Newly Diagnosed

“You don’t get told anything, they don’t do anything and nothing changes”

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Newly Diagnosed

What are my diagnosed with?
Newly diagnosed

• Ataxia is a combination of symptoms due to progressive deterioration of the cerebellum and its connections.
Newly diagnosed

• Symptoms of ataxia include,

• Motor symptoms,

• Vestibular symptoms

• cognitive and psychiatric symptoms
Newly diagnosed

- Motor symptoms;
- impaired walking, like when one is drunk,
- poor balance falls
- clumsy, hands, and feet,
- slurred speech, stiffness, and
- swallowing difficulties
Newly diagnosed

- vestibular symptoms include
  - dizziness or vertigo,
  - poor balance,
  - visual symptoms, such as blurred vision, double vision, or jumping visions
Newly diagnosed; cerebellar cognitive mood changes include

- emotional dysregulation,
- impulsive behaviors,
- Apathy
- anger, irritability, and
- some of the cognitive symptoms
- frontal executive difficulties with planning, dual tasking and sequencing
- language, and sometimes reasoning are some of the early features
Newly diagnosed

- Other clinical features depend on the type of ataxia include;
- Visual changes
- Presence or absence of neuropathy
- Parkinsonism
- Seizures
Neurodegenerative Ataxias

Genetic

Sporadic
Newly diagnosed

- Idiopathic/ Sporadic Ataxia’s: late onset cerebellar ataxia, Multiple system atrophy - cerebellar type
- Genetic Ataxia’s: Autosomal dominant, Autosomal recessive, X linked or Mitochondrial.
- Symptomatic / secondary ataxia
Newly diagnosed

ONCE DIAGNOSIS IS GIVEN; WHAT ARE THE NEXT STEPS
Newly diagnosed; Educating self.

✓ What does this mean?

✓ Informing yourself, vetting your sources of information.

✓ What sources if information have you found helpful regarding your condition?

✓ Do you received written information from Health professional? What was it like?

✓ Have you found information on the internet — what was it like?
Information resources

Ataxia Community:
• National Ataxia Foundation (NAF)
• Local Ataxia Support Groups
• Other patients and caregivers
Newly diagnosed : Understanding yourself

• How would you want to best receive care academic v.s local neurologist collaborative care.

• Helping your self

• Give yourself: research or not, resources, support
Newly Diagnosed

Research

• Observational studies; Natural history studies
• Interventional studies
• Clinicaltrials.gov
Support

✓ Who helps you
✓ Do you have support from friends and family.
✓ Are you a member of any support group.
✓ Maintaining connections is crucial
Multidisciplinary Approach to treatment is key

• All ataxias are treatable
  • A few cerebellar ataxias have specific drug treatments
  • Knowing cause of ataxia informs treatment
  • Treatment is tailored to individual needs

• Multidisciplinary team approach
CARE TEAM

• Neurologist:
  • MOVEMENT DISORDER or one with great interest in ATAXIA
• Psychiatrist
  • Psychologist
• Cardiologist
• Endocrinologist or Internal Medicine doctor
• Sleep specialist
• Ophthalmologist
• Neurorehabilitation
• Genetic Counselor
• Social Worker
  • Caregiver and family support
Multidisciplinary team

Research team

• Patient and family
• Research Coordinators
• NAF
• Research sponsors
  • Biohaven (Phase 3 study of Troriluzole)
  • NIH & NINDS
• Other Industry sponsors
• https://clinicaltrials.gov
  • 102 studies on ataxia nationally and internationally
Multidisciplinary team

Palliative Care team

• Social Workers, Nurse specialists
• Advance care planning
• Patient and family Counseling
• Home health
• Dysphagia treatment
• Hospice care
Multidisciplinary team

Neurologist, clinic staff, research team
Internist’s team
Genetics Counselor
NAF and Local Support Groups
Subspecialists
Neurorehabilitation
Palliative care
Patient and family
Newly Diagnosed – checklist
enpowering yourself

- Seek out the most advanced and specialized care that is available to you
- Join your support group.
- Educate yourself
- Designate a support team
- Consider a clinical trial


IV. Manto, et. al. Cerebellar Ataxias-an update, Curr Opin Neurol, 2020

V. Ramirez-Zamora, et. al. Treatable causes of cerebellar ataxia, Mvt. disorders, 2015

VI. Perlman, S, Update on the Treatment of Ataxia: Medication and Emerging Therapies, Neurotherapeutics, 2020

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QUESTIONS