

MYOCLONIC JERKING (TREMORS OR SEIZURES)

Myoclonic jerking may happen, but does not in all situations. This does not create pain for the patient but is often difficult for the patient's loved ones who witness it.

Management includes:

- Minimize touching, turning and movement
- Promote a calm, quiet approach and create a serene environment
- Relax the muscles
 - ✓ Use of gentle massage may help
 - ✓ Contact your medical care provider to talk about possible medications.

SENSORY DISTURBANCE (HYPERSENSITIVITY TO TOUCH AND ENVIRONMENTAL NOISE)

Heightened sensitivity is common. The extent varies for unknown reasons. Reactions occur more commonly to unexpected touch, loud or sudden noises and music. This may produce immediate signs of distress and agitation.

Management includes:

- Careful planning to reduce the need for touching
- Controlling environmental activity and noise
- Using soft lighting
- Explaining to visitors:
 - ✓ How to approach the patient
 - ✓ How to talk to the patient
 - ✓ What to expect from the patient

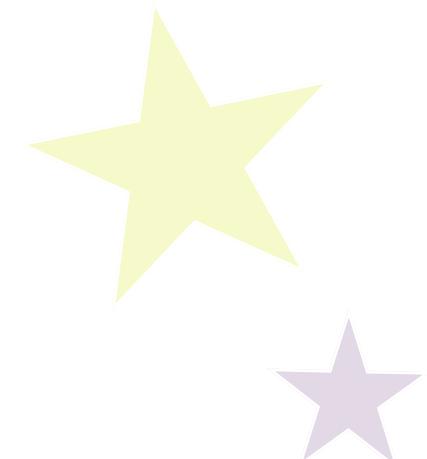
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- Covering glass tables, other pieces of furniture with a high gloss or mirrors as this may create a visual disturbance for the patient
- Turning off the television - flickering or changing light can induce hallucinations



Creutzfeldt-Jakob Disease
Foundation, Inc.

SUGGESTIONS FOR PATIENT CARE



Creutzfeldt-Jakob Disease
Foundation, Inc.

The CJD Foundation, Inc.
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HelpLine 1.800.659.1991
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Suggestions for Patient Care

- Always treat the patient with dignity and respect.
- Reassess the patient daily (e.g. when to ask for Home Health Care Assistance).
- Activities of Daily Living: Does your loved one need more help than previously with bathing, shaving, toiletry, dressing, eating, etc.
- Nutrition: Let your loved one be in charge of their diet. Nutrition needs may alter as the disease progresses.
- Visitors: Pay attention to how your loved one responds to visitors. Are they welcomed? Are visits tiresome? Do they make your loved one more restless or agitated? Short visits that have no expectation of "entertaining" the guest are best.

Conversations

- Always include the patient in conversations even if they don't or can't respond. They may very well be able to hear and understand but not be able to respond.
- Reminisce: For example, complete the following:
 - ✓ I remember when...
 - ✓ Thank you for...
 - ✓ I'm proud of...

Questions for Medical Professionals

Questions to ask your loved one's medical professional (Physician, Home Health Nurse, Hospice Nurse, etc.):

- Are there changes in nutrition needs I should watch for?
- Is there a medication that can make my loved one more comfortable?
- Is the patient on the correct medication and/or dosage?
- Are there changes in breathing I should watch for?
- When should I call you?
- There are family members who don't want to be in the room or visit at all. Is that OK? Should I convince them to come?

When talking with the physician always encourage honesty, including what he or she does not know.

Keep the CJD Foundation's phone number handy – **1.800.659.1991**. Encourage anyone involved in the care of the patient to call us (including healthcare providers and friends) with their questions. If we don't have the answer, we know how to get it.

HelpLine: **1.800.659.1991**
www.cjdfoundation.org

Common Symptoms

The following are a few common symptoms your loved one may experience. This is only a partial list because symptoms can vary from patient to patient.

PYREXIA (FEVER)

Wide fluctuations in temperature may occur even in the absence of diagnosed infection. This may be due to the effects of the disease on the central nervous system.

Management includes:

- Seeing your medical care provider for a medication that may help with the controlling of the fever.
- Controlling the environment by using tepid sponging and fans to cool the room.

DYSPHAGIA (DIFFICULTY SWALLOWING)

Some patients may find swallowing difficult. Your medical care provider can help with suggestions about changing the manner in which food is prepared. Regular mouth care is often a very important comfort measure.

It can be helpful to remember that nutrition and hydration are often more important to the family than the patient. These needs alter with time.

INCONTINENCE

This is a universal problem and can cause agitation, restlessness and distress.

Management includes:

- Discussion with the daily medical care provider to assess ways to address incontinence.
- Learning how to change the bedding and the patient's clothing with minimal touching.

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