

A Guide for How to Ask for Help – for Teens

When you have a connective tissue condition, like Marfan syndrome, Loeys-Dietz syndrome, or Vascular Ehlers-Danlos syndrome (VEDS), you sometimes need extra help. Everyone needs help at different times, and there may be times when you need even more of it.

Are you recovering from surgery? Restricted by the brace(s) you need to wear? In pain in one part of your body or all over? Too tired for school and activities? Feeling anxious? Whether you're experiencing any of these or other things that sometimes come along with having been born with your condition, one thing is for sure...you'll need some help!

Maybe you need help with things like getting dressed, bathing or brushing your teeth? Or maybe you need help getting your school assignments or setting up your instrument for band practice? Every day tasks can become difficult.

It's not always easy to ask for help or receive it. Some reasons may include:

- Not wanting to rely on other people to help you with things.
- You value being more independent and receiving help feels uncomfortable.
- You feel like it's a sign of weakness and you "should" be able to do these things.
- You're worried about what people will think.
- You don't want your family or friends to have to do "extra work" by helping you.

Whatever your reasons, it's okay to not be okay. And it's okay to ask for what you need.

The people in your life, like parents, guardians, siblings, grandparents, friends, neighbors, and classmates, often want to help but just aren't sure what you need. Sometimes, when people are trying to help you, the help they give may not seem very helpful at all.

For example:

- A friend might bring over a movie, not knowing it's hard for you to sit up for that long.
- A neighbor might text often to check in, not realizing how hard it is for you to respond.
- Your father might bring your favorite dessert, not realizing you're too nauseous to eat it.

People mean well, but without really knowing how best to meet your needs, they have to guess. And sometimes that leads to some uncomfortable situations. By letting people know ahead of time what's helpful and what's not, it's win-win. You'll get more of what you really need, and the people in your life will feel better about being able to help in the way that's most valuable to you.

Asking for what you need doesn't always come naturally. But, with some thought and practice, you can learn. To help you communicate your needs more effectively, complete the worksheet and share it with the people in your life who want to help and will be glad to know how.

A Guide to Helping Me

As you know, having been born with a connective tissue condition makes everyday life challenging for me at times. I'm learning that it's okay to ask for help. It's difficult for me to ask for the kind of care I need, and I know you are willing to help but don't know exactly how. So, I'm sharing this document to assist us both.

I like it when you do _____.

I don't like it when you do _____.

I like it when you say _____.

I don't like it when you say _____.

Other _____.

I prefer you reach out to me by:

- Phone call.
- Text.
- Email.
- Social media.
- Snail mail.
- Personal visit.
- Other _____.

I tend to have more energy in:

- Early morning.
- Late morning.
- Early afternoon.
- Late afternoon.
- Evening.
- Nighttime.
- Other _____.

When I'm upset, I usually like:

- Alone time.
- To talk about it.
- To be distracted.
- Having regular check-ins.
- Other _____.

When I'm not feeling well, please:

- Ask me what I need.
- Wait for me to ask for help.
- Respect my desire to be alone.
- Check on me more often.
- Other_____.

It makes me uncomfortable when:

- I talk about my health.
- I ask for help.
- People see me in bed.
- Other_____.

When I get stressed I:

- Forget to do things/need reminders.
- Shut down.
- Like to talk things through.
- Other_____.

When you visit, I prefer you:

- Contact me right before to make sure I'm still up for it.
- Ask me how long you should stay, which is usually no more than _____.
- Wait for me to ask for help, rather than doing things for me.
- Talk about _____ and not _____.
- Bring _____ and not _____ if you were planning to bring something. In particular, I would appreciate: _____
_____.
- Other_____.

When we spend quality time together, I would love to:

- Play a board game.
- Listen to music.
- Work on a puzzle.
- Watch an episode of a show we both enjoy.
- Watch a movie.
- Go outside for fresh air.
- Talk and catch up.
- Eat a meal.
- Other_____.

These are some other ways you can help:

- Bring me materials and assignments from school. My classes are: _____

_____.
- Tell me what's going on in school. It helps me feel more a part of things.
- Bring me whatever I may need from the clubs and activities I participate in: _____
_____.
- Take photos or movies at sports or social events I can't attend. This helps me enjoy occasions I miss. Some activities coming up are: _____
_____.
- Allow me to feel sad or afraid. Sometimes it helps to cry with someone.
- Tell me what's going on in your life. It helps me stay connected to the outside world.
- If people ask what's going on with me, I prefer you tell them: _____
_____.
- Other: _____.

Thank you so much for being there for me when I need it and in the way that I need it! Please don't share this document with anyone since I included a lot of personal information.
With love and appreciation!