

CARE CARD

Created for bereaved parents
by bereaved parents

WAYS TO CONTACT ME:



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PEROXISOMAL
DISORDERS

Community

- ♥ Check in with me and continue to invite me even if I often say no
(If I cancel or leave early, don't be upset—just check in)
- ♥ Decision fatigue is real. Please provide me with 2–3 options for what we can do or where to go, with one being to simply rest and do nothing
- ♥ Become involved in raising awareness, fundraising, advocacy and/or attend remembrance events or fundraisers in child's honor
- ♥ Other: _____

Assist

- ♥ Feed me! ☐ Prepared Meals ☐ Gift Card ☐ Delivery ☐ Grocery Shopping ☐ Other: _____
- ♥ Assist with communication ☐ Create a list of people/organizations who need to be notified of a death
☐ Reach out and communicate notifications to medical companies, pharmacies, equipment suppliers, etc.
- ♥ Help with inside chores ☐ Laundry ☐ Dishes ☐ Cleaning ☐ Other: _____
- ♥ Help with outside chores ☐ Gardening/Landscaping ☐ Cut the grass ☐ Shovel sidewalk/driveway ☐ Other: _____
- ♥ Support my self-care (e.g., massage, physical activity, etc.)
- ♥ Other: _____

Remember

Name: _____ Birthday and Death Anniversary: _____

- ♥ Acknowledge the important dates annually (e.g., holidays, birthday, death anniversary) - grief does not end after the first year
- ♥ Don't wait for a holiday—send a quick note, text or card anytime you think of my child
(a simple "I was thinking of [Child's Name] today" means so much)
- ♥ Take the initiative to keep my child included in traditions and holiday activities
- ♥ Ways to Remember: listen to my child's story, say their name, share memories about them, and ask me questions about my child (show interest and a willingness to learn more about them)
- ♥ Attend remembrance events or fundraisers in my child's honor
- ♥ Other: _____

Empathy

- ♥ Give me permission to grieve and understand that my grief is lifelong
- ♥ Respect my need for space and boundaries (this may differ from day to day)
- ♥ Simply listen with compassion, without judgment or trying to fix
- ♥ Don't compare our losses (e.g., my child dying is not the same as your pet dying, grandparent, friend, etc.)
- ♥ Acknowledge secondary losses of my identity and community that occur after my child dies
(e.g., professionals and the supports, relationships that were there are now gone, etc.)
- ♥ Other: _____

Show You **CARE**: What Hurts, What Helps

WHAT HURTS

✗ Please do not...

- ❖ Say "let me know if you need anything" - it puts pressure on the grieving person to ask for help
- ❖ Say things like "Now you can do the things you couldn't do before"
- ❖ Pressure someone to do something they are not ready to do yet
- ❖ Put a timeline on someone's grief
- ❖ Tell someone how to grieve
- ❖ Compare losses
- ❖ Use platitudes and euphemisms (*e.g., s/he is in a better place, everything happens for a reason, etc.*)
- ❖ Use religious references unless you know the family's religion
- ❖ Start any sentences with "At least..."
- ❖ Shush or stop kids from asking questions
- ❖ Other: _____

WHAT HELPS

✓ Please do...

- ❖ Use this card: save it, share it with others, and refer back to it regularly
- ❖ Ask me about my comfort level with topics or questions
- ❖ Show up with compassion, not a solution
- ❖ Keep checking in even after the first year
- ❖ Share how you can help (*be specific* - "I can bring dinner Tuesday")
- ❖ Answer kids' questions honestly and simply, help them use kind words, and admit when you don't know something
- ❖ Other: _____



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TO STAY ENGAGED, FOLLOW US AT

