

Hmm, How can I help?



- Leave dinner at the door
- Plant flowers in my flower pots
- Fold laundry
- Put away monthly supplies
- Grocery shop
- Take my car for a wash

1

HOME

2

SUPPORT

- Sleep over for a night
- Come to my house and send me on a walk
- Get to know my kid, like really know him/her
- Come sit with me during a procedure
- Bring me lunch in the hospital and visit with me for 1hr
- Bring over yoga mats and stretch with me



- Ask for books & podcasts to learn more
- Talk about rare diseases and educate others
- Volunteer & engage at my events
- Be a point person during hospital stays & home

3

ACTIVATE

4

HANG IN

- Continue to invite me
- Understand I am living in crisis mode
- Check In regularly- send a text and be ok without a response
- Pick me up and take me to the movies
- Treat me the way you did before



Once Upon A GENE

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