Q1 Have you/your child with LDS experienced headaches?

Yes: 94% (139)  No: 6% (132)

Q2 Headaches have significantly impacted my/child's quality of life. Do you?

Agree: 81% (112)  Disagree: 19% (27)

Q3 Have you/your child ever seen a neurologist or headache specialist for this reason?

Agree: 81% (112)  Disagree: 19% (27)
Q5: PLEASE DESCRIBE ANY INTERVENTIONS THAT HAVE BEEN HELPFUL IN YOUR HEADACHE MANAGEMENT.

OF NOTE: this is community feedback, NOT medical advice. Before trying any new regimen involve with your healthcare, please consult your physicians.

1. Medications: Tylenol, Ibuprofen (37), Excedrine migraine (3)
2. Room with no lights/noise, go to sleep (21)
3. Massage, PT, reflexology, pressure point therapy, acupuncture, osteopathy, chiropractor, myopathy massage, meditation (17)
4. Medication: vasoconstrictors/Triptans (10)*
5. Increase fluids (water, coconut water, electrolytes (7)
6. Ice packs/cold compresses (9)
7. Hot showers, hot packs (5)
8. Botox (5)
9. Magnesium +/- B2 (8)
10. Medication: Seizure medication (5)
11. Medications: Sinus medications (3)
12. Medications: Beta blockers (3)
13. Medications: Muscle relaxants (3)
14. Medications: other prescription Pain medications (4)
15. Increased caffeine (2)
16. Medications: Antidepressants (2)
17. Surgical considerations (3): headaches increased after brain aneurysm surgery, headaches decreased after aortic surgery
18. Wearing neck brace and/or avoiding certain neck positions (3)
19. Paying attention to diet (less sugar, more protein, track food sensitivities and avoid triggers, avoid caffeine that elevates BP, avoid MSG, more plant based diet)
20. Others: CBD oil, herbal rubs, watch amount of stress, get enough sleep

*There is some theoretical concern about use of vasoconstrictors in headache/migraine management in someone with an underlying vascular disease. Pros and cons of the use of this medication should be discussed with your physicians.