


Without Making it Obvious

- Mow the lawn or wash the car
- Shovel the sidewalk
- Do the dishes or laundry
- Clean the bathroom
- Take dinner without the expectation of sitting and talking - use disposable dishes
- Drop off some fruit or healthy snacks
- Tell them you are going to the store and ask, "What do you need me to pick up for you?" Have a list of "basics" available such as milk, bread, etc.
- Pick up prescriptions
- Organize friends to bring in meals and be sure to make the meals realistic (Make appropriate amounts for a home where fresh meals are being brought in daily)
- Clean out the refrigerator
- Offer to run any other errands

With Permission

- Take the kids out to a movie, dinner or anything fun
- Listen to their fears
- Listen to their stories
- When they are ready, share favorite stories or memories with them
- Be available to sit with the patient so that your friend can go for a walk, take a nap or just get out for a few minutes

Extra  Thoughts
Too often *people worry about*

what to say. Here are a few suggestions:

- Leave *ought's* and *should's* out of conversations. There is no single right way to move through this illness. These words only create unnecessary guilt.
- Keep judgments out of the conversations
- Do not try to change the feelings that are expressed to you
- Allow tears. They are not a sign of weakness, but a sign of love and pain.
- Honor the privacy the patient and family may desire
- Remember concentration may not be good during this process
- Listen to whatever your friend needs to share
- Remember you cannot fix this reality



Creutzfeldt-Jakob Disease
Foundation, Inc.

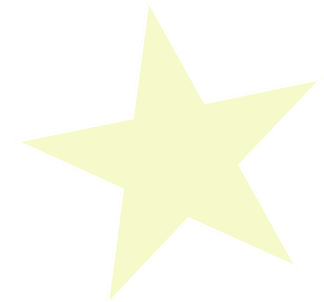
The CJD Foundation, Inc.
P.O. Box 5312
Akron, OH 44334

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



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HOW TO HELP A FRIEND WHO IS COPING WITH CJD



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How To Help A Friend Who is Coping With CJD

Introduction

A friend or the loved one of a friend has been diagnosed with CJD. For some, the first reaction is shock. What? What is that? How can that happen? What happens now? What can I do to help? Your compassion and support during a difficult illness process is important to both the patient and the family.

Your Feelings

There are many feelings involved when you hear about a CJD diagnosis. These feelings may range from fear to surprise to pain to sadness. All of these are normal. It is very important to acknowledge them. Find a safe person to talk to about your feelings. Be sure it is someone not directly affected by this diagnosis. If a safe person is not available, consider writing in a journal.

It can be important to remember that feelings are just that, feelings, not problems to be fixed. There is no need to try and change what you are feeling.

Responding to the Patient

Respect the Patient's Wishes

The first and perhaps most important action is to respect the patient's wishes. CJD is typically a rapidly progressive disease. Respecting the person's wishes means to listen without interruption or judgment. If the person does not want to talk, make that comfortable as well. Perhaps your friend simply wants or needs to be quiet. Respect the patient's agenda. The person with CJD may not want to see friends and only wants to spend time with family. Respect that request and do not be insulted. Your friend is asking for time with the most important people in his/her life. This deserves to be honored.

Be Present

If visits are welcome find the best time for the patient and family. Share your love, concern and memories in a SHORT visit. Remember it takes energy to visit with friends and family. Again, please make your visits short and pleasant.

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Responding to the CJD Patient's Family

They are most likely overwhelmed, exhausted and looking for answers. It can be hard to find accurate information about CJD. Please refer anyone to the CJD HelpLine at **1.800.659.1991** or **help@cjdfoundation.org**. We are available to provide information and offer support.

Do not share stories of other people and their illnesses with your friend. This does not help and only adds to their fears and feelings of being overwhelmed.

Be willing to listen without judgment or comment. Listen. Listen, and when you can, listen some more. Let the person talk as much as is needed.

How to Help

DO NOT tell them to call you anytime they need help. They probably will not. Typically at this point your friend is feeling overwhelmed, tired and is very busy trying to figure out how to survive. They do not have enough energy and are feeling vulnerable.

What you can do instead is very specific. The list on the back of the trifold are some simple suggestions.

