

# Opsoclonus Myoclonus Syndrome

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**Goal:** To describe psychosocial support that will benefit the parent of a child with OMS, and, benefit the child with OMS in the home and school setting.

**Objectives:**

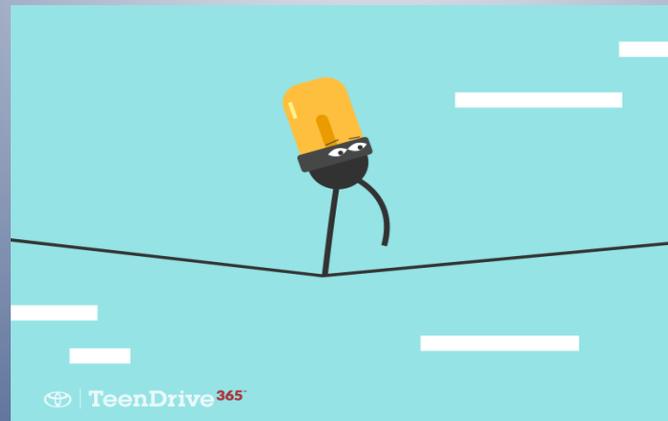
1. Participant will be able to discuss the effect of a diagnosis of OMS on a parent's life
2. Participant will be able to explain an IEP and it's purpose
3. Participant will be able to identify 1-2 approaches to increase positive parenting skills

# SELF CARE FOR THE PARENT

Research emphasizes the importance of the parent's emotional well-being to assist the child in gaining positive outcomes

Providing support for yourself may include

- Understanding the notion of medical trauma
- Understanding the notion of a tight rope, balancing btw living today and preparing for tomorrow



# Self Care

Self care includes looking at the notion of medical traumatic stress on receiving a devastating diagnosis

- **Medical traumatic stress**

- What is medical traumatic stress

- How does it affect some people

- How do you address it so it does not negatively impact your life

## Medical traumatic stress refers to,

- ▶ The **psychological and physiological response** of the parent (or child) to pain, injury, serious illness, medical procedures, and invasive or frightening symptom or treatment experiences.
- ▶ **It includes a fear of the future** because the certainty and safety of the present has been challenged



For some **parents** the response to their child's diagnosis may be **medical traumatic stress**



# What contributes to the sense of trauma

## The journey to diagnosis may be traumatic

1. **Opsoclonus myoclonus** ataxia is a diagnosis that is unexpected and unknown
2. Words associated with OMS that evoke the same sense of shock or trauma are: Neuroblastoma, Tumor, Cancer
3. OMS is a **rare** condition
4. There is a **lack of shared public knowledge** about OMS
5. **Out-dated knowledge** about OMS and lack of knowledge about new treatments leads to **low expectations** of outcome



The following feelings may result from the  
**parent's** sense of **medical trauma**

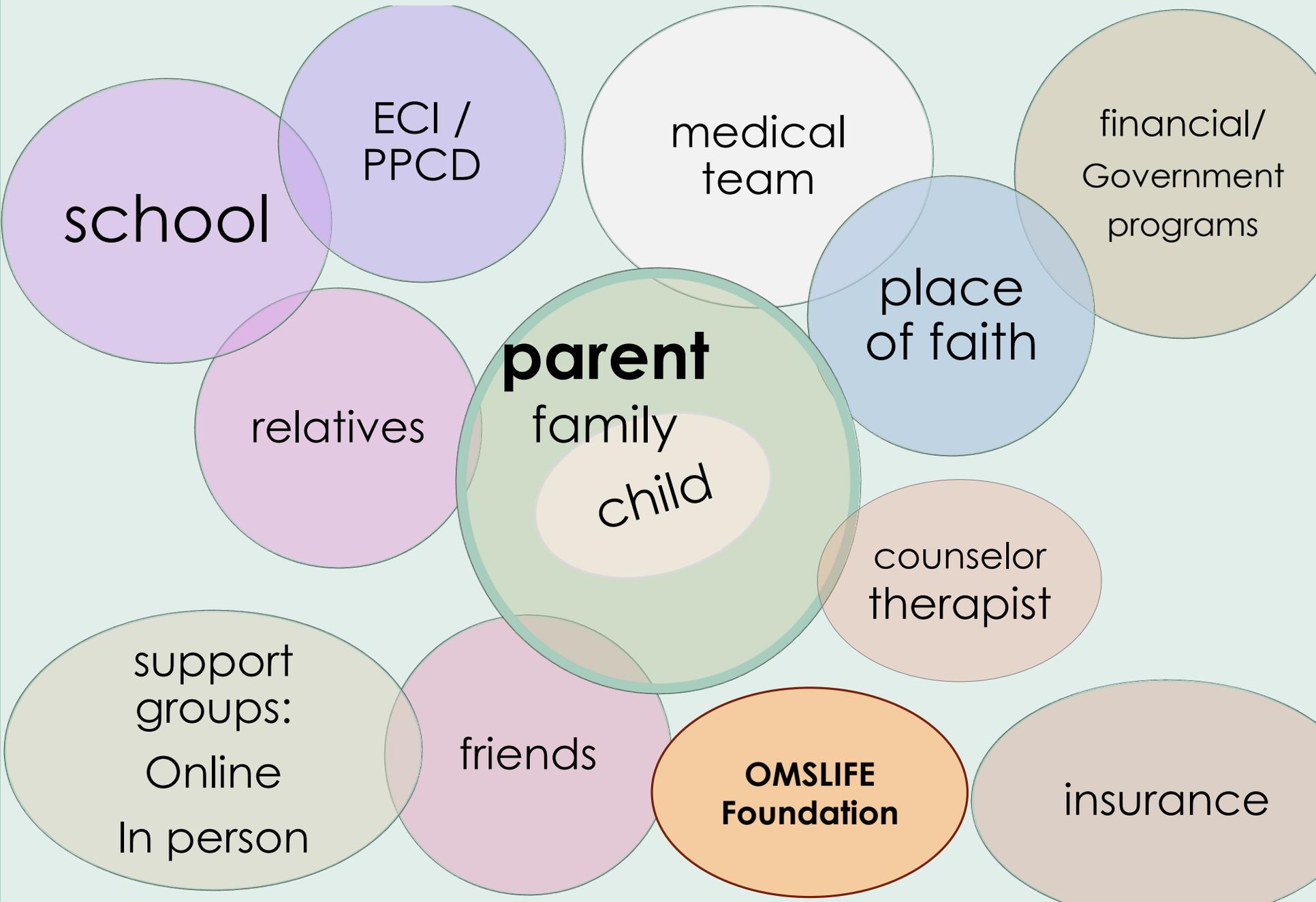
- **Loss of** feelings of safety and **security**. *May cause fear, hopelessness, **powerlessness***
- The **parent's response may affect the child**, may create anxiety in the child, the child may develop a self-perception of being disabled. The *parent may become over protective*
- *Free floating feelings* of anxiety, anger, depression, guilt, fears
- If not addressed this may ultimately lead to ongoing stress and anxiety for the parent and a *failure to progress* through the normal developmental stages of independence by the child

# If you have experienced feelings of trauma stress here are suggestions

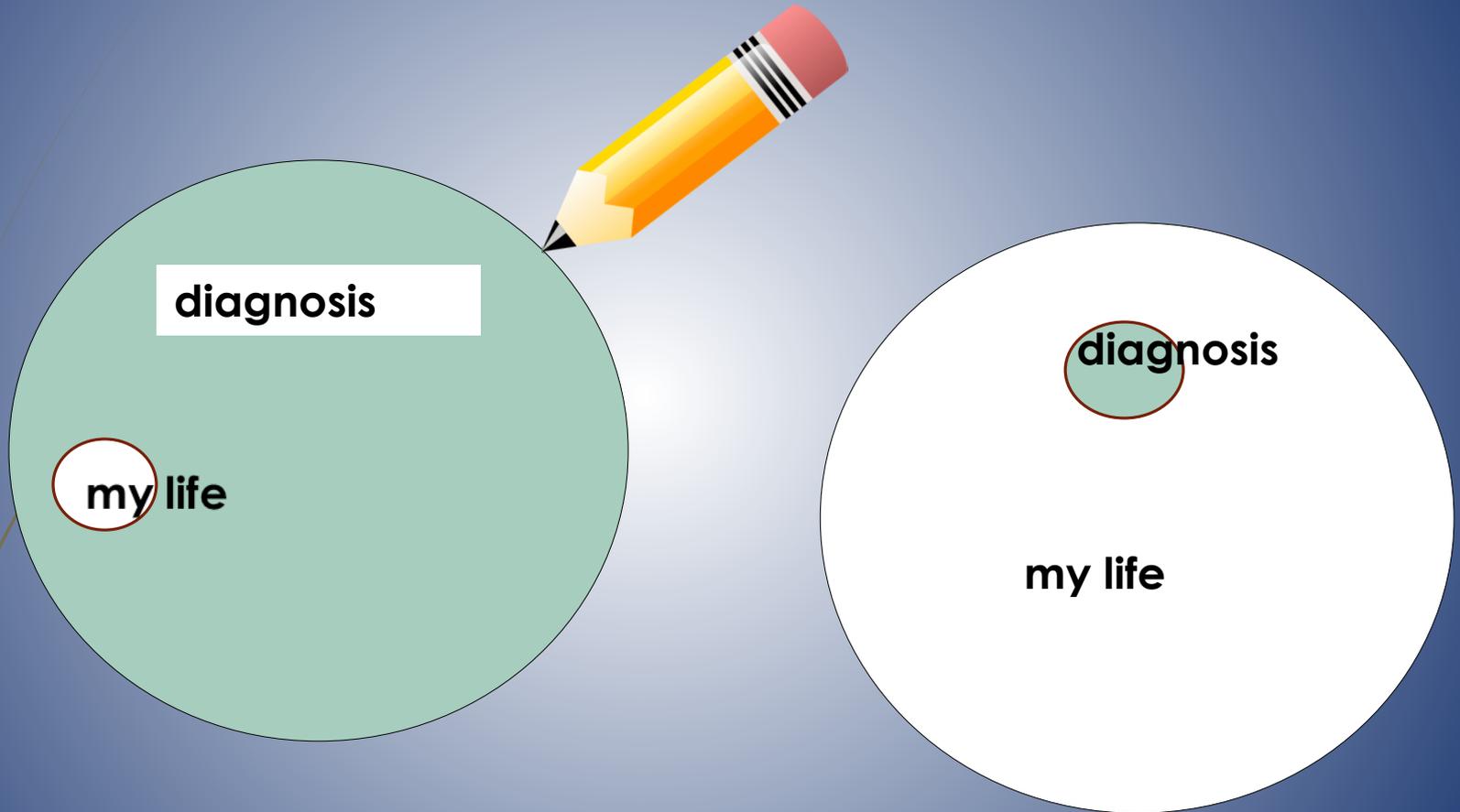
**Trauma informed care** is an approach to engaging people with a history or incident of trauma. It recognizes the presence of trauma symptoms and acknowledges the role trauma plays in their life.

- **Psychological First Aid:** Your perception of how terrible this is, is real, to you. Acknowledge your **physiological response**. Acknowledge your senses
- **Validate the shock.** Respect the emotional response. Don't allow others to intellectualize it and rationalize it away. **Accept** grief and anxiety as normal
- You need friends who can provide **empathic listening**. Talk about it.
- Allow time for yourself to **absorb the shock and process feelings**. Should you continue at a high level of anxiety or inhibit the child from developing on a normal trajectory of psycho- social development then locate a mental health provider / counselor

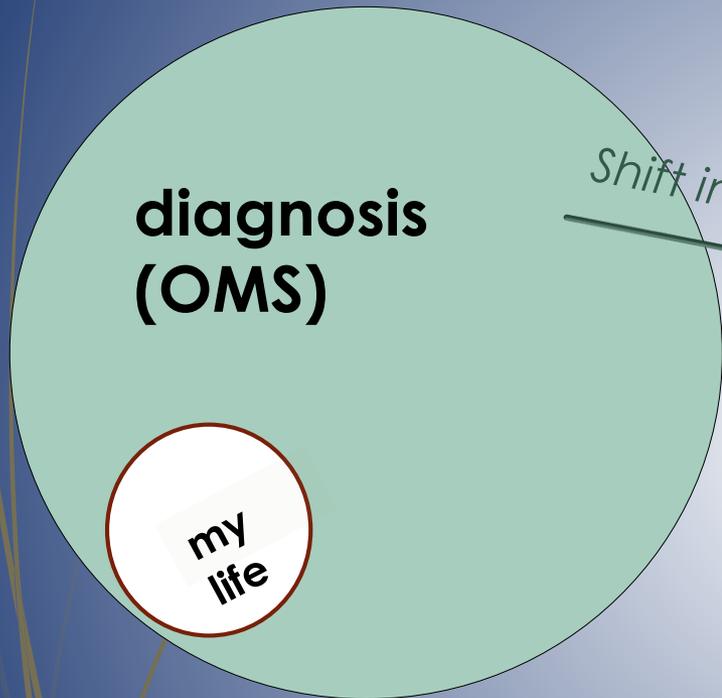
# Systems of Support and Care



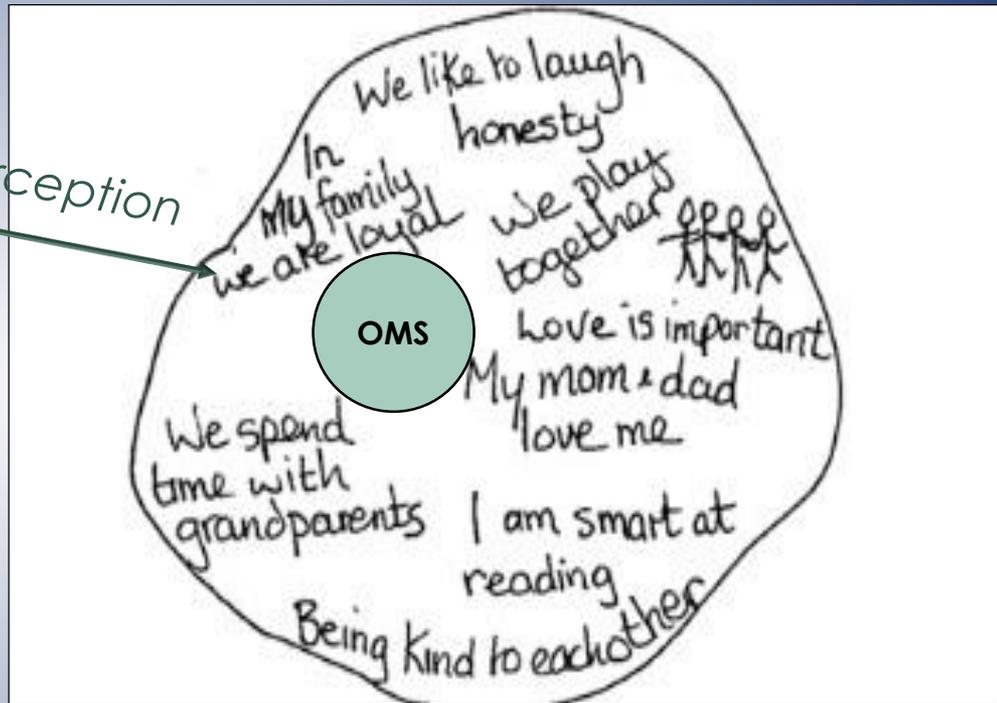
# Journey through the diagnosis



# Adjustment to diagnosis



Shift in perception



Focus on family values which are larger than the diagnosis

# Preventing and Coping with Burn-Out

**Parent reactions:** “Trauma brain”- unable to retain info, forgetfulness, difficulty problem solving • Emotionally overwhelmed • Overwhelmed by tasks • Feel helpless

- Realistic goals: nothing is too small a goal to set
- Reach for the incremental steps of progress – not perfection
- Reduce blame and criticism of self and others and child
- Recognize negative feelings and frustrations about disease management as normal and important to voice

# Organize your story so the diagnosis does not become your sole identity

- ▶ OMA is a problem saturated story – the disease is a journey that lasts a different length of time for each family but the story can be altered, changed, re-negotiated, externalized
- ▶ You are the expert on your story. You re-write your family's story allowing positives in
  1. Survival questions
  2. Support questions
  3. Esteem questions



# Survival questions

- ▶ How have you managed to survive or thrive thus far, given all the challenges you have had to contend with?
- ▶ How have you been able to rise to the challenges put before you?
- ▶ What was your mind set as you faced these difficulties?
- ▶ What have you learned about yourself and/or your world during these struggles?



# Support questions

- ▶ Who has given you special understanding, support or guidance on this journey?
- ▶ Who are the special people on whom you can depend?
- ▶ What is it these people do for you that is exceptional?
- ▶ What did they respond to in you?
- ▶ Which associations, organizations or groups have been especially helpful to you in the past?



# Esteem questions

- **When people say good things about you, what are they likely to say?**
- **What is it about your life, yourself and your accomplishments that give you real pride?**
- **How will you know when things are going well in your life?**
- **What gives you genuine pleasure in life?**

*I have what it takes to walk the tightrope*

