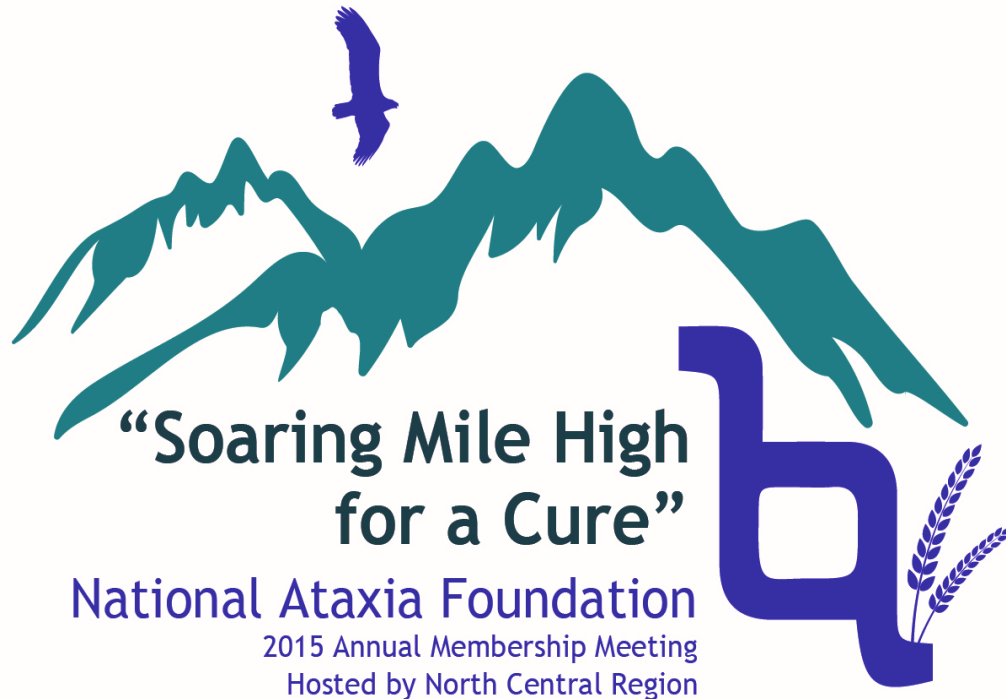


# Strategies for Living with Ataxia

**Bailey Vernon, MPH, CHES**

*Johns Hopkins Ataxia Center*



# Disclaimer

- The information provided by speakers in any presentation made as part of the 2015 NAF Annual Membership Meeting is for informational use only.
- NAF encourages all attendees to consult with their primary care provider, neurologist, or other health care provider about any advice, exercise, therapies, medication, treatment, nutritional supplement, or regimen that may have been mentioned as part of any presentation.
- Products or services mentioned during these presentations does not imply endorsement by NAF.

# Presenter Disclosures

- List Speaker(s)
- The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:
- No relationships to disclose or list



# Strategies

1. Execute a care plan
2. Exercise
3. Eat Well
4. Education
5. Effective Communication
6. Effective Coping
7. Exploring Options



# Strategies

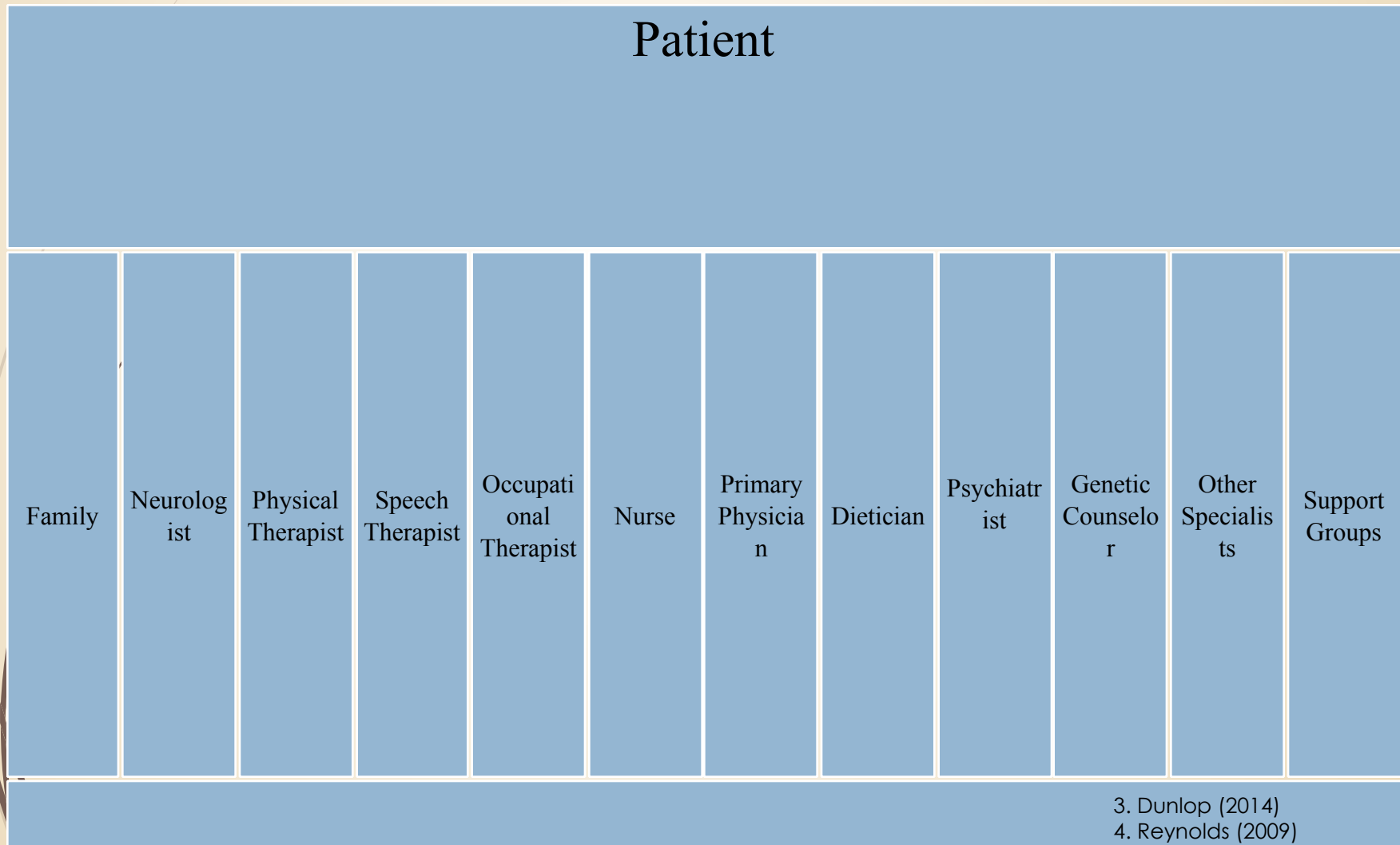
1. **Execute a care plan**
2. Exercise
3. Eat Well
4. Education
5. Effective Communication
6. Effective Coping
7. Exploring Options

# Your Care Plan

- Be an **ACTIVE** participant
- Develop a **TEAM** of individuals dedicated to your care
  - Seek care providers you trust <sup>1</sup>
  - Build a strong relationship with your physician <sup>2</sup>
  - Identify your care partner(s)




# Build Your Care Team





# Strategies

- ➡ Execute a care plan
  - ➡ **Exercise**
  - ➡ Eat Well
  - ➡ Education
  - ➡ Effective Communication
  - ➡ Effective Coping
  - ➡ Exploring Options
- 



# Exercise

- Benefits
  - Helps with mood
  - Improve physical conation
  - Maintain function and **independence**
- Important part of the treatment plan




# Exercise

- Where to start?
  - Seek a physical therapist
  - Community centers
  - Library
- What type?
  - Incorporate aerobic, strength, and stretching
  - Find exercise that you **enjoy** and **adapt** it into your daily routine





# Strategies

- Execute a care plan
  - Exercise
  - **Eat Well**
  - Education
  - Effective Communication
  - Effective Coping
  - Exploring Options
- 

# Eat Well

- Balanced nutritious diet
- Limit Alcohol
- Moderation
- Address chewing and swallowing difficulties



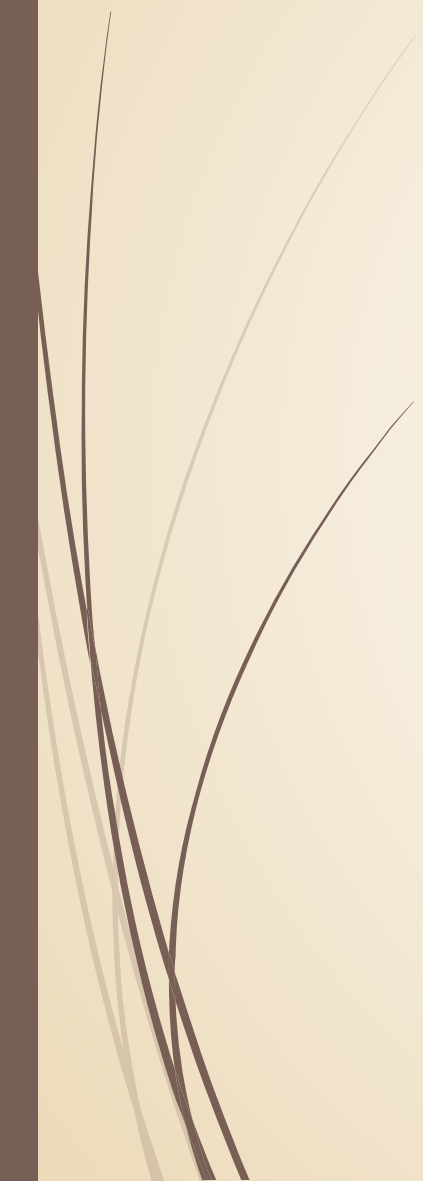


# Strategies

- Execute a care plan
- Exercise
- Eat Well
- **Education**
- Effective Communication
- Effective Coping
- Exploring Options




# Educate Yourself

- ➡ **Knowledge is power**
  - ➡ Know where to find reliable information
  - ➡ Beware “Information overload”
- 



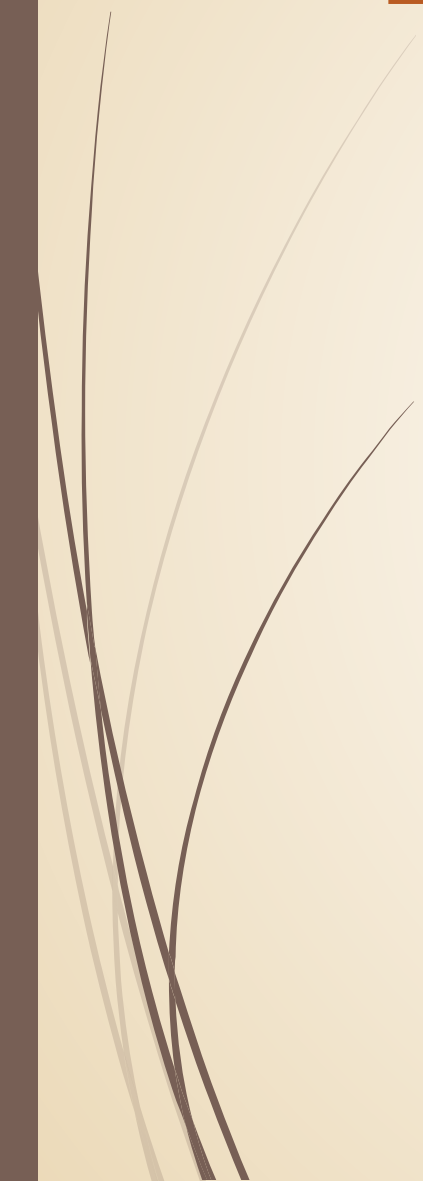
# Strategies

- Execute a care plan
  - Exercise
  - Eat Well
  - Education
  - **Effective Communication**
  - Effective Coping
  - Exploring Options
- 






# Effective Communication

- Knowing the vocabulary of ataxia
  - Communication between providers
  - Voice health
- 



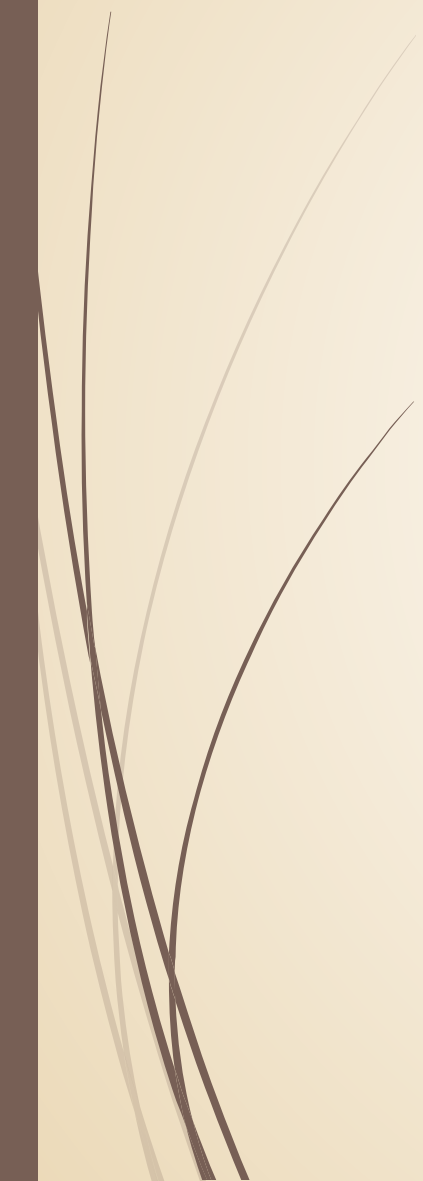


# Strategies

- Execute a care plan
  - Exercise
  - Eat Well
  - Education
  - Effective Communication
  - **Effective Coping**
  - Exploring Options
- 



# Effective Coping

- 
- Anger
  - Denial
  - Helplessness
  - Isolation
  - Guilt
  - Fear
  - Frustration
  - Disappointment
  - Confusion
  - Uncertainty
  - Embarrassment
  - Anxiety

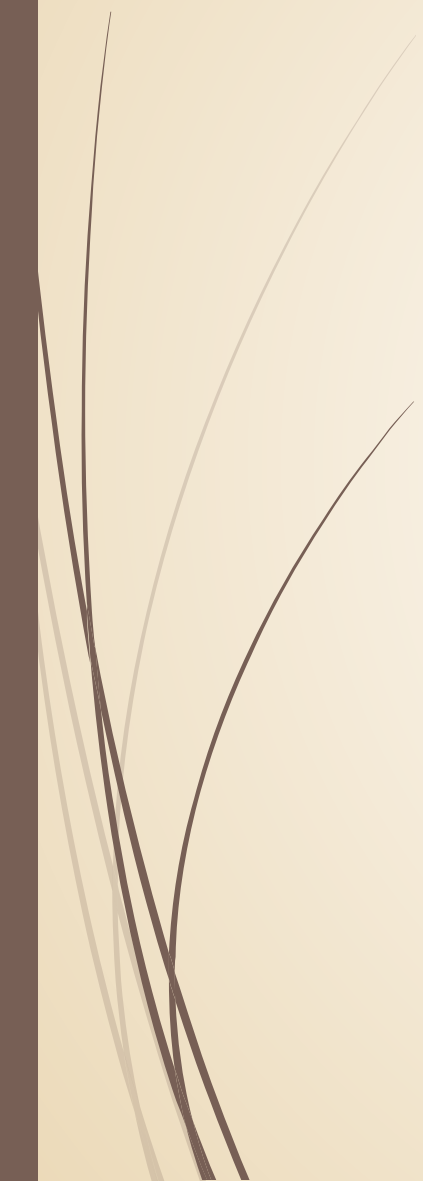


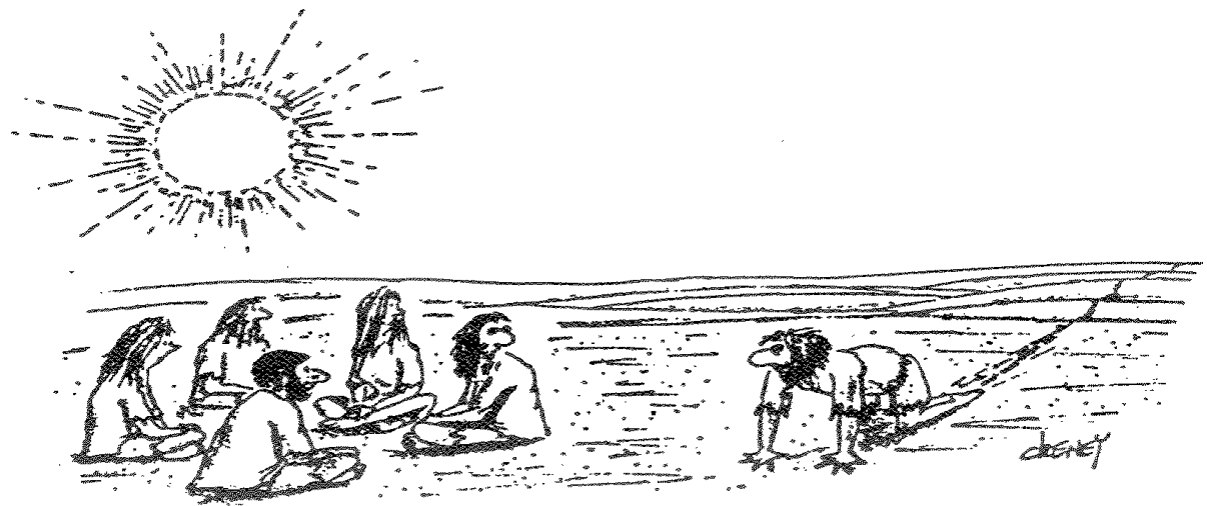
# Effective Coping

- **Additional stress**
  - Relationship changes
  - Altered communication
  - Family conflicts
  - Apathy
- **Disease progression can change emotions**
  - Loss of independence
  - Loss of privacy
  - Lowered self-esteem
  - Guilt



# Effective Coping

- Stress management
  - Find the positive
  - Develop and maintain your humor
  - Professional services
  - Know your limits and make adaptations
  - Social support
  - Support groups
- 



FINALLY, A SUPPORT GROUP!




# Effective Coping

## ➤ **Caregiver Support**

- Ataxia impacts entire families and communities
- Prevent caregiver burnout
- Find ways to continuously support one another
- Caregiver health
  - Care partner support groups
  - Take breaks
  - Visit your doctor



# Strategies


- Execute a care plan
  - Exercise
  - Eat Well
  - Education
  - Effective Communication
  - Effective Coping
  - **Exploring Options**
- 



# Explore Options

- Learn what resources are available in your community
  - Activity centers
  - Wellness programs
  - Financial resources
  - Future planning
  - Case managers





*“Life consists not in  
holding good cards  
but in playing those  
you hold well”*

**-Josh Billings**



# References



- 1. Gomez, C. M. (2014). Finding the Best Ataxia Care. *The University of Chicago*.
- 2. Nance, M. A. (2003). Living with Ataxia. *National Ataxia Foundation*
- 3. Dunlop, S. R. (2014). The Parkinson's Disease Management Plan. *Johns Hopkins Parkinson's Disease and Movement Disorders Center*
- 4. Reynolds, A. (2009). Patient-centered Care. *American Society of Radiological Technologists*.
- 5. Dokin, R. D. (2014). Cognitive Behavioral Therapy. *Rutgers University*.