St. Jude Children's Research Hospital®

Relationship Toolkit

Introduction

Dear Caregiver,

We created this toolkit after hearing from couples who have been through the challenge of caring for a sick child together. Many shared how hard it was to consider their own needs or relationship when their child was sick. Looking back, they realized how important it was to take care of themselves and their relationship.

They wanted us to provide a way for caregivers to be proactive about maintaining the health of their relationship—not only for their own sake, but because they realized that a strong relationship helps caregivers be the best versions of themselves for their child and their family.

The good news is that while marriages and relationships can be strained by pediatric cancer or other serious illness, research suggests that, generally speaking, having a child with pediatric cancer does not increase the likelihood of divorce or separation. In fact, many partners feel even closer to one another after going through this together.

As one caregiver put it,

We did come out on the other side stronger, but it didn't seem that way in the middle of it.

We know there is no easy answer for how to become stronger as a couple, but we hope this toolkit can make getting through this together feel a bit less overwhelming. Many people find that it's impossible to fully process the impact of their child's illness as they're experiencing it —let alone to fully process it with their partner. Instead, many couples may find it most helpful to focus on the small things. While it can seem almost too simple, being intentional about connecting with each other, processing with each other, and supporting each other little by little, day-by-day, can be the thing that ends up getting you through the long journey. This toolkit is designed to help you do just that.

Sincerely,
St. Jude Psychosocial Services staff

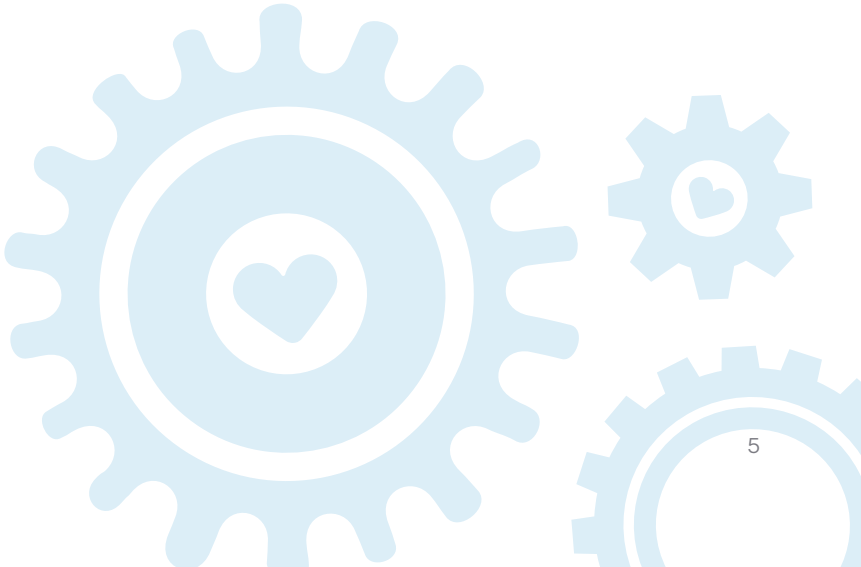
Before you continue...

- This toolkit does not take the place of professional counseling. If you need additional support, contact your social worker, chaplain, or another member of your support team.
- This toolkit is not intended for use within abusive relationships or when there is violence in the home. According to the National Domestic Violence Hotline, relationship abuse is "a pattern of behaviors used by one partner to maintain power and control over another partner in an intimate relationship." For more information or help, visit **thehotline.org**, contact your social worker, or reach out to someone else you can trust.

How to use this toolkit

- This toolkit is intended for romantic partners of all kinds who are experiencing pediatric cancer together.
- There is no "one right way" to navigate this illness journey as an individual or as a couple. Adapt the guidance here in ways that work for you. You may even find that what helps in one phase of the journey may need adjustment as time goes on. Think of this as an ongoing dialogue with yourself and your partner.

- The content is divided into several sections based on themes. Each section has brief reading material, followed by reflection and discussion activities. It may be best to work through this material in small chunks as you have the time and energy to engage with it.
- You can work through this toolkit individually or with your partner. Each section has activities that can be engaged with individually and ends with an option for you and your partner to engage with the material together.
- When completing activities together, make sure you and your partner have the time and ability to engage. Partners who have one another's full attention as they share will have the best chance to make the most of these important conversations.
- Feel free to move through the material in any order. It's OK to skip readings, reflective questions, or even entire sections if you'd like.



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Acknowledging Differences, Finding Strengths

CHAPTER

1

Our differences were our strengths,

said one mother about her relationship with her husband.

Acknowledging Differences, Finding Strengths

You and your partner are on the same journey, but you'll experience it in different ways. That might be because of distance, with one of you mostly at home and the other mostly at the hospital. Or, you may just have a different way of coping, processing, and talking about everything happening to your family. For example, your partner may hurt just as much emotionally but show their pain in different ways. The bottom line is that you and your partner will experience this journey differently. That's normal!

"Our differences were our strengths," said one mother about her relationship with her husband. The fact that she was a night owl while he was an early bird ended up coming in handy when their daughter needed round-the-clock care. It wasn't just that, but also the unique approaches each of them brought to decision making. She tended to bring more emotion to conversations, while he made sure they were looking at all the facts. "I just stuck to the facts, but I needed that emotion to be part of our decisions," said her husband.

Activity

Without judging, consider how the differences between you and your partner may be showing up during this illness journey with your child. Ask yourself the following questions:

- Are there ways in which your differences might complement each other during this illness journey?
- What trait do you appreciate about your partner that is different from you?

Partner Activity

Expand on the idea of appreciation and actively consider your strengths together. You and your relationship don't need to be perfect to be appreciated. It can be easy to take it for granted that your partner knows you appreciate them. This is an opportunity to let them know.

Remember, while differences can be frustrating at times, taking them with a dose of acceptance and grace is often more productive than trying to change one another. Doing so can even make it easier to navigate differences and compromise when you need to. There's an opportunity at the end of this section to talk about the challenging parts.

- Take turns sharing what you appreciate about one another, especially aspects where you may differ.
- What are your strengths together as a couple? What are you doing well?
- How can you continue to make the most of these strengths?
- How are your differences challenging? Brainstorm ways to manage them more effectively if you need to.

Notes:

Offering Support and Maintaining Connection

CHAPTER

2

“

You might be surprised at how much it means to say,

I’m going to get a cup of coffee; do you want one too?

especially if your partner is having a difficult time asking for help.

Offering Support and Maintaining Connection

Most partners want to be supportive and connected to their partner. But it can be harder to notice and respond to your partner's attempts to connect or their requests for support due to barriers like distance, fatigue, stress, and lack of time.

It can even be hard to make attempts to connect when you're under stress. And yet, that doesn't mean connection, support, and even love aren't important during this journey. In fact, they may be more important than ever. The challenge is figuring out what that looks like when your child is sick.

One option is to broaden your perspective about what love, support, and connection mean in your relationship right now. That might mean paying a little more attention to small moments throughout the day that can often seem insignificant.

Think of these small moments as opportunities to show and receive love. You might be surprised at how much it means to say, "I'm going to get a cup of coffee; do you want one too?" especially if your partner is having a difficult time asking for help.

You might also be surprised how much it matters when you respond positively to small verbal and non-verbal attempts at connection, like if your partner reaches for your hand, smiles at you, or starts to tell you about their day. As The Gottman Institute for couples notes, small things often can make a big difference.

You might also consider how Gary Chapman's book, *The 5 Love Languages,* can be adapted to the illness journey. Although the idea of love languages is not perfect or all-inclusive, the concept can help you begin to think about ways to support each other despite any barriers in place. Even if you don't focus on the romantic part of your relationship while your child is sick, this section can help you cope together and stay connected.

We've included brief descriptions of the Love Languages with real examples from caregivers about how they adapted when their child was sick.

Words of affirmation: Using your words to show care and appreciation for your partner.

- *"Compliments for just handling situations and events. Saying, 'I'm proud of you.'"*
- *"Words of appreciation meant a lot because I felt very overwhelmed. He did not complain about things that I neglected to do because he knew I was doing my best."*
- *"My husband needed to hear what a great provider he is."*

Quality time: Showing care through undivided attention and meaningful time together.

- "Spending a few minutes together when the kids were asleep."
- "He would arrange for us to have dinner alone and talk."
- "When we could be together, we soaked it all in."

Note: Quality time can be a challenge for long-distance couples. Focusing on secondary love languages might bridge the gap until you can be together again.

Physical touch: Expressing affection in appropriate physical ways, including sex as well as non-sexual touch like holding hands or a gentle touch while walking by.

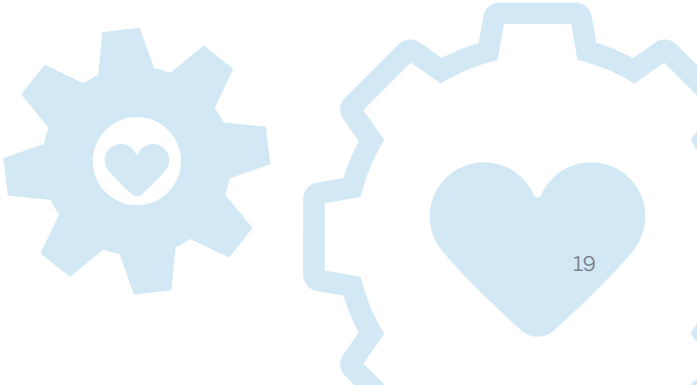
- "Very difficult being thousands then hundreds of miles apart, so when we were together, I made sure to hold hands, hug, and cuddle after the kids went to bed."
- "Sometimes we both gave massages to each other while we were tired."
- "Just held each other."

Receiving gifts: Giving a gift that symbolizes you care about them, know them, and took the effort to get something for them.

- "Bringing little gifts home when he missed appointments."
- "Sending flowers to housing, buying little things online for delivery without being asked."
- "We sent gifts home from the gift shop!"

Acts of service: Doing kind and helpful things to take a load off your partner and show you care.

- "Both of ours is acts of service. We would take turns doing chores or who slept with our son and got up with him."
- "Not being scared to take on things that may have been traditional 'mom' things like [helping with] showering, changing soiled clothes."
- "Going to get coffee, food, or running to get special things for our son to help pass the time during treatment visits."



Activity

Now that you've had a chance to consider these ideas, ask yourself the following questions.

- When I'm looking for support or connection, how do I let my partner know?
- What love language(s) do I appreciate most? Why?
- What love language(s) do I think my partner appreciates most? Why?

Partner Activity

The key isn't just knowing your own love language. It is just as important, if not more important, to understand your partner's love language. Talk through each of your answers to the above questions. This is an area in which acknowledging and understanding the differences between you and your partner can be helpful. As you talk, consider the following questions, and get curious!

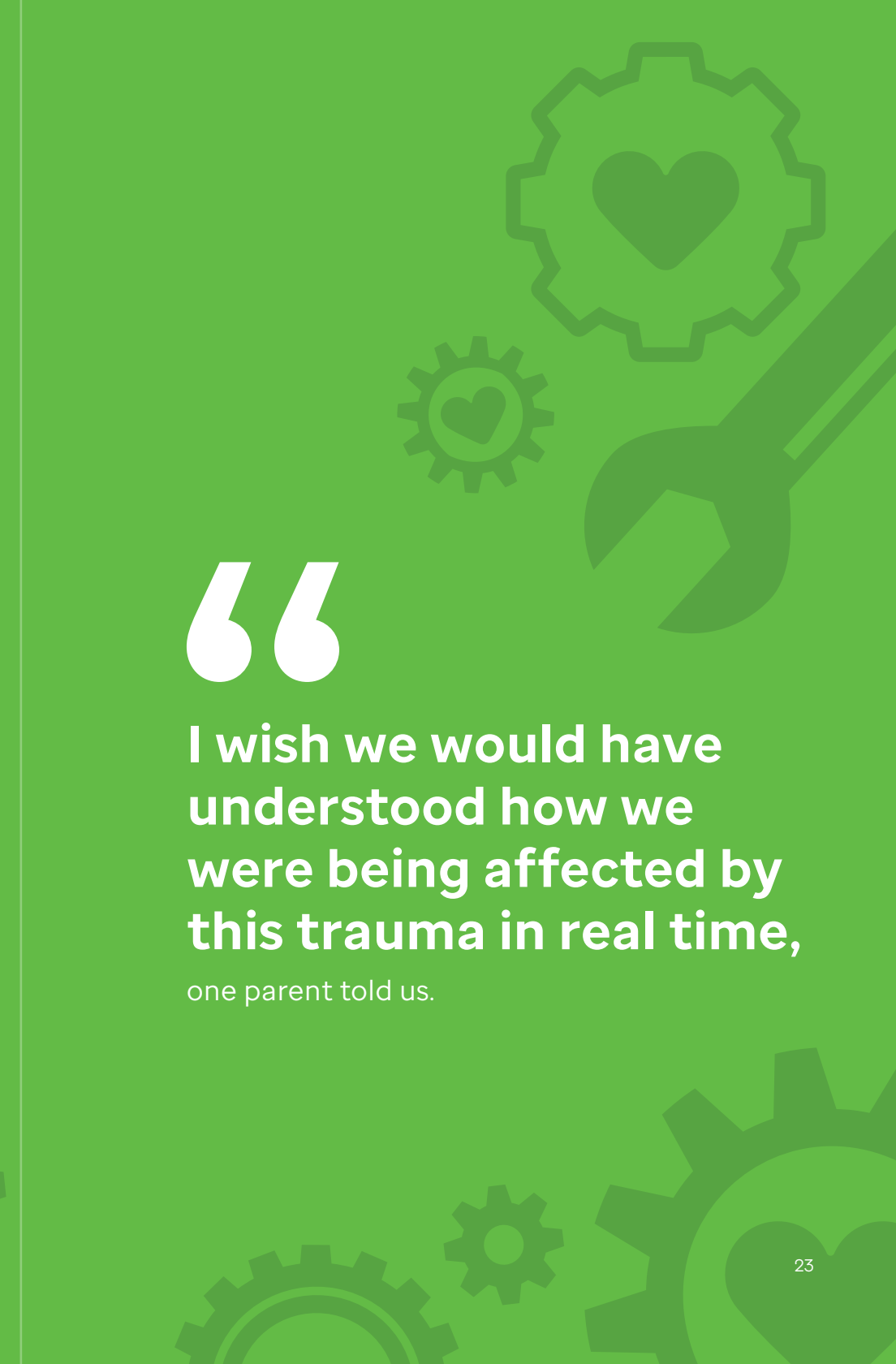
- What did you learn about each other and your relationship by talking through your answers?
- How can you use this information to better support and care for one another?

Notes:

Understanding Each Other's Experience

CHAPTER

3



I wish we would have understood how we were being affected by this trauma in real time,

one parent told us.

"I wish we would have checked on each other like we checked on our child. I wish we would have understood how we were being affected by this trauma in real time," one parent told us. It can be easy to assume that our partner knows what we're thinking, feeling, or needing.

The truth is we often miss more than we realize about our partner's experience—sometimes we even miss what's going on in our own experience. The challenge can be magnified if we're separated from our partner by distance.

Activity

Think of this as a "snapshot" of what this experience has been like for you. The intent is to help you reflect and understand yourself in ways that can benefit both you and your relationship. These questions may feel emotional and vulnerable. Feel free to focus on those that stand out to you and that you feel ready to consider. You can always revisit these.

Activity Questions

1. What has been one of our strengths as a couple during this journey?
2. When have I felt closest to my partner during this experience?
3. What have I appreciated most about my partner during this time?
4. What am I proud of myself for?
5. In what unique ways has the illness affected me?
6. How do I tend to cope during the hardest moments?
7. How do I tend to react during the most joyful moments?
8. What are some signs that I'm really struggling?
9. How can my partner easily offer support when I'm struggling?
10. How has this experience impacted my faith or spirituality?

Partner Activity

Invite your partner to complete the prompts if they haven't. Share your answers with each other and discuss them. If you are short on time, try selecting one or two to share with each other and discuss those. You can always share more later. If only one partner has completed the prompts, you can use your answers to start a conversation while creating space for your partner to share their own experience too.

Remember, this activity isn't about deciding who is "right" or who has it harder. It's about understanding the unique experiences of each partner. Differences in thoughts, feelings, emotions, and coping are normal. When partners feel understood, appreciated, and connected, it makes uniting to face inevitable challenges easier. As you talk, consider the following questions.

- What did you and your partner learn about each other by talking through these answers?
- Was there anything that surprised you?
- How can you use these new understandings to connect, support each other, or work together more effectively?
- How will you continue to keep each other "in the know" about your experiences?

Notes:

Communicating Effectively Along the Journey

CHAPTER

4

“Communication about our feelings was hard, but when it was there it helped us navigate through.

Communicating Effectively Along the Journey

One of the most important things couples can do when facing the illness of their child is to keep an open line of communication with one another. Sometimes that might be about sharing your feelings or expressing support for each other. Other times, it may be about more practical matters. Some important questions to ask each other may be:

- How are we going to handle work and finances?
- What are our roles now? How do we divide responsibilities?
- How and when do we communicate best? How do we keep that going?
- How will we parent our sick child during this time? What about our other children?
- How will we make treatment decisions? How do we talk about worst-case scenarios?
- What will we share with people outside of our family about what's going on? How?
- What do we expect from each other?
- How is our relationship changing? Our sex lives?
- How can we best support each other? What do we need from each other?
- What's important for our family now?

There is no one-size-fits-all answer to these questions, and they can be challenging for any couple to navigate. But it can be helpful, when possible, to be intentional about talking these things through and making considered, collaborative decisions. It takes work on the front end, but it can pay off

with a greater sense of teamwork and a better plan in the long run. The answers to these questions may change many times while your child is ill or in treatment. Some couples find it helpful to set aside regular time to talk about important things daily or weekly, like a "team meeting."

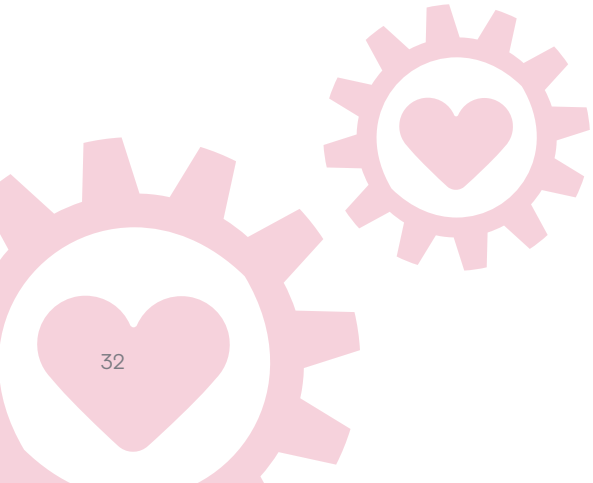
We've included some reflections, important topics, and suggestions from real couples about how they communicated when their child was sick.

- "Communication about our feelings was hard, but when it was there it helped us navigate through."
- "I wish we told each other what we needed and how we wanted to communicate from the beginning. We got there eventually, but I wish we had that from the start."
- "Talking about the positive things we still had in our life despite all the negatives surrounding us. Also keeping our sense of humor. Laughing helped our sadness but didn't take it away."
- "I wish I had told him how much I really needed him instead of acting as if I was OK."
- "Talking through it and remembering that our emotions were charged because cancer was coloring every thought, feeling, and experience. Also acknowledging how exhausted we were."
- "Sometimes talking was difficult as the conversation could get heated. Sometimes emails and text messages proved to be more effective when discussing difficult topics."

Communicating Effectively Along the Journey

It's important to acknowledge the challenges that can come with communicating about difficult topics while under tremendous stress. If you're finding communication to be challenging, consider the following tips:

- If one or both of you are too overwhelmed, consider setting a time to return to the conversation when you've calmed down. Take steps to calm yourself down, if needed.
- Keep difficult conversations focused on one topic at a time and avoid interrupting each other.
- Let your partner know what kind of conversation you're looking to have. For example, "I really just need someone to listen" or "I really need your help figuring this out."
- If you need to tell your partner something about their behavior, try starting your sentence with "I" rather than "you," and try to start softly. This can help your partner react less defensively. For example, "I miss you when we don't check in with each other. I need to hear from you."



Activity

What important conversations do you and your partner need to have or revisit? Write them down.

Partner Activity

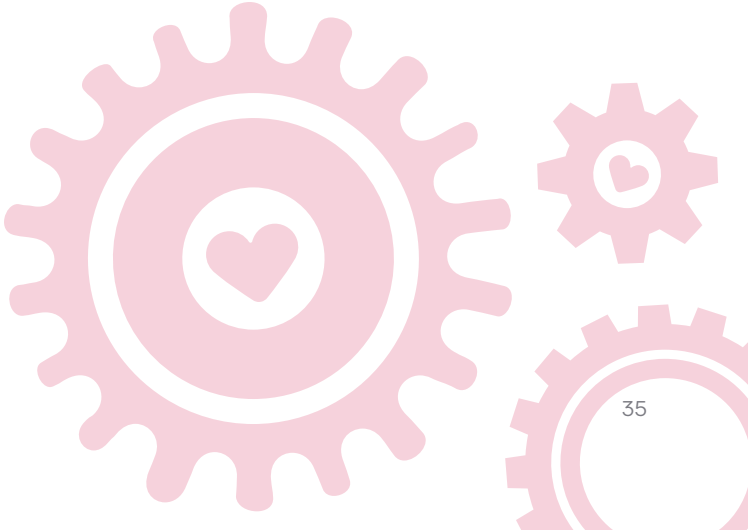
First, get together and plan a time when you can have or revisit the important conversations either of you noted. Take them one at a time and use the strategies on the previous page to manage conflict if needed. You don't need to rush to talk through everything in the same day. Prioritize what is most important, and plan to discuss other items later.

Second, brainstorm ways you can stay in touch about the little things too. If it's helpful, make a plan to communicate regularly about how each of you are feeling and what's been going on. The point is to help you and your partner stay "in-the-know" about what's really going on for each of you both practically and emotionally, day-by-day and week-by-week. Feel free to get creative and make this work for you. That might mean coming up with your own questions that reflect what is most important to you. You might even include questions unrelated to treatment, like "Did you get to watch any TV shows this week? What was your favorite?" Making it work for you could also mean discovering which methods of communication, like texting, work best for which conversations.

Questions to Consider:

As a starting point, consider regularly asking each other questions like:

1. What was the best thing that happened today/this week?
2. What was the hardest thing that happened today/this week?
3. How are you feeling about the news we received today/this week?
4. How are you coping today/this week?



Notes:

Wrapping Up

"The good days, the days that [we] saw hope, and to be honest even the bad days. We were there for each other to lean on."

While we recognize that nothing can take away the pain of having a sick child, we hope this resource leaves you feeling more equipped to lean on one another, in good times and bad. Whether you worked through a portion of the toolkit or every page, you have taken at least a bit of time to care for yourself and your relationship. Your efforts, even small ones, matter. Remember, kids and families do better when caregivers get the support they need.

Additional resources

If you find you or your relationship could use more support, reach out to your social worker, chaplain, or another member of your child's care team. They can work with you to find the kind of support that best fits your needs.

- *Together by St. Jude™* is an online resource for trusted information about relationship health, caregiver coping, and so much more.
- *Caregivers SHARE, a St. Jude podcast* is a place for family caregivers to hear advice, reflection, encouragement, and real stories from families and hospital staff.

What Does Your Love Look Like?

Love Language Ideas from Couples:

Physical Touch

Ideas:

- Hold hands
- Hug
- Massage
- Sit close together
- Rest your head on your partner
- Simple kiss

Caregiver Quotes:

- “We traded places sometimes in the hospital and hugged in parking lots.”
- “I would try to remember to thank him for all the hard work he was doing to provide financially for our family. And just hugging him…kissing him on the cheek. Little things.”
- “My partner’s [love language] is physical touch which was very difficult being thousands then hundreds of miles apart, so when we were together, I made sure to hold hands, hug, and cuddle after kids went to bed.”

- “Would walk around Target House or Overton Park and hold hands and talk.”
- “Physical touch, holding hands, long hugs.”
- “My partner’s [love language] is physical touch so I made sure to hold his hand, sit close to him, rest my head on him. Mine is acts of service so the calls, visits, and errands helped.”

Quality Time

Ideas:

- Spend time together intentionally in the waiting room
- A few minutes of quality time after kids are asleep
- Go for a walk together
- Go out for food together
- Go to the hospital cafeteria together

Caregiver Quotes:

- “Quality time was spent many days sitting in waiting areas between appointments.”
- “Spending a few minutes together when the kids were asleep.”
- “Slipping away to eat together during inpatient stays.”
- “We would eat on benches/in housing and talk about us – not cancer.”
- “Sitting in the parent room together or having a meal together, even if it was downstairs by ourselves.”

Acts of Service

Ideas:

- Small acts of service
- Do something your partner usually has to do
- Care for home life
- Provide updates on patient
- Run errands
- Take turns sleeping or doing visits

Caregiver Quotes:

- “He would save me chocolate chip cookies from the cafeteria when I couldn’t get there early enough.”
- “Taking care of our younger one at home while working full time. These were not little things. These were the most important things for me to be at St. Jude with our son.”
- “My partner’s love language is acts of service – I took an extra responsibility of his every now and then to show him I cared. Mine is quality time – he would arrange for us to have dinner alone to talk.”
- “He continued to work and help raise our youngest while I stayed with our child as he battled cancer. He kept the bills paid with the help of our church.”
- “He switched places with me on our anniversary. He let me go home and sleep in a nice bed instead of being subjected to the inpatient parent bed. At the time, it meant everything.”
- “Not being scared to take on things that may have been traditional “mom” things like showering, changing soiled clothes.”

Words of Affirmation

Ideas:

- Say “Thank you”
- Say “I’m proud of you”
- Say “I love you”
- Send appreciative texts
- Send notes
- Write letters
- Listen to your partner
- Give compliments

Caregiver Quotes:

- “My husband likes affirmation, so I make sure to tell him how much I appreciate all he does.”
- “My husband thanked me often for taking such good care of our daughter.”
- “We did our best with old fashioned letters and called and FaceTimed often.”
- “I would try to remember to thank him for all the hard work he was doing to provide financially for our family.”
- “Leaving notes of love and appreciation for them.”
- “We both verbally acknowledged each other’s abilities and our gratitude for them. We hugged and supported each other and made sure to keep our relationship strong by communicating.”
- “Compliments for just handling situations and events. Saying, ‘I’m proud of you.’”

Gifts

Ideas:

- Gifts from gift shop
- Bring snacks
- Bring coffee
- Flowers
- Remember anniversaries or special days

Caregiver Quotes:

- “Bringing little gifts home when he missed appointments.”
- “We would try remembering holidays and anniversaries. I remember going out to a nice dinner for our anniversary and celebrating Sweetest Day just to do something nice.”
- “For my spouse’s birthday, although I was not at home, I managed to get a cake delivered to my home.”
- “Sending flowers, inviting her to eat, trying to stay in touch even in the distance.”

Special Thanks

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Sources

Chapman, G.D. (2010). *The five love languages*. Northfield Publishing.

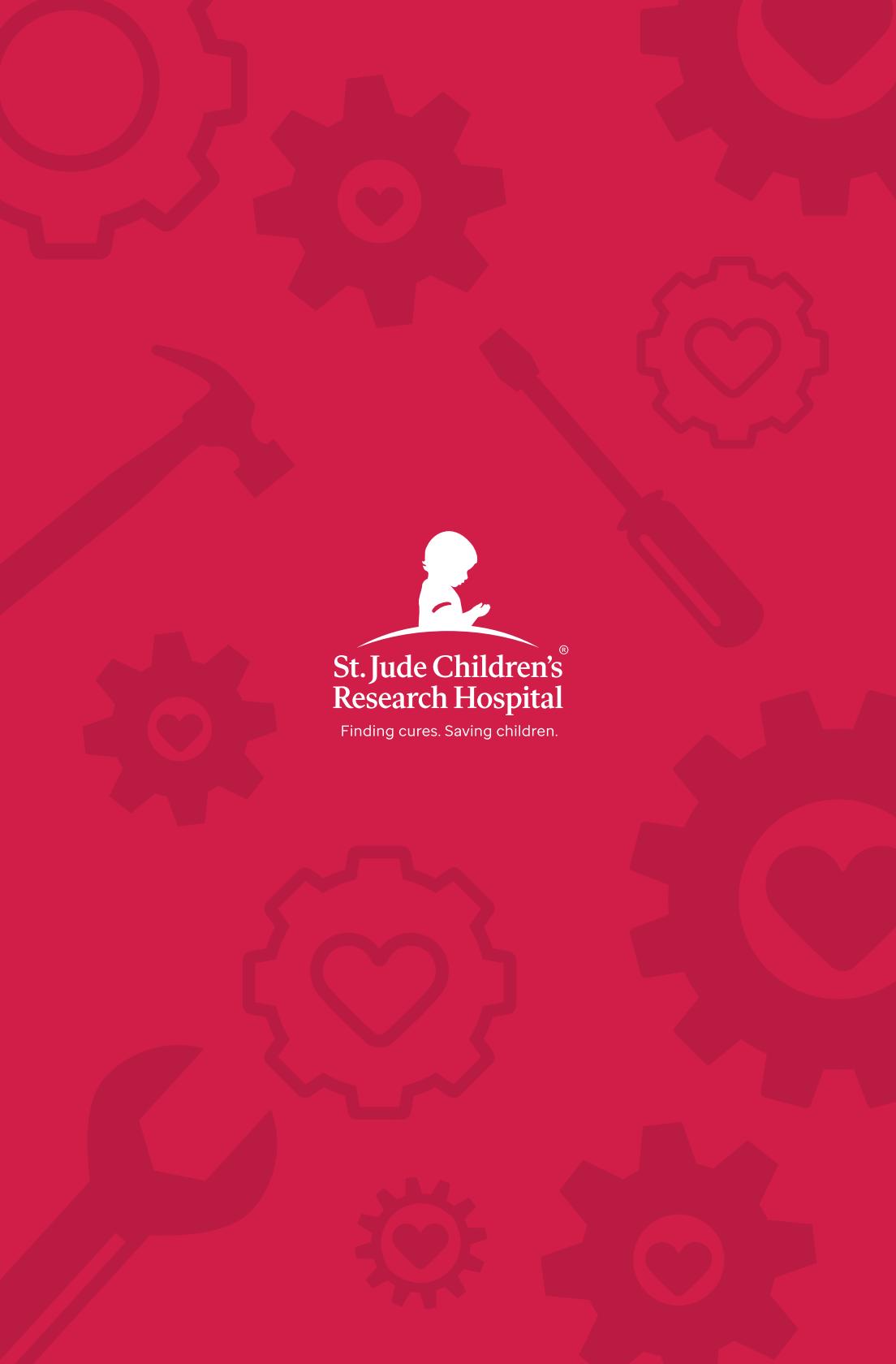
Gajda, J., Johns, C., & Zimmermann, T. (2024, April). “Impact of pediatric cancer on parents’ relationships.” European Journal of Oncology Nursing, 69, 102514. https://doi.org/10.1016/j.ejon.2024.102514

The Gottman Institute. (2024, May 6.) “Small things often: Quick tips about relationships.” https://www.gottman.com/podcast/

Mader, L., Hargreave, M., Frederiksen, L. E., Bidstrup, P. E., Dalton, S. O., Kjaer, S. K., Nielsen, T. T., Kroyer, A., Winther, J. F., & Erdmann, F. (2020). “The impact of childhood cancer on parental separation, divorce, and family planning in Denmark.” *Cancer*, 126(14), 3330–3340. https://doi.org/10.1002/cncr.32901

National Domestic Violence Hotline. (2024, May 6). “Understand relationship abuse.” https://www.thehotline.org/identify-abuse/understand-relationship-abuse/

Syse, A., Loge, J. H., & Lyngstad, T. H. (2010). “Does childhood cancer affect parental divorce rates?” A population-based study. *Journal of Clinical Oncology*, 28(5), 872–877. https://doi.org/10.1200/JCO.2009.24.0556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