



NEWLY DIAGNOSED & Prepping for a Neurologist Visit

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NAF
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No relationships to disclose or list



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Newly Diagnosed

What it means to be newly diagnosed



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CASE STUDY

- 71-year-old female , previous Las Vegas dancer she danced for some of the greatest shows on the stripe ,avid hiker.
- History of gait changes in the last 1 -2 year
- No Family History
- Clinical symptoms;
- Gait incoordination
- Slurring of speech
- Having difficulty iADL brushing her hair , teeth , things that require fine finger movements



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Navigating path to diagnosis

- Acuity of presentation
- +/- Family history
- Diagnostic imaging



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Seeking expertise in Ataxia care

- Recognition and identification at the early stages is not uniform among providers
- Access to care
- Improving education to general neurologist and even other movement colleagues



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SYMPTOMATIC PRESENTATION

- Symptoms of ataxia include,
- Motor symptoms,
- Vestibular symptoms
- cognitive and psychiatric symptoms



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Clinical manifestation

MOTOR

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

Vestibular

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

Cognitive and mood

- 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



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DIAGNOSTIC ALGORITHM

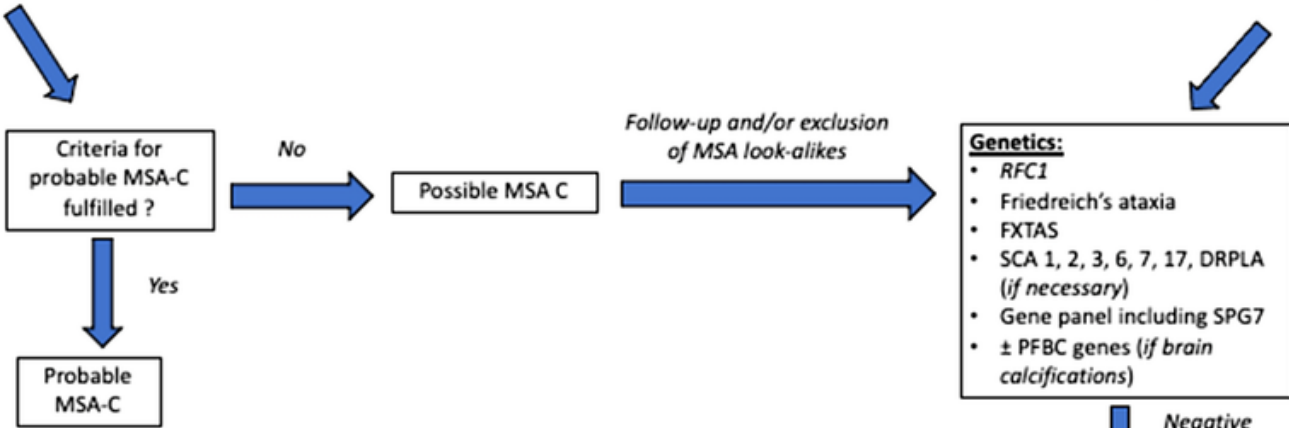
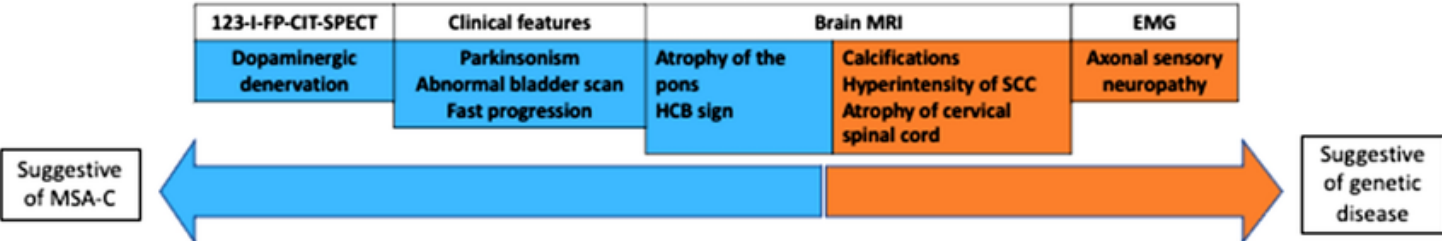


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Sporadic late-onset cerebellar ataxia

Acquired late-onset cerebellar ataxia: MS; Sjogren's syndrome; superficial hemosiderosis; Arnold-Chiari; anti-GAD antibody mediated ataxia; gluten ataxia; PCD...

- Exclude acquired causes of late-onset cerebellar ataxia:**
- Brain MRI ± Spine MRI
 - Laboratory including ANA, antineuronal, antiganglioside, antiphospholipid, anti-TG, anti-GAD, anti-TPO antibodies, ACE, copper, ceruloplasmin, cholestanol, vitamins B1, B6, B9, B12 and E, and phytanic acid
 - CSF analysis : protein level, bacteriology, oligoclonal bands, antineuronal and anti-GAD antibodies
 - HTO; bladder-scan; clonidine test
 - ¹²³I-FP-CIT-SPECT
 - EMG
 - ± Body CT scan ± PET-scan (if suspicion of paraneoplastic syndrome)



Negative

Only if mitochondrial disease is suspected :

- Muscle biopsy
- Genetic testing for MELAS and/or MERRF



CASE STUDY

- MRI Brain
- GENETIC TESTING
- Common Ataxia genes
- Whole exosome sequencing



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Nuances of Diagnosis

- +/- Family history
- Acuity of symptoms
- Importance of History and Exam
- Increasing we are able to diagnosis more genetic forms of Genetic Ataxia
- But it always starts with relationship Neurologist



Diagnosis entails a long-term relationship with your physician

- Diagnosed with SCA 8



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CLASSIFICATION



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Idiopathic/ Sporadic

Idiopathic/ Sporadic Ataxia's: late onset cerebellar ataxia , Multiple system atrophy-cerebellar type

Genetic Ataxia

Autosomal dominant , Autosomal recessive, X linked or Mitochondrial.

Symptomatic

Trauma , Stroke , paraneoplastic , infections



NEWLY DIAGNOSED

ONCE DIAGNOSIS IS GIVEN ; WHAT ARE THE NEXT STEPS



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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 receive written information from Health professional ? What was it like?
- Have you found information on the internet – what was it like ?



Planning ahead

- Fertility , Job opportunities , long term disability
- Genetic testing for family members



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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



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Support

- Who helps you
- Do you have support from friends and family.
- Are you a member of any support group.
- Maintaining connections is crucial



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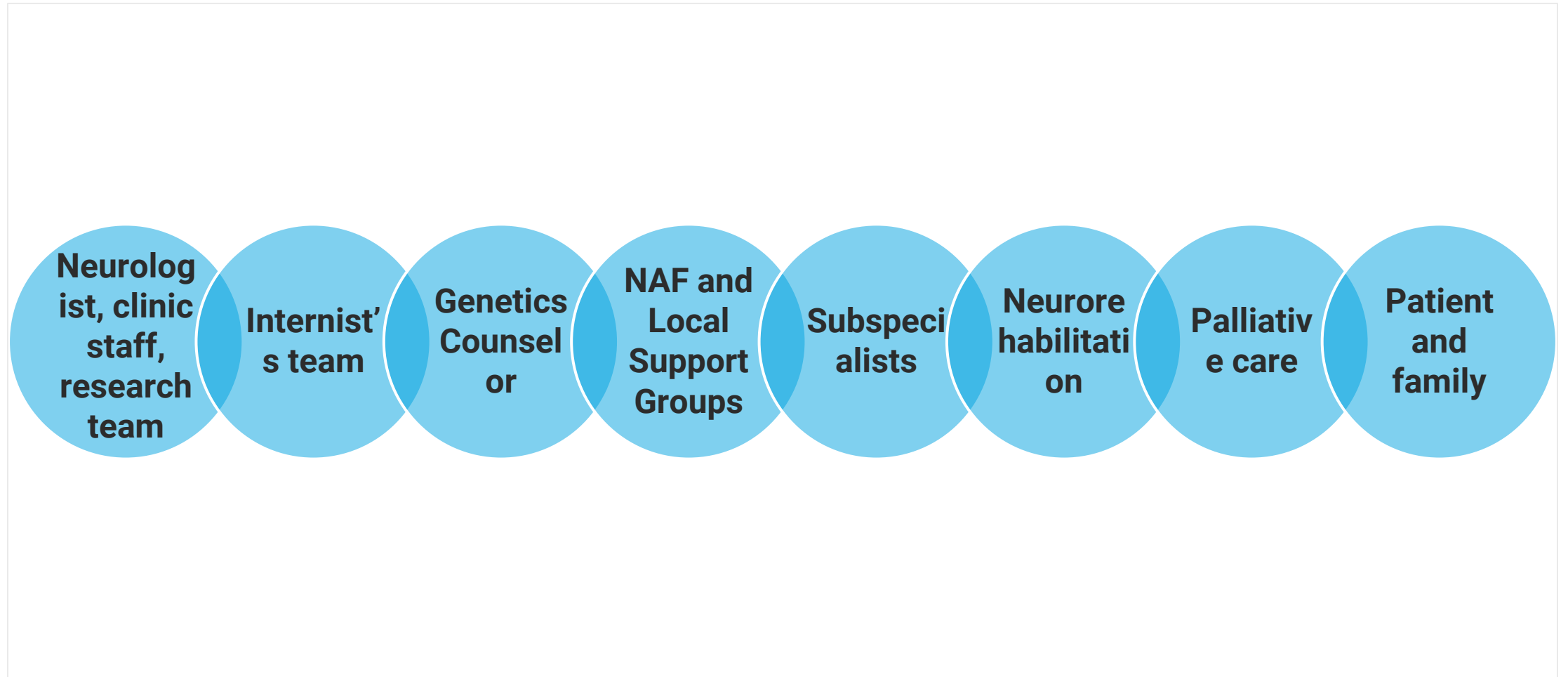
Treatment

- 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
- Focused Symptomatic therapies



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Multidisciplinary team





Newly Diagnosed –checklist empowering yourself

- Preparing Your Question List
- It would help if you thought about what to tell your neurologist. Here are the main issues you should be aware of:
 - The symptoms that are currently bothering you.
 - You should inform and ask about diagnoses.
 - You should know about the methods and ways of treatment.
 - Ask how the treatment will take place.
 - Ask about possible consequences and complications.
 - Discuss the following methods of communication.



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