will find most of our resources at [www.stjude.org/bereavement](http://www.stjude.org/bereavement). For assistance, contact Lisa Clark at (901) 595-2658 or at [lisa.clark@stjude.org](mailto:lisa.clark@stjude.org).”
  - Resources will also be listed in the closure email you send after you complete all 4 months of contacts

### Program Support

You may call the bereavement coordinator, Lisa Clark, at any time for support and guidance. If you experience an interaction with a caregiver that is upsetting or disturbing, please contact her right away. If she is unavailable, please call either Kristin Canavera, psychologist, or Traci Adams, social worker. (See page 26 for contact information.)

A phone call will be scheduled with Lisa Clark or a more experienced Stay in Touch parent adviser upon request by you, Lisa or a supervising parent adviser to debrief, provide more training and to reflect on your experience as a bereaved parent in the program. This will also be a time to review program strengths and areas for improvement. It is important that this experience be a positive, healing one for you and we want to make sure that you are engaging in self-care and monitoring your emotions. You may end your participation in this program at any time. We value and appreciate your generosity with your time, effort and input and will do everything we can to support you!



## Helpful St. Jude Resources

Below is a list of St. Jude resources for newly bereaved parents. Descriptions are provided to help you when discussing resources with parents.

**Bereavement Mailings:** Our bereavement coordinator sends a series of mailings to our families. These mailings contain information about grief and grief resources, such as books, national organizations, grief camps and more. Parents are also mailed information about events at St. Jude specifically for bereaved parents. Below is a timeline of the mailings:

- 2 weeks after notification of death—Coping with Loss: A Grief Support Guide
- 10 weeks after notification of death—Seasons of Change booklet
- Late October/Early November—Holiday brochure
- Late May—Day of Remembrance Save the Date card (only if family is at least 6 months out from the death of their child)
- Early August—Second Day of Remembrance Save the Date card
- One year—Anniversary card

Samples of these mailings are included in your training packet.

**QoL Parent Mentor Program:** Quality of Life mentors are bereaved St. Jude parents whose children passed away at least 2 years ago. They have been trained to mentor newly bereaved parents. Bereaved parent mentors provide support, encouragement and insight to help families navigate through grief. They draw on their own experiences to provide a special connection for those trying to adjust to life without their child. Mentors are matched with mentees for at least 15 months.

**St. Jude Voice--Legacy Voice:** An online St. Jude advisory community of bereaved parents and caregivers. Through surveys and forums, Legacy Voice members share their perspectives and opinions on topics related to end-of-life and bereavement care for patients and families. Any St. Jude bereaved parent or caregiver is eligible to apply. Members can also keep up with the latest St. Jude news and receive community support through articles, newsletters and videos. To learn more, go to <https://www.stjude.org/treatment/patient-resources/patient-family-centered-care/volunteer-opportunities/st-jude-voice-virtual-advisor-community.html>.

**St. Jude Annual Day of Remembrance:** An annual event hosted by St. Jude each fall, Day of Remembrance was created by a task force of bereaved parents who wanted to ensure that other St. Jude families had the opportunity to honor the memories of their children here at the hospital. This is a 2-day event (Friday and Saturday) during which families and staff can remember their child, meet other bereaved families, and celebrate the lives of their children. Once you are 6 months out from the death of your child, you should receive invitations for 5 years. A Save the Date card is mailed out in late May and a second reminder is mailed in August. Families can register online at [www.stjude.org/dor](http://www.stjude.org/dor). If you don't receive an invitation, email [lisa.clark@stjude.org](mailto:lisa.clark@stjude.org) or call (901) 595-2658. Let us know if your contact information changes so that we can keep in touch with you.

Local Bereaved Parent Peer-Support Group: This group of St. Jude caregivers meets the third Thursday of each month from 6:30-8:00 p.m. at Island Community Church, just off the campus of St. Jude. It is open to any bereaved St. Jude parent or caregiver. The meetings are unstructured, informal and provide an opportunity to meet and connect with other bereaved parents. Child care is provided. Contact Lisa Clark, [lisa.clark@stjude.org](mailto:lisa.clark@stjude.org) or (901) 595-2658 for more information.

Grief resource library: An extensive list of grief resources for all groups and ages is located on the Grief and Bereavement Support webpage at [www.stjude.org/bereavement](http://www.stjude.org/bereavement). The bereavement coordinator also has grief books she can mail to families. Let her know an age or specific grief topic a family needs.

Assistance with locating grief resources: Our bereavement coordinator can assist with locating grief resources such as support groups, camps, and bereavement counseling, in a family's local community. Contact Lisa Clark at [lisa.clark@stjude.org](mailto:lisa.clark@stjude.org) or at (901) 595-2658.

St. Jude bereavement website: <http://stjude.org/bereavement> Find information about grief, helpful resources, St. Jude events and programs for bereaved families, and St. Jude volunteer opportunities.

#### Online grief resources

- Coalition to Support Grieving Students: <https://grievingstudents.org/> Provides information for educators on supporting grieving students. Lots of helpful information and resources.
- Compassionate Friends: [www.compassionatefriends.org/](http://www.compassionatefriends.org/) Online national organization for bereaved parents. Local chapters across the country. Enter your zip code to find the chapter nearest you.
- Bereaved Parents of the USA: <https://bereavedparentsusa.org/> Online national organization for bereaved parents. Local chapters across the country. Enter your zip code to find the chapter nearest you. Annual national conference is called The Gathering.

## Part 4: Encounter

Below is an example of what an encounter form looks like and the link you can use to reach the encounter form online. There is also a closure email that you will send parents when you either complete your last successful call during the 4<sup>th</sup> month of the program or there is no successful contact has been made after three consecutive attempts. Both emails are typed out and specify which one to use in which situation.

### Encounter Form

Access the Encounter Form here:

<https://hospital.stjude.org/apps/forms/fb/bereaved-encounter-call/>

Use your St. Jude username and password to login. Utilize the check boxes and drop-down menus and then briefly summarize the contact.

### General Information

Caller Name  
Patient First Name  
Patient Last Name  
MRN  
Caregiver First Name  
Caregiver Last Name  
Relationship to Patient (dropdown list)

### Encounter Information

\*An Encounter is your attempt at contacting a parent. Please mark whether it is a successful or unsuccessful contact and the date you attempted contact. A contact is successful when you receive a response.

Text

- Successful contact
  - o Date:
- Unsuccessful contact
  - o Date:

Email

- Successful contact
  - o Date:
- Unsuccessful contact
  - o Date:

Phone Call

- Successful contact
  - o Date:
- Unsuccessful contact
  - o Date:

Encounter Number (dropdown list)

Length of Call – Minutes (text box)

Supports being utilized: (check all that apply)

- Family
- Friends
- Church/Faith
- Grief support group
- Other support group
- Mental Health Professional
- Other

### Concerns

Sleep (dropdown list)

Appetite (dropdown list)

Other Concerns (Select all that apply)



- Expressed suicidal ideation
- History of depression
- History of anxiety disorder
- Emotional dependence
- Social isolation
- Experienced traumatic death
- Multiple losses
- Alcohol or drug use/abuse
- Personal health concerns
- Lack of family/social support
- Dependent living in home (children/elderly)
- Conflicted relationship with deceased
- Conflicted or stressed relationship with spouse/significant other
- Concern for siblings
- Financial/employment concerns
- Other concern not listed

Level of Concern

- No concern
- Pink flag concern
- Red flag concern

Additional Information

Brief Summary of Call



### Closure Emails

Send THIS email if your last contact at the 4<sup>th</sup> month is SUCCESSFUL. You may change the email to fit your personal style.

### CLOSURE EMAIL FOR SUCCESSFUL CONTACT

Dear \_\_\_\_\_,

It was a pleasure speaking with you over the course of the last few months. I know this is such a difficult time for you and your family. I want you to know that St. Jude is here for you. Below I listed out several of the resources we talked about during our conversations, as well as some other resources you might find helpful at another time.

### St. Jude Grief Resources

1. St. Jude Grief and Bereavement Support website
  - a. <https://www.stjude.org/bereavement>
2. Bereavement mailings
  - a. Coping with Loss: A Grief Support Guide—helpful information about grief and when and where to turn for help
  - a. Seasons of Change—a St. Jude parent-created booklet. Parents share stories related to their “firsts” after child loss and bits of wisdom they took from their experiences.
  - b. Holiday brochure—how to navigate and survive the first holidays after the loss of your child
3. Additional grief resources via mail

Wide selection of grief books
4. Bereaved parent mentor program

Many bereaved parents say that no one can understand what they are going through except another bereaved parent. Bereaved St. Jude parents who have been trained as mentors provide support and encouragement as they “walk alongside” newly bereaved parents. Communication may occur by phone, text, or email depending upon the preferences of the parent. Contact Lisa Clark, PhD, bereavement coordinator, at [lisa.clark@stjude.org](mailto:lisa.clark@stjude.org) or at 901-595-2658, if you would like to talk to another bereaved parent.
5. Bereavement Coordinator--Lisa Clark, PhD

[lisa.clark@stjude.org](mailto:lisa.clark@stjude.org)  
(901) 595-2658

- can locate grief counselors and support groups in your local community and help you determine which might be most helpful for you or your family member
  - can connect you with St. Jude and other grief resources
6. St. Jude Day of Remembrance
- Families are invited to return to St. Jude each fall for the annual St. Jude Day of Remembrance. This is a 2-day event (Friday and Saturday) during which families and staff can remember their child, meet other bereaved families, and celebrate the lives of their children. Once you are 6 months out from the death of your child, you should receive invitations for 5 years. You can register online at [www.stjude.org/dor](http://www.stjude.org/dor). If you don't receive an invitation, email [lisa.clark@stjude.org](mailto:lisa.clark@stjude.org) or call (901) 595-2658. Be sure to let us know if your contact information changes so that we can keep in touch with you.
7. St. Jude Voice—Legacy Voice
- Bereaved caregivers can offer feedback and insights from their St. Jude experiences. Through survey results, forums and other activities, end-of-life and bereavement care for St. Jude patients and families is improved. Members can see survey results and helpful information from bereaved parents and St. Jude staff. **To learn more, go to <https://www.stjude.org/treatment/patient-resources/patient-family-centered-care/volunteer-opportunities/st-jude-voice-virtual-advisor-community.html>.**

Don't hesitate to reach out to me at any time if you would like to communicate with me in the future. We are on this journey together, walking a path in life that we never wanted to be on. Please know that you are not alone.

[Your name here]

### END EMAIL FOR UNSUCCESSFUL CONTACT

Send **THIS** email when contact has been **UNSUCCESSFUL** for *three* consecutive months. Fill in the blanks with the appropriate information.

### CLOSURE EMAIL FOR UNSUCCESSFUL CONTACT

Dear \_\_\_\_\_,

My name is \_\_\_\_\_. I am a St. Jude bereaved parent and an official St. Jude volunteer. After my child died, I felt lost and alone, like no one could possibly understand how I was feeling. I didn't know where to look for support. It helped me to talk with other bereaved families who understand. That is why I volunteer with the St. Jude *Stay in Touch* program. We

attempt to contact all St. Jude parents after the loss of their child. I want to let you know about St. Jude's grief resources and to see if there are any other resources that might be helpful for you or your family.

I tried to contacting you by [text/phone] on \_\_\_\_\_ (date/times you tried contacting) \_\_\_\_\_, so if you saw the phone number \_\_\_\_\_, that was me. I certainly want to respect your privacy and won't continue to contact you unless I hear from you. However, I want you to know about the many grief resources available through St. Jude and so I encourage you to keep this email to refer to in the future.

## St. Jude Grief Resources

1. St. Jude Grief and Bereavement Support website

<https://www.stjude.org/bereavement>

2. Bereavement mailings

- a. Coping with Loss: A Grief Support Guide—helpful information about grief and when and where to turn for help
- b. Seasons of Change—a St. Jude parent-created booklet. Caregivers share stories related to their “firsts” after child loss and bits of wisdom they learned from their experiences
- c. Holiday brochure—how to navigate and survive the first holidays after the loss of your child

3. Additional grief resources via mail

Wide selection of grief books available upon request—[lisa.clark@stjude.org](mailto:lisa.clark@stjude.org)

4. Bereaved parent mentor program

Many bereaved parents say that no one can understand what they are going through except another bereaved parent. Bereaved St. Jude parents who have been trained as mentors provide support, encouragement and insight as they “walk alongside” newly bereaved parents. Communication may occur by phone, text, or email depending upon the preferences of the parent. Contact Lisa Clark at [lisa.clark@stjude.org](mailto:lisa.clark@stjude.org) or at (901) 595-2658 for more information.

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If you would like to communicate with me in the future, you can reach out to me at any time. We are on this journey together, walking a path in life that we never wanted to be on. Please know that you are not alone.

Your name here

**END EMAIL**



Call Tracker

Name of Parent	Encounter Number & Date	Means of Contact (text, email, call)	Successful (Yes or No)	Summary
Ex: Jane Smith	Encounter #1 (5/5/2018) (5/7/2018)	-Text (5/5) -Call (5/7)	-No (5/5) -Yes (5/7)	(5/5/18) I texted Jane to set up a time to call her, she responded on 5/6 and we scheduled to speak on 5/7/18 at 3pm. I will submit an encounter form after I talk to her (5/7/18) Called Jane at 3pm, we talked for 45 minutes. Submitted an encounter form under Encounter #1

## Parent Caller Tips for Tracking Contacts

*"I print out the Information Form and put the same information from the Call Tracker in the margins of that form so that I have all the pertinent information for this parent when I am making a call – and when I am submitting my encounter form."*

*"I print off every Information Form and put it in my Stay in Touch binder. I put a little sticky note on it and write the dates of calls 1, 2, & 3 so that I can easily see when I am due to contact them again. I print off all the encounter forms and keep them in the binder for reference. After call #4 and the encounter form is complete, I remove that family's info from the binder and shred it."*

## Part 5: Quick References

### Important Contacts

- Lisa Clark, PhD—Bereavement Coordinator
  - P: (901)595-2658-office, (901)848-8392-cell
  - E: [lisa.clark@st.jude.org](mailto:lisa.clark@st.jude.org)
- Brittany Barnett:
  - P: (901)595-7560
  - E: [brittany.barnett@stjude.org](mailto:brittany.barnett@stjude.org)
- Traci Adams
  - P: (901) 595-3667
  - E: [traci.adams@stjude.org](mailto:traci.adams@stjude.org)
- Kristin Canavera
  - P: (901) 595-6053
  - E: [kristin.canavera@stjude.org](mailto:kristin.canavera@stjude.org)

## St. Jude Resources

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\*\*Samples of mailings are included in your training packet.

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Legacy Voice: An online advisory council that gives St. Jude bereaved parents and caregivers an opportunity to give input and advise St. Jude around care of patient families at end-of-life and in bereavement. Parents and caregivers apply to become advisers and share their perspectives and suggestions via online surveys. Any St. Jude bereaved parent or caregiver is eligible to apply. To learn more, go to <https://www.stjude.org/treatment/patient-resources/patient-family-centered-care/volunteer-opportunities/e-council.html>.

St. Jude Annual Day of Remembrance: This annual event, hosted by St. Jude each fall, was created by a task force of bereaved parents who wanted to ensure that other St. Jude families had the opportunity to honor the memories of their children here at the hospital. The first Save the Date card goes out in late May. This is a 2-day event (Friday and Saturday) during which families and staff can remember their child, meet other bereaved families, and celebrate the lives of their children. Once you are 6 months out from the death of your child, you should receive invitations for 5 years. If you don't receive an invitation, please email [lisa.clark@stjude.org](mailto:lisa.clark@stjude.org) or call (901) 595-2658. Please let us know if your contact information changes so that we can keep in touch with you.

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Extensive grief resource library: An extensive list of grief resources for all groups and ages is located on the Grief and Bereavement Support webpage at [www.stjude.org/bereavement](http://www.stjude.org/bereavement). The bereavement coordinator also has grief books she can mail to families. Let her know if there is age or grief topic a family needs a grief book for.

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St. Jude Grief and Bereavement Support: <http://stjude.org/bereavement> Provides information about grief, helpful resources, St. Jude events and programs for bereaved families, and St. Jude volunteer opportunities

### Other Resources

Link to article about importance of bereavement support:

<https://www.sciencedirect.com/science/article/pii/S0885392416312015?via%3Dihub>

### Helpful Websites:

- Coalition to Support Grieving Students: <https://grievingstudents.org/> Provides information for educators on supporting grieving students. Lots of helpful information and resources.
- Compassionate Friends: [www.compassionatefriends.org/](http://www.compassionatefriends.org/) Online national organization for bereaved parents. Local chapters across the country. Enter your zip code to find the chapter nearest you.
- Bereaved Parents of the USA: <https://bereavedparentsusa.org/> Online national organization for bereaved parents. Local chapters across the country. Enter your zip code to find the chapter nearest you. Annual national conference is called The Gathering and will be held in Memphis in 2018.