

WAYS TO HELP?

CONTACT INFO:

Home

- Feed me! Prepared Meals Gift Card Delivery Meal Prep
- Watch our loved one to allow us to run errands
- Help with inside chores, such as laundry, dishes, monthly supplies (delivery day!), putting groceries away, cleaning, organizing pantry/linen closet, paperwork, medical supplies, etc.
- Help with outside chores, such as grocery shopping, taking car for a wash, plant flowers, cut the grass, shovel sidewalk/driveway, etc.

Encourage

- Join me in healthy movement (e.g. bring over yoga mats, stretch, send me on a walk, etc.)
- If I say no often, please still invite me
- Invite all members of our household to events and activities
- Assist other household members who wish to attend outside events and activities
- Regularly check in - send a text and be okay with no response

Learn

- Learn my child's communication method(s) and communicate with him/her
- Get to know my child, like really know him/her (e.g. learn about their equipment, diet, sensory preferences, likes/dislikes, when and how to administer medications, etc.)
- Learn safety considerations for our child
- Find out how you can help raise awareness and advocate for rare diseases at the local, state, and/or national levels

Provide

- Provide your presence and support by Attending an appointment Sit with me during a procedure Travel with us to appointments/events to help with Warrior, others kids &/or give us break
- Overnight support
- Act as a point person during hospital stays and/or at home
- Bring me lunch and spend an hour with me in the hospital
- Provide support in obtaining and making accessible materials

FOR YOUR CONSIDERATION



LOVE FROM AFAR

Ways to help when loved ones are not physically nearby

- Streaming Service Watch Party
- Text and call to check in and be okay with delayed or no response
- Zoom coffee date *combine with sending coffee to a loved one!
- Meal delivery
- Providing gift cards for meals or coffee (e.g., DoorDash, Uber Eats, coffee shops, etc.), especially when in hospital, as well as memberships can make life easier
- Support self-care (e.g., massage, physical activity, etc.)
- Send a card
- Give words of encouragement (e.g. call, text, email, etc.)
- Send fun things you can do at home (e.g., indoor date night, etc.)
- Provide gas cards
- Be available to be a sounding board. Having a trusted person to vent to can mean so much
- Remember important dates (e.g., surgery dates, diagnosis dates, etc.)
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HELPFUL TIPS

When supporting loved ones

- Please understand that I am often living in crisis mode.
- When I am sharing, ask me if I need help, advice, or if I just need you to listen. There may be times when I need a safe person to share with and other times when I need help and suggestions.
- Be sure to include our Warrior (e.g., in conversations, pictures, invitations, etc.)
- Ask how you can communicate with our Warrior.
- Help educate others (adults and kids) about my Warrior and their rare disease.
- Don't shush kids or dissuade them from asking questions. Instead, answer them honestly and simply. Help them use the right words if they chose words in their question that may be hurtful or offensive. It's okay to say "I don't know" too!
- Your understanding and respect of my boundaries is important to me. Depending on what challenges I am facing and when, this may look different.
- Ask me about my comfort level with topics or questions.
- Please keep inviting me, I may say no, or not now but I need to know I'm still included. If I decline, please do not take it personally.
- _____

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TO STAY ENGAGED, FOLLOW US AT

