

* 2. Do you currently live in Saskatchewan?

Yes

No

* 3. Are you a person with ALS or a caregiver for someone with ALS? (A caregiver is defined as a person who provides direct care to a person with ALS).

- Person with ALS
- Caregiver for someone with ALS
- None of the above

4. What is your race/ethnicity?

- Black
- Indigenous (e.g., First Nation, Métis, Inuit)
- White
- South Asian (e.g., East Indian, Pakistani, Sri Lankan)
- Chinese
- Filipino
- Arab
- Latin American
- Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, Thai)
- West Asian (e.g., Iranian, Afghan)
- Korean
- Japanese
- Other (please specify)

5. What is the race/ethnicity of the person with ALS that you are caring for?

- Black
- Indigenous (e.g., First Nation, Métis, Inuit)
- White
- South Asian (e.g., East Indian, Pakistani, Sri Lankan)
- Chinese
- Filipino
- Arab
- Latin American
- Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, Thai)
- West Asian (e.g., Iranian, Afghan)
- Korean
- Japanese
- Other (please specify)

6. What is your age in years?

7. What age in years is the person with ALS that you are caring for?

8. What is your sex?

- Male
- Female
- Prefer not to specify
- Other (please specify)

9. What is the sex of the person with ALS that you are caring for?

- Male
- Female
- Prefer not to specify
- Other (please specify)

10. Do you travel outside of your community for the person you are providing care to access ALS treatment?

- Yes
- No

11. Where do you get your ALS-related nutrition information?

12. Who provides your ALS-related nutrition information?

13. What form of nutrition education do you find the most useful? (check all that apply)

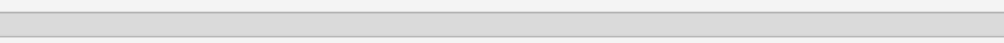
- Brochures/Handouts
- Videos
- Verbal Recommendations
- Written Recommendations
- Pictures and Diagrams
- Other (please specify)

14. What is the biggest nutrition challenge you face as a caregiver for a person with ALS?

15. How important do you think nutrition is in ALS management?

0 - not important

10 - very important



16. Have you consulted with a registered dietitian regarding ALS management?

Yes

No

17. Where did you see a registered dietitian for ALS? (check all that apply)

- ALS Clinic
- Inpatient (Hospital Admission)
- Outpatient (Community Setting)
- Private Practice
- Other (please specify)

18. What did the registered dietitian recommend for ALS management?

19. Did you find the nutrition recommendations regarding ALS from the registered dietitian practical?

0 - not practical 10 - very practical

20. How would you rate your experience with the registered dietitian for ALS management?

0 - negative 5 - neutral 10 - positive

21. What do you think the role of a registered dietitian is in ALS management?

22. How frequently do you meet with a registered dietitian for ALS management?

- Never
- Twice per month
- Once per month
- Once every 2-4 months
- Once every 5-6 months
- Once every 7-12 months
- Less than once a year

23. How frequently would you like to meet with a registered dietitian for ALS management?

- Never
- Twice per month
- Once per month
- Once every 2-4 months
- Once every 5-6 months
- Once every 7-12 months
- Less than once a year

24. Do you have any advice or suggestions for registered dietitians to provide better nutrition education/management for ALS?

25. If a family member/friend was diagnosed with ALS, would you recommend they see a registered dietitian?

- Yes
- No

Please explain:

26. Is the person you are providing care for currently taking any nutritional supplements for ALS?

Yes

No

If yes, please specify:

27. Do you find the supplements have a positive impact on ALS?

Yes

No

Perceptions of Nutrition Interventions in Individuals with Amyotrophic Lateral Sclerosis (ALS)

28. Has the person you are providing care for tried these diets before as management for ALS?

	Have tried it	Explored it but never tried it	Want to explore it	Do not want to explore it
Ketogenic Diet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High Protein	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High Fat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low Fat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vegetarian	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vegan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High Carbohydrate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low Carbohydrate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Paleo Diet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Mediterranean Diet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please specify "other" diet

29. Are you concerned about weight loss due to ALS in the person you are providing care for?

- Yes
- No

Please explain:

30. Are you concerned about weight gain due to ALS in the person you are providing care for?

- Yes
- No

Please explain:

31. List three or more words that come to mind in regards to "tube feeding" in ALS.

32. Does the person with ALS you are providing care for have a feeding tube?

- Yes
- No
- Yes, but not currently using it.

33. Tell us about your experience with a tube feed regarding ALS.

34. How long has the person with ALS you are providing care for been receiving tube feeds?

- Less than 1 month
- 1-3 months
- 4-6 months
- 7-12 months
- Greater than 1 year

35. After a diagnosis of ALS, when would it be a good time to have a discussion about starting tube feeds?

- Less than 1 month
- 1-3 months
- 4-6 months
- 7-12 months
- Greater than 1 year

36. Is there any topic regarding nutrition you wish you knew more about when the person you are providing care for was diagnosed with ALS?

- Yes
- No

Please explain:

37. Do you feel your nutrition goals of care to manage ALS align with that of the person you are providing care for?

- Yes
- No

Please explain:

38. Do you feel like an active member in the decision making process regarding ALS nutrition care?

- Yes
- No

Please explain:

39. What advice would you give to future caregivers regarding nutrition in the management of ALS?

40. What advice would you give to future patients regarding nutrition in the management of ALS?

41. Is there anything you would like to share regarding nutrition and ALS that was not covered in this survey?
Please do not share any identifiable information such as name, location, or date of birth.

- Yes
- No

If yes, please explain.

42. What is your race/ethnicity?

- Black
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- Other (please specify)

43. What is your age in years?

44. What is your sex?

- Male
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- Other (please specify)

45. Do you travel outside of your community to access ALS treatment?

- Yes
- No

46. Where do you get your ALS-related nutrition information?

47. Who provides your ALS-related nutrition information?

48. What form of nutrition education do you find the most useful? (check all that apply)

- Brochures/Handouts
- Videos
- Verbal Recommendations
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- Pictures and Diagrams
- Other (please specify)

49. What is the biggest nutrition challenge you face as a person with ALS?

50. How important do you think nutrition is in ALS management?

0 - not important 10 - very important

51. Have you consulted with a registered dietitian regarding ALS management?

- Yes
- No

52. Where did you see a registered dietitian for ALS? (check all that apply)

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- Inpatient (Hospital Admission)
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- Private Practice
- Other (please specify)

53. Did you find the nutrition recommendations regarding ALS from the registered dietitian practical?

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54. What did the registered dietitian recommend for ALS management?

55. How would you rate your experience with the registered dietitian for ALS management?

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- Once every 7-12 months
- Less than once a year

59. Do you have any advice or suggestions for registered dietitians to provide better nutrition education/management for ALS?

60. If a family member/friend was diagnosed with ALS, would you recommend they see a registered dietitian?

- Yes
- No

Please explain:

61. Do you currently take any nutritional supplements for ALS?

Yes

No

If yes, please specify:

62. Do you find that the supplements have a positive impact on ALS?

Yes

No

63. Have you tried these diets before as management for ALS? (check all that apply)

	Have tried it	Explored it but never tried it	Want to explore it	Do not want to explore it
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Please specify "other" diet

64. Are you concerned about weight loss due to ALS?

- Yes
- No

Please explain:

65. Are you concerned about weight gain due to ALS?

- Yes
- No

Please explain:

66. List three or more words that come to mind in regards to "tube feeding" in ALS.

67. Do you have a feeding tube?

- Yes
- No
- Yes, but not currently using it.

68. Tell us about your experience with a tube feed.

69. How long have you been receiving tube feeds?

- Less than 1 month
- 1-3 months
- 4-6 months
- 7-12 months
- Greater than 1 year

70. After a diagnosis of ALS, when would it be a good time to have a discussion about starting tube feeds?

- Less than 1 month
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71. Is there any topic regarding nutrition you wish you knew more about when you were diagnosed with ALS?

- Yes
- No

Please explain:

72. Do you feel your nutrition goals of care to manage ALS align with that of your caregiver's?

- Yes
- No

Please explain:

73. Do you feel like an active member in the decision making process regarding ALS nutrition care?

Yes

No

Please explain:

74. What advice would you give to future caregivers regarding nutrition and the management of ALS?

75. What advice would you give to future patients regarding nutrition and the management of ALS?

76. Is there anything you would like to share regarding nutrition and ALS that was not covered in this survey?

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Yes

No

If yes, please explain.