

Ask for Help

We all hate this one. Very few people ever want to admit that they need help. Many people fear that they are weak if they ask for help.

We are not meant to be completely independent all the time. We have relationships because we need people. During this difficult time it is vital to take care of yourself and understand your needs.

Ask yourself this question, "What would happen if I caught a cold and could not care for my loved one?" It is an important reason to take care of yourself. Now, let others know how they can help.

When people offer to help, give them the opportunity to feel useful and to help you by running an errand or picking up something from the grocery store. You have enough to deal with at this time. Let others help you and your loved one.



Creutzfeldt-Jakob Disease
Foundation, Inc.

The CJD Foundation, Inc.
P.O. Box 5312, Akron, Ohio 44334
330.665.5590

HelpLine 1.800.659.1991
www.cjdfoundation.org
help@cjdfoundation.org



Creutzfeldt-Jakob Disease
Foundation, Inc.

SUGGESTIONS FOR FAMILIES



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About You

Your loved one has CJD or is suspected of having CJD. This means you are a caregiver. As such, you have many things in common with others in this situation. The following is a short list of possible concerns you may have.

Feeling Overwhelmed

This feeling is very real and common for most people dealing with CJD. CJD can move rapidly and the change in symptoms can be too rapid to understand. Questions with no answers can only add to the feeling of being overwhelmed.

For information and support, contact the CJD Foundation's HelpLine at **1.800.659.1991** or **help@cjd.foundation.org**. We are here to support you.



Lack of or Mixed Information

Relatively little is known about CJD. Because of this, many of your questions may have to go unanswered. Researchers are working to find answers, but research takes time. The CJD Foundation has a comprehensive pamphlet that may help you understand the disease. You can download it from our website **www.cjd.foundation.org** or call us and we will mail you a copy.

There are many unsubstantiated theories that pretend to answer questions. These theories and the lack of information cover the spectrum and may be confusing. You do not need to live in confusion. The CJD Foundation's HelpLine will give you the most current and accurate information.

Frustration

Frustration exists. How can it not exist when you have so little information and are watching helplessly as your loved one is changing before your eyes?

As difficult as it may be and as much as you may hate this, the situation is out of your control. You can only control how you respond.

You may find the following suggestions helpful

- Call the CJD HelpLine at **1.800.659.1991** or email us at **help@cjd.foundation.org**. We are available to listen anytime and we can offer up-to-date information.
- Find someone who will stay with your loved one so you can take a walk. Even if it is only for 20 minutes, that time alone can help clear your mind.
- Find someone to talk to who will listen without judgment, suggestions or more information.
- In the midst of your exhaustion and confusion you have this moment to be present with your loved one. Love them, be with them, even if it's to sit quietly together. Do what you absolutely must do and let the rest of it go. This time is precious.
- When someone offers to help, give them something to do. They need to help.

www.cjd.foundation.org