

ASK FOR HELP

Some of us hate this one. In fact few people ever want to admit that they need 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 help you by running that errand or picking up something from the supermarket. You have enough to deal with. Let others help you and your loved one.

NEED MORE INFO?

CJD SUPPORT GROUP NETWORK

Email: contactus@cjdsupport.org.au

Web: www.cjdsupport.org.au

Family Representative

Mandy Newton

Toll Free 1800 884 897

National Co-Ordinator

Suzanne Solvyns

Toll Free 1800 052 466

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SUGGESTIONS FOR FAMILIES

CREUTZFELDT-JAKOB DISEASE

This information brochure has been provided by the



CJD Support Group Network
CJDSGN.

www.cjdsupport.org.au

ABOUT YOU

If your loved one is suspected of having CJD you maybe 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 set a rapid pace and the change in symptoms can be too rapid to understand. Questions with no answers can only add to the feeling of being overwhelmed.

HOW DID MY LOVED ONE DEVELOP CJD?

The majority of cases of CJD are sporadic CJD (sCJD), occur at random and there is no known cause. There is no proof that classical CJD is transmitted by blood, or from anything your loved one may have eaten.

Variant CJD (vCJD), or the human form of BSE, is very different type of CJD and relates to the consumption of BSE contaminated beef products. This form of CJD has not occurred in Australia.

Familial forms of CJD are extremely rare and usually there is a family history.

LACK OF OR MIXED INFORMATION

Relatively little is known about CJD. Because of this, many questions you have may go unanswered. Researchers are working hard to find answers but research takes time. The CJDSGN is happy to provide you with additional information that may help you to understand the disease more easily.

There are many unsubstantiated theories that pretend to answer questions. These theories and the lack of information cross the spectrum and may be confusing. The CJDSGN is available to help you access the most current information.

FRUSTRATION

Frustration exists. How can it not exist when you have so little information and you 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 it, the situation is out of your control. You can only control how you respond.

THE FOLLOWING SUGGESTIONS MAY HELP:

- * Find someone who will stay with your loved one so you can take a break. Even if it is for 30 minutes. That time alone can help clear your mind.
- * Find someone to talk to who will listen without judgment, suggestions or 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 is just to sit quietly together. Do what you absolutely must do and let the rest go. This time is precious.
- * When someone offers to help, give them something to do. They need to help.
- * Call the CJDSGN. We are available to listen and assist you anytime.