UNSEEN

How We're Failing Parent Caregivers & Why It Matters

VIEWER SCREENING KIT

v.11.17.22.a

INSIDE

Discussion & Reflection Guides

Meet our partners who serve caregivers and their families.

How You Can Help

DISCUSSION & REFLECTION GUIDES

DISCUSSION & REFLECTION GUIDE

FOR EVERYONE

1. Do you know any parent caregivers personally? Where do you encounter parent caregivers in your everyday life?
2. What was your perception of the parent caregiving experience before watching the film? In what ways did your perception change or stay the same after watching?
3. What surprised you about the parent caregiver experiences portrayed in the film?
4. What moments of the film or caregiver testimonies stood out to you?
5. Do you think parent caregivers can be both loving parents and stressed about circumstances at home?
6. If you are a parent of a nondisabled child, what aspects of the parent caregiver experience could you relate to as a parent? What aspects make it a unique parenting experience?
7. Do you feel parent caregivers are in need of additional support? If so, what factors do you think contribute to the lack of support?
8. Jess Ronne remarks in the film, "Society is only as healthy as the caregivers." Do you agree? What does this mean for our society?
9. Kameron Dawson says in the film, "At some point in our lives...we are going to either become a caregiver for our family members or need care for ourselves. It really is important for folks to get involved in what polices around caregiving look like." What is your reaction to this statement? How might policies around caregiving impact your life now or in the future?
10. Are there ways you could be more supportive of parent caregivers and their families?

DISCUSSION & REFLECTION GUIDE

FOR PARENT CAREGIVERS

1. Do you feel parent caregivers are misunderstood? Why or why not?
2. Do you feel parent caregivers are in need of additional support? If so, what factors do you think contribute to the lack of support?
3. Do you have difficulty asking for support from others? Why or why not?
4. Do you think parent caregivers can be both loving parents and stressed about circumstances at home?
5. Have you ever experienced judgment or rejection from others when sharing about your experience?
6. Has a professional ever checked on your wellness in relation to your role as a caregiver? If not, do you think it would be beneficial?
7. What aspects of the caregiver experiences in the film did you relate to? What aspects are not part of your experience? What did you feel was missing?
8. What would you tell your younger self when you were starting out as a parent caregiver?
9. What do you wish others knew about being a parent caregiver?

By Crystal Polk, Better Tomorrow Therapy
Crystal is a licensed independent clinical social worker in South Carolina. She works with parent caregivers through a strengths-based and solution-focused approach to therapy to empower the family systems within the disability community. Learn more about services and parent workshops at bettertomorrowtherapy.com.

BETTER
TOMORROW
THERAPY

DISCUSSION & REFLECTION GUIDE

FOR HEALTHCARE PROFESSIONALS

1. What was your perception of the parent caregiving experience before watching the film? In what ways did your perception change or stay the same after watching?
2. What moments of the film or caregiver testimonies stood out to you?
3. Do you feel that your practice/organization is more provider-driven or more patient/family-focused? Would parent caregivers agree? Do you have a way to get honest, informal feedback from parent caregivers?
4. How open is communication in your organizational culture and patient/family relationships? Would parents feel comfortable sharing about their challenges?
5. Jess Ronne remarks in the film, “The child is only as healthy as the caregiver.” Do you agree? What does this mean for your work? What can you do to support the caregiver as they support the patient at home?
6. How can seeking healthcare for a child with complex medical needs or other disabilities be a traumatic experience for parent caregivers? In what ways can you provide support to the caregiver to limit the trauma during and after the experience?
7. Jess Ronne says in the film, “Your to-do list is probably five-times longer than another family’s to-do list because the needs of your child are so intense and so all-consuming and never end.” What does this mean for a family’s ability to follow medical guidance? How can you partner with the family to make realistic recommendations and goals?
8. If you work in specialty care, how can you better partner with the family’s primary care provider to be more effective and efficient?
9. What can healthcare professionals do to make the family’s priorities their priorities?

By Esme Gerogeorge, BAN, RN, PHN, Care Manager, Gillette Children’s

DISCUSSION & REFLECTION GUIDE

FOR EMPLOYERS

1. Do you have any colleagues who are caregivers for their loved ones?
2. What was your perception of the parent caregiving experience before watching the film? In what ways did your perception change or stay the same after watching?
3. What surprised you about the parent caregiver experiences portrayed in the film?
4. Do you think someone can be both a caregiver and an effective employee?
5. Do you think caregivers face any stigma in the workplace?
6. Do you feel that care work is valued in our society? Why or why not?
7. How are women in particular impacted by the lack of support for caregivers?
8. Do you feel parent caregivers are in need of additional support in the workplace? If so, what factors do you think contribute to the lack of support?
9. How open is communication in your workplace culture? Would employees feel safe sharing about their caregiving role or asking for specific accommodations?
10. What policies or programs are in place that affect caregivers? How can you get feedback directly from caregivers?
11. Are there changes or new polices or programs that could be explored to better support caregivers and other employees? What barriers might need to be addressed?
12. What impact might caregiver-friendly policies have on your organization?

DISCUSSION & REFLECTION GUIDE

FOR EDUCATORS & SCHOOLS

1. What was your perception of the parent caregiving experience before watching the film? In what ways did your perception change or stay the same after watching?
2. How is being a parent different from being a parent caregiver?
3. Do you think parents of children with disabilities face any stigma in the educational environment?
4. What moments of the film or caregiver testimonies stood out to you?
5. Do you feel parent caregivers are in need of additional support? If so, what factors do you think contribute to the lack of support?
6. How effective is your school or district at serving students with disabilities and their families? Would parent caregivers agree? Do you have a way to get honest, informal feedback from parent caregivers?
7. How open is communication between families, faculty, staff, and administrators? Would parents feel comfortable sharing about their challenges?
8. Jess Ronne remarks in the film, "The child is only as healthy as the caregiver." Do you agree? What does this mean in your role? What can you do to support the caregiver as they support students at home?
9. Jess Ronne says in the film, "Your to-do list is probably five-times longer than another family's to-do list because the needs of your child are so intense and so all-consuming and never end." What does this mean for a family's ability to participate and engage at school?
10. Are there changes or new polices or programs that could be explored to better support caregivers and their families? What potential barriers might need to be addressed?

CAREGIVER TOOLBOX

Meet our partners who serve caregivers and their families.

Team Select
Home Care

Creating **Positive Change** Throughout Our **Patients' Journeys**

Since beginning our organization in 2008, Team Select has aimed to provide exceptional in-home patient care with new methods of reducing re-hospitalizations and driving clinical outcomes for our patients and their families.

Core **Values**

Our Team Select Core Values Include:

- Culture
- Passion
- Ingenuity
- Accountability
- Collaboration
- Impact

Our **Mission**

Team Select's mission is to take every opportunity to do right by all. To provide high-quality home care that delivers measurable, enhanced outcomes for our patients, families and physicians; while fostering a dynamic culture our employees are proud of. We are the practical innovators in home care, driving sustainable solutions for long term success.

Proudly **Offering:**

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- Long-Term Adult and Pediatric Care
- Mobile Outpatient Therapy
- Pediatric Therapy
- Personal Care Services
- Senior Living Services
- Mobile Physician Services

Family **CNA Program**

The Family CNA Program offers an alternative, cost-effective care model that provides a solution for struggling medically fragile families and their loved ones. This program allows parents and legal guardians of medically fragile children to become paid, certified caregivers for their medically fragile loved one at no cost to them or the state.

Contact a Member of Our Team Today!

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Conquer Your Professional Goals Without Compromising Your Personal Ones

Who We Are

Boulo (boo-low), a career mobility platform free to our members, connects women to companies that value women's influence in the workplace, prioritize diversity, and promote a flexible work culture.

Who We Serve

Boulo serves thousands nationwide who have or are making tough decisions between caretaking responsibilities and maintaining their careers.

Flexible work means work arrangements that promote a **fulfilling** work-life balance.

Translate your personal achievements into professional assets through our unique **360˚ Profile**

Common Skills

- Marketing
- Accounting/Bookkeeping
- Project Management
- Administrative Support
- Sales
- Customer Success

Become a Member

- Create your profile
- Get Matched
- Speak with Boulo
- Interview with companies
- Start work!

www.boulosolutions.com **info@boulosolutions.com**

COURAGEOUSPARENTSNETWORK

Courageous Parents Network is a non-profit organization and educational platform that orients, empowers and accompanies **families** and **providers** caring for children with serious illness.

HOW WE CAN HELP

Through **videos**, **podcasts**, **printable guides**, **guided pathways**, **events** and **blog posts**, you will find wisdom from families and pediatric care providers to help you navigate and move forward.

- **The Beginning - Diagnosis**
- **Advocating for Your Child**
- **Understanding Interventions**
- **Coping, Family & Relationships**
- **End of Life and Bereavement**

Get started at

CourageousParentsNetwork.org

Available 24/7 on web and mobile

THE LUCAS PROJECT

Recognition & Respite for Special Needs Caregivers

thelucasproject.org

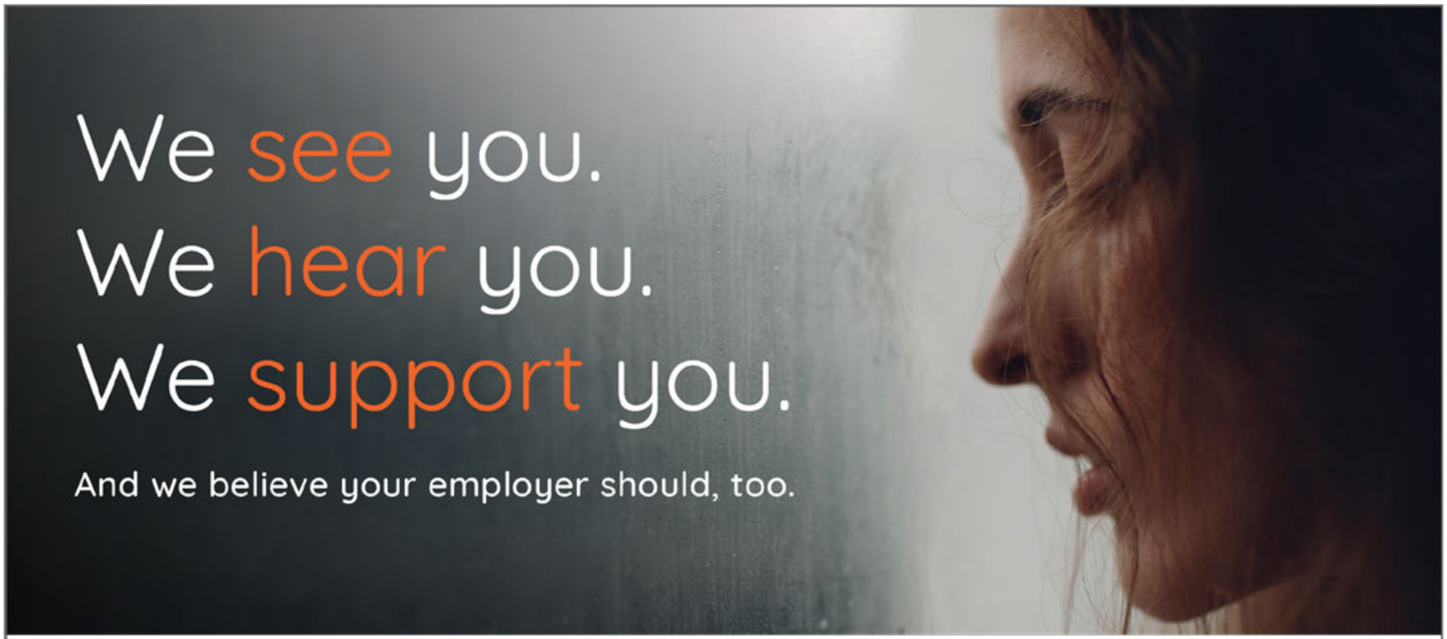
- Care Packages & I.See.You Gift Bags
- Community Respite Grants
- Private Facebook Support Group
- "Coffee with Caregivers" Podcast

Tucker's House

...so every child feels at home.

Making Homes Safer and More Accessible for Families of Children or Young Adults with Disabilities

tuckershouse.org


We see you.
We hear you.
We support you.
And we believe your employer should, too.


you are
NOT alone

Hey there,

Did you enjoy the documentary? Eye opening, isn't it? Yeah, a bit painful for me too.

This parenting thing is hard. I get it. My son is 4 and sometimes the best I can do is drink my cold coffee while I struggle to get his pants over his leg braces and almost miss the school bus. Oof.

In case no one has told you today, you're doing a great job. Really. The last two years have been tough, like really tough, but you're still here. Proud of you.

Do good. Be well.

\- *Kassondra*

The Striped Stable

We teach caregivers how to crowdfund for medical expenses that insurance won't cover so they spend less time worrying about finances and more time on what matters, being a family.

@THESTRIPEDSTABLE f WWW.THESTRIPEDSTABLE.COM

Spreading Sunshine

a Community of support for medical families

Spreading Sunshine serves families whose children have critical or chronic illnesses by providing practical, emotional, and spiritual support.

Serving Families Through:

A Year of Sunshine
Encouraging through monthly care packages and one-on-one care partner support.

Sunshine Boxes
Sending bright care packages to encourage children or caregivers.

Family Care
Providing direct services to meet non-medical needs.

spreading sunshine

a better balance

Free Work-Family Legal Info: 1-833-NEED-ABB

A Better Balance's free and confidential legal helpline can help you understand your workplace rights around caring for yourself and your loved ones.

We assist workers nationwide facing issues at work related to:

- Sick leave
- Family and medical leave
- Flexible scheduling for doctors' appointments
- Disability accommodations
- Accommodations for pregnancy, childbirth, or breastfeeding like break time, light duty, a water bottle or stool
- Discrimination based on being a parent or caregiver
- Other related workplace needs

A Better Balance is a national, nonprofit legal advocacy organization. If you have questions about your workplace rights as it relates to the issues listed above, we can give you clear, understandable answers about what the law is and how it has been used. Our consultations are for information only. We can discuss possible options with workers seeking legal advice and/or representation.

Call: 1-833-NEED-ABB (1-833-633-3222)
Visit: abetterbalance.org/get-help

A+J Patient Advocacy

A+J Patient Advocacy is your personal healthcare navigator – supporting children, teens, and young adults living with chronic illness. We believe in a collaborative approach to healthcare and work to ensure that every patient has timely and appropriate care. All services are provided to patients and families free of charge

heart4advocacy.com

The Heart of the Caregiver

Drowning in the emotions and responsibilities of caring for someone? You're not alone. We're here to help. The Heart of the Caregiver® provides the essential emotional and spiritual support YOU need.

theheartofthecaregiver.com

HOW YOU CAN HELP

If you're looking to show your support for caregivers and their families, start here.

Learn more at
caregiverdoc.com/help

IDEAS FOR SUPPORTING PARENT CAREGIVERS

1. Acknowledge and empathize.

> "Know that our life has both ups and downs, and a set point that we experience most often, just like yours." Lisa T.
>
> "I need people to try and see how hard life is." K.
>
> "Be the safe place for difficult emotions, but also the first one to celebrate our kids' wins with us." Lisa T.

2. Check in. Be a friend.

> "A check-in text or message is greatly appreciated. We just need to know we are thought of." Becky Z.
>
> "Texts and notes of encouragement mean so much to me." Chesna C.
>
> "Don't forget us! We're still here desperately longing for connection while we're in the trenches of everyday life." Jessica G.
>
> "I need friends who will stand by me, at my lowest and worst." Cheryl L.

3. Listen. Don't give unsolicited advice.

> "I appreciate when people show a genuine interest and are open to just listening. Instead of offering unsolicited advice, it's helpful for people to ask, 'Do you want me to listen or do you want advice?'" Shelby A.
>
> "Be slow to speak." Gina V.
>
> "Just listen without having a 'logical answer' for every time we need to vent." Janeth K.
>
> "Stop with the unsolicited advice. Just listen and care without correcting." Heather T.
>
> "Don't act as though you know better. We are the experts on our child, please follow our lead." Erin L.

4. Come visit.

> “Include us but understand we must host more than usual. Our homes are our children’s safe places. Stay after and help us clean up.” Melanie S.
>
> “I would love someone to just stop by and chat. Even for a little while.” Kristina M.
>
> “Bring me coffee so we can chat at my house, so I don’t have to take my child out of the house, but I can have a moment with friends.” Cheryl L.

5. Invite us, even if we can’t go.

> “Continue to invite us to things...even though 9 of 10 times we will back out or say no because something comes up. But it always feels nice to continue to be included or know that someone wants you there no matter what.” Matt F.
>
> “Keep inviting us even if we frequently decline. The invite alone helps to know we’re thought of.” Jessica G.

6. Offer specific help. Show up.

> “Please offer concrete help. ‘Let me know if you need anything’ is too hard for me to figure out.” Pat M.
>
> “Don’t ask how to help, just do it.” K.
>
> “It adds so much pressure to carers when you say ‘just let me know.’ We don’t want to feel like a burden and we don’t always have the time to reach out.” Deborah
>
> “Tell me you’re bringing a meal one night. Make it in a container I don’t have to worry about returning, and something I can put in the freezer or use immediately.” Cheryl L.
>
> “Offer help at any capacity possible. Even do a load of laundry!” S.

7. Be an advocate. Vote.

> “We don’t want to spearhead any more special needs programs.” Amy F.
>
> “Advocate for [accessibility] whenever you can. We are tired yet we are the ones advocating for change. Advocate for change in education, medical and social services sectors.” Lisa S.
>
> “Please be our voice. We are in the trenches and many times don’t have the energy to advocate.” Deb L.
>
> “Vote for people who will work to improve disability support systems and invest in those systems.” Whitney

8. Be encouraging.

> "Tell me something positive about how we are taking care of our children." Darcy S.
>
> "Never stop verbally encouraging and supporting. It means more than anyone knows." Lauren M.

9. Take an interest in my child. Engage with my child.

> "I appreciate how people talk to my son and play with him...because he is nonspeaking a lot of people just don't interact with him and he misses out and gets ignored. So I really appreciate the people who give him the attention he deserves." Sharna K.
>
> "Truly want to spend time with and get to know the child." Jill G.
>
> "Participate in my child's life the way [you] participate in the neurotypical children's lives in our family." Lori O.

10. Offer respite, even for short periods.

> "Entertain my child for 30 minutes, an hour, a day... just talking to her on the phone gives me some respite I so desperately need!" Christine D.
>
> "Even small breaks are huge for the mental health." Kim P.
>
> "Offer to have the kids for a few hours or a night sometimes. Just a rest or sleep in would be great. Learn more about their disability and how to do things the way we do it with them." Sharna K.

11. Take my child or their siblings out.

> "Ask the person with the disability to do things without the caregiver." Maureen V.
>
> "Take my son for an outing now and again. He would love to go for a ride and get ice cream and watch trains. It's so simple." Kate S.
>
> "Take my neurotypical kids out...They need a break and to just have fun, worry free! They need to be seen and valued as their own selves...There's a lot I don't get to do with them, but I am so happy for them to have great experiences even if it's without me!" Alison G.

12. Don't judge. Trust us.

> "Assume that we are competent in caring for our child." Heather B.
>
> "Believe that we really are doing the best we can." Heather T.
>
> "Respect the "no."...Let me not have guilt for skipping an event that will be a ton of unnecessary work." Penny L.
>
> "Please don't stare or judge us when we are in public." Colleen R.

SAY THIS, NOT THAT:

Parent Caregiver Edition

Sometimes it can be confusing to know the right thing to say. Here are some suggestions submitted by parent caregivers to guide you.

INSTEAD OF THIS...

- ⊗ I don't know how you do it. / I could never do what you do.
- ⊗ You're a superhero / saint / inspiration.
- ⊗ God knew you could handle it. / God only gives special kids to special people.
- ⊗ Have you tried _______?
- ⊗ It'll get better. / Things could be worse. / At least it's not _______.
- ⊗ You poor thing. / What a shame.
- ⊗ Let me know if you need anything. / What can I do for you?
- ⊗ What's wrong with your child?
- ⊗ Your child doesn't look like they have _______.
- ⊗ You're lucky to get to stay home.
- ⊗ Why don't you take a break? / Don't stress too much.
- ⊗ You should practice self care. You should ask for help. / You should get a babysitter. / You should _______.
- ⊗ It's the same for my [nondisabled] child.

TRY THIS...

- ✓ You're doing a great job!
- ✓ I see what a loving and devoted parent you are.
- ✓ I'm happy to listen if you want to talk.
- ✓ Thank you for trusting me with this. I'm sure it's hard to talk about.
- ✓ Tell me about your week. / What's new with you?
- ✓ How are you doing...really?
- ✓ I just want you to know I'm thinking of you.
- ✓ Tell me about your child. / What are their interests?
- ✓ I'm bringing over dinner tomorrow night.
- ✓ Can I come over with coffee this afternoon?
- ✓ I'm coming over to watch your kids while you rest or go out.
- ✓ I'm going to do _______ for you on _______.

IMPACT PARTNERS

Support These Organizations That Support Caregivers

We've partnered with organizations who are dedicated to serving caregivers and their families. If you're looking for tangible ways to support caregivers, consider supporting these organizations. Learn more at caregiverdoc.com/help.

NONPROFITS

The Lucas Project

The Lucas Project supports caregivers by providing recognition and respite.

thelucasproject.org

Tucker's House

Tucker's House partners with the families of children with disabilities to make their homes safer and more accessible.

tuckershouse.org

Key Ministry

Key Ministry promotes meaningful connection between churches and families of kids with disabilities accessible.

keyministry.org

Courageous Parents Network

Courageous Parents Network orients, empowers and accompanies families and providers caring for children with serious illness.

courageousparentsnetwork.org

Rising Above Ministries

Rising Above seeks to be a source of inspiration to families impacted by disability all over the world

risingaboveministries.org

Spreading Sunshine

Spreading Sunshine brings joy to families impacted by childhood illness by sending care packages to children and providing support to the entire family.

spreading-sunshine.org

A Better Balance

A Better Balance uses the power of the law to advance justice for workers, so they can care for themselves and their loved ones without jeopardizing their economic security.

abetterbalance.org

A Mother's Rest
RESPITE RETREATS
FOR PARENTS & CAREGIVERS
amothersrest.org

A Mother’s Rest

A Mother’s Rest coordinates therapeutic respite retreats for caregivers who have loved ones with disabilities and/or chronic medical conditions.

amothersrest.org