



Notes from ALD Connect's Symptomatic Women Community Call

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Featuring ALD expert neurologist Dr. Amena Smith Fine

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****Disclaimer****

These notes are from ALD Connect's Symptomatic Women Community Call with guest Dr. Amena Smith Fine on May 20, 2024. These notes are for informational purposes only. They are not intended to be a substitute for professional medical advice, diagnosis or treatment. If you or a family member are ill or suspect that you or a family member are ill, seek professional medical attention immediately. ALD Connect does not recommend or endorse any specific physicians, treatments, procedures or products even though they may be mentioned in these notes.

Questions and Answers

Q. What level of medical care should I pursue as a woman with ALD? Where is the best place to go to seek care?

A.

- ALD is rare enough that the doctors, scientists, and other health care providers know each other.
- There are a number of "Leukodystrophy Centers of Excellence" where providers will feel comfortable seeing patients with ALD.
- A care team should consist of: A neurologist, physiatrist, physical therapist etc.
 - These team members will be present at all Leukodystrophy Centers of Excellence.
- Many people see their expert team once every 1-2 years, then take the recommendations from the center of excellence and work with their local care team.
 - The center of excellence can write a care plan which you can take to your local providers.
- Routine monitoring for cerebral ALD is not recommended for women, but some neurologists ask women with ALD to get a brain MRI as part of baseline assessments. Other neurologists obtain a brain MRI only if warranted by the clinical presentation.
- Most of the time, adrenal labs are ordered at a first visit for women with ALD. However, adrenal insufficiency in women with ALD is also rare.

Q. How can we treat leg pain in women with ALD?

A.

- Leg pain can occur for multiple reasons in women with ALD:
 - Neuropathic pain can occur in women with ALD which can feel like a tingling or burning.
 - Nerve pain medications such as Gabapentin and Lyrica can be useful.
 - Pain can occur from spasticity (e.g. legs seize up).
 - Anti-spasticity medications such as Baclofen or Botox can be useful.
 - Exercise is important – sometimes working with a rehab doctor or trying a medication can help you feel comfortable enough to do the exercises recommended to you.



- Talk to your doctor about what kind of pain you experience and what medications or exercises might be helpful.

Q. Will physical therapy cure ALD symptoms for women?

A.

- Exercise has health benefits for everyone, including women with ALD.
- However, we do not have evidence that exercise can slow or halt the progression of symptoms associated with ALD.

Q. Are there ALD-related symptoms that can contribute to mortality for symptomatic women with ALD?

A.

- While not common in women, adrenal insufficiency can occur rarely in women with ALD. Adrenal insufficiency can be life threatening if not caught and treated promptly.
 - Intermittent screening labs, especially in the case of symptoms (e.g. intense fatigue, getting very sick frequently, etc.) that are suspicious of adrenal insufficiency, can help to detect adrenal insufficiency.
- Risk of injuries from falls
 - While falls themselves are usually not life-threatening, complications from falls, such as hip surgery, can be problematic.
 - Therefore, paying attention to balance and walking aids is critical.

Q. Is neck pain a symptom of ALD in women?

A.

- Dr. Smith Fine typically does not hear about neck pain in the patients she has seen, although she cannot rule out that neck pain could be related to ALD, and many women on the call reported having neck pain. More frequently, she hears about lower back pain from her patients.
- It can be complicated to identify which symptoms are related to ALD and which are not, particularly in older individuals who may have other explanations for their symptoms (e.g. a car accident).
- Having a physiatrist or physical therapist evaluate this would be ideal.

Q. Is hip weakness a symptom of ALD in women?

A.

- Yes, hip weakness often comes up in Dr. Smith Fine's patients.
- Hip strength is important for the rest of the lower body strength.
- Physical therapy can be designed to help strengthen the hip flexors.

Q. What provider should someone see when they have urinary incontinence or other bladder issues?

A.

- The answer depends on the expertise of the individual doctor.
- Most neurologists or physiatrists may be comfortable treating patients with a few first-line or second-line medications.
- The next step may be a urologist.



- A one-time assessment with a urologist doing a urodynamic study to diagnose which specific problem the individual has in the urological system is recommended.
 - Only a urologist can order and interpret a urodynamic study.
- The bottom line is that you may want to ask your neurologist or physiatrist about treatments when symptoms first appear, but if the symptoms persist and advance, then you may want to consider seeing a urologist.

Q. What is suggested for women with neurogenic bowel?

A.

- Constipation, loose stool, and diarrhea are common in women with ALD.
- A total “clean-out” (i.e. as you would prepare for a colonoscopy) can be helpful before starting on other medications (like stool softener, suppositories, or enemas, etc.).

Q. What is the value of alternative medicine vs traditional medicine for symptomatic women with ALD?

A.

- Dr. Smith Fine’s institute is primarily focused on traditional medicine.
- The most important thing is that what is tried is safe, whether it is traditional or alternative medicine.
 - Beyond this, it can be important to use things sparingly. Sometimes medications can have overlapping side effects or overlapping mechanisms of action.
 - Often, starting medications “low and slow” can be a good strategy. Taking the least amount of a medication that will be effective for the symptoms can be a good strategy. This is something that should be discussed with your prescribing doctor.

Q. Should all my health care providers know that I have ALD? How can I make ALD relatable to healthcare providers who are not experts in ALD?

A.

- Yes, at least all those trying to treat symptoms that may be related to ALD should be aware that you have ALD.
- It can be helpful to tell health care providers that you have ALD, and that it is a disease similar to multiple sclerosis (MS). While ALD and MS are NOT the same, most health care providers are more familiar with MS and this may serve as a useful reference.

Q. What neurologists around the country are familiar with treating ALD?

- Many expert centers can be found on ALD Connect’s website - <https://aldconnect.org/centers-and-experts/>
- Here is a list of providers on the United Leukodystrophy Foundation website: <https://ulf.org/resources/find-a-physician/>

Q. What are some resources that that my doctor, who is not an ALD expert, could use to help them familiarize themselves with ALD?



- This website created by LD center of excellence colleagues provides helpful information for clinicians on diagnosis and treatment of different forms of ALD: <https://adrenoleukodystrophy.info/>
- ALD Connect also has a series of webinars created by ALD experts that are useful for doctors, patients and families: <https://aldconnect.org/webinars/>