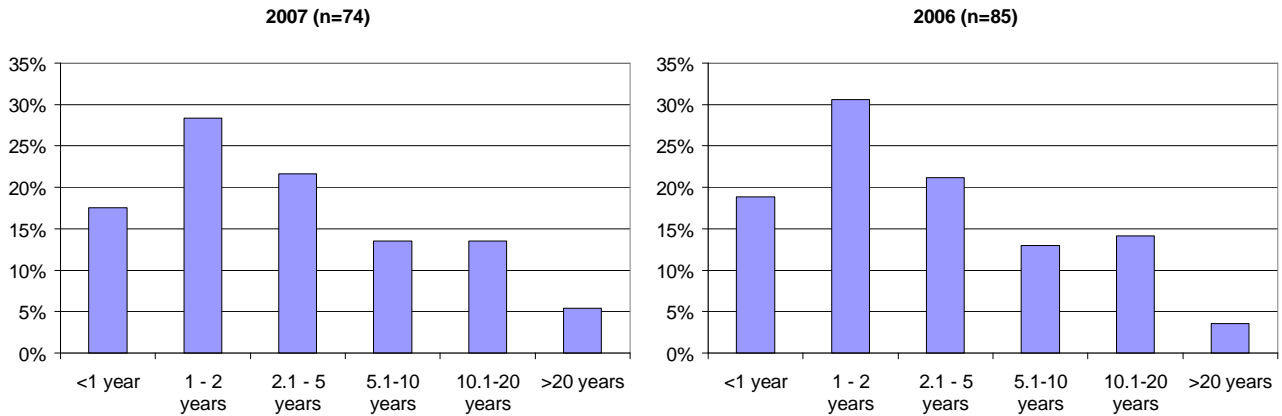


2007 - ALS PATIENT PRIORITIES SURVEY (for Patients)

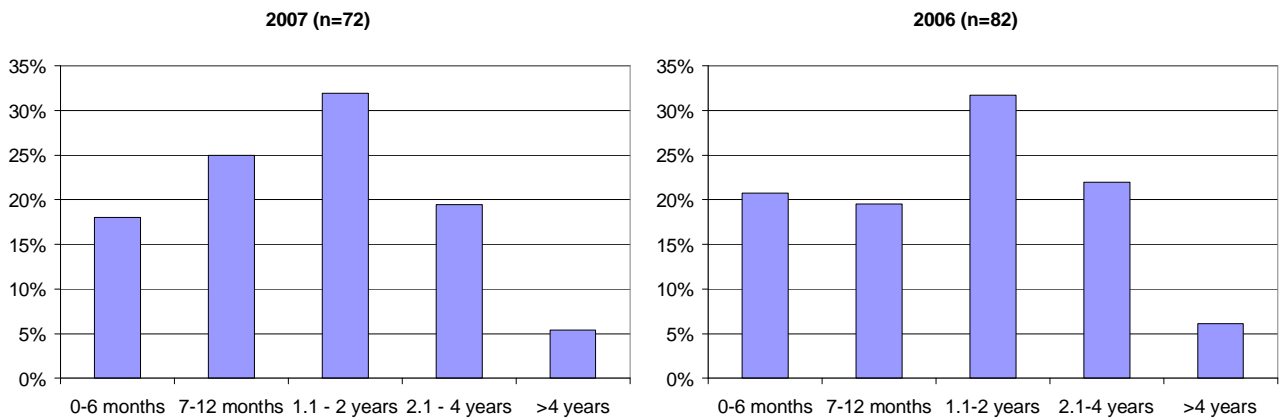
261 surveys mailed; 4 undeliverable; 77 returned

GENERAL INFORMATION

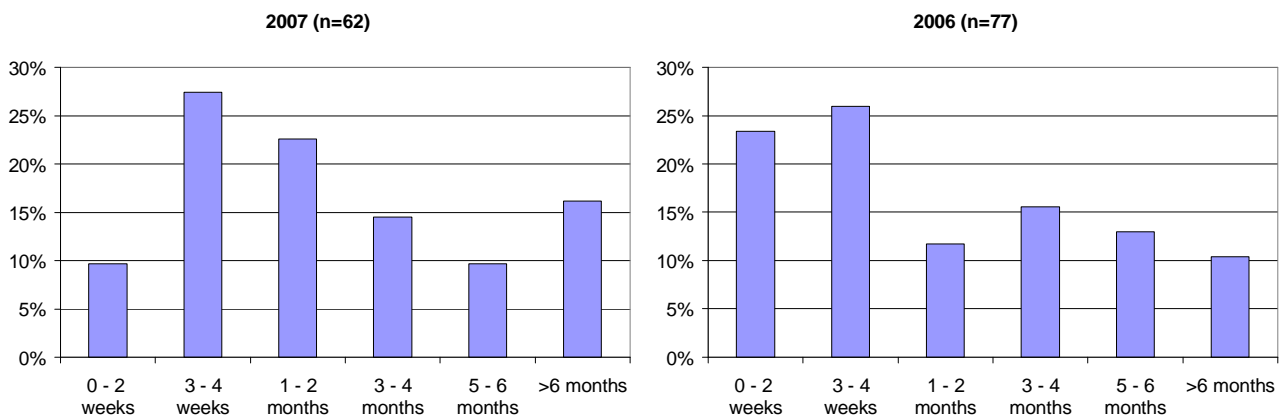
1. How long has it been since your diagnosis of ALS?



2. Estimate the time interval between your first symptoms and your initial diagnosis:



3. Estimate the time interval between your initial diagnosis and the confirmation of your diagnosis (for example at the ALS Centre):



4. What, if anything, have you been told about your rate of progression? (n=74)

8% (7%) Fast	57% (44%) Slow
11% (12%) Average or Moderate	23% (37%) Don't know

5. What, if anything, have you been told about your stage of progression? (n=73)

12% (9%) Advanced	12% (10%) Early
16% (22%) Average or Moderate	59% (59%) Don't know

6. Have you registered with the ALS Society of BC? (n=74)

97% (100%) Yes	0% (0%) No	3% (n/a) Don't know
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7. Did you participate in last year's 2006 ALS Patient Priorities Survey? (n=74)

43% (n/a) Yes	47% (n/a) No	9% (n/a) Don't know
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SURVEY INFORMATION

MEDICAL CARE

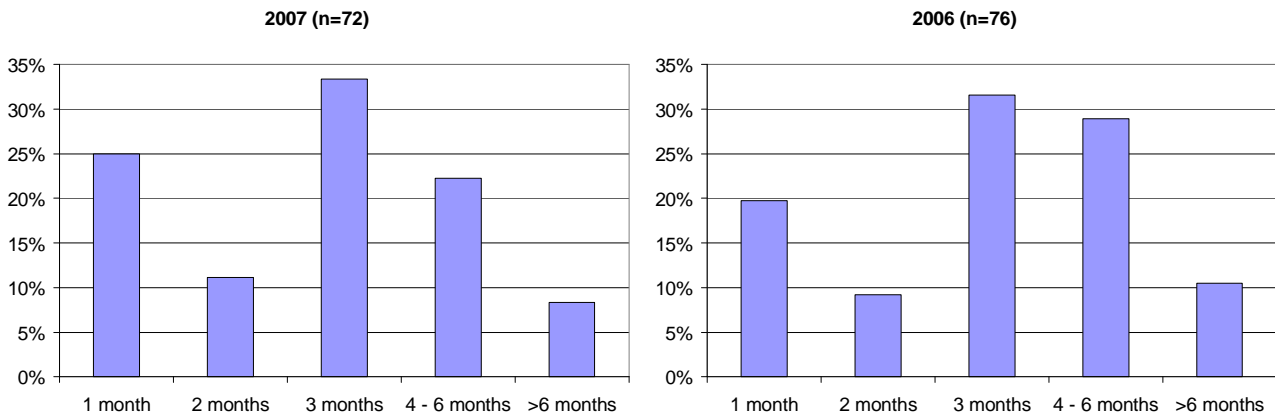
1. Are you regularly followed up by medical practitioners? (n=74)

80% (72%) Yes	20% (28%) No
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2. If yes, which medical practitioners do you regularly see? [check all that apply] (n=73)

71% (62%) Family Doctor	37% (32%) ALS Centre Doctors
5% (4%) Physiatrists	53% (49%) Other Doctors elsewhere (such as Neurologists, Respiratory Specialists, etc.)

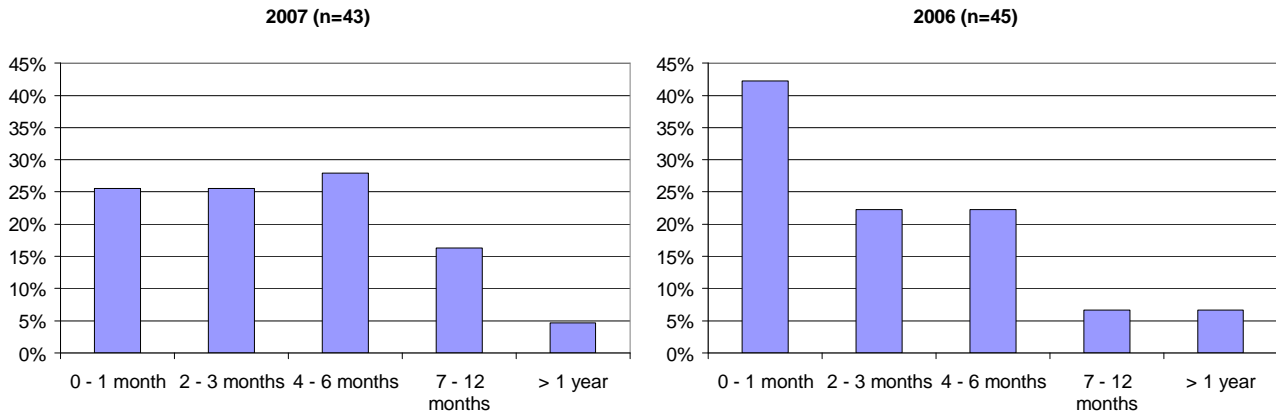
3. How often, on average, would you see a medical practitioner?



4. How informed do you feel your family doctor is about ALS? (n=72)

35% (29%) Well informed	53% (52%) Somewhat informed
11% (19%) Not informed	

4. How often, on average, would you see such non-medical professional staff?



5. How do you rate the quality of service you have received? (n=64)

59% (46%) Excellent	5% (6%) Poor
28% (32%) Fair	8% (15%) None received

6. How important are therapy services and outreach care to you? (n=64)

72% (68%) Very important	22% (25%) Somewhat important
5% (7%) Not important	

EQUIPMENT SUPPORT

1. How are you satisfying your equipment needs? [check all that apply] (n=72)

54% (48%) Self-Purchased	7% (9%) Self-Rented
86% (75%) ALS Society	31% (31%) Extended Benefits Plan

2. How important is meeting your equipment needs, to you? (n=71)

99% (92%) Very important	1% (8%) Somewhat important
0% (0%) Not important	

3. How do you rate the quality of service you have received (including speed of equipment service, speed of repair, quality of equipment)? (n=69)

75% (71%) Excellent	4% (5%) Poor
17% (16%) Fair	3% (8%) None received

COUNSELLING

1. Have you been receiving professional counselling? (n=74)

15% (13%) Yes	85% (87%) No
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2. If you answered "no" in the previous question, could you please elaborate as to why professional counselling was not sought? (n=52)

4% (5%) Financial cost	19% (12%) Too far
33% (40%) Not aware of services	44% (43%) Other

3. How important is professional counselling to you? (n=70)

24% (18%) Very Important	39% (48%) Somewhat Important
37% (34%) Not Important	

4. How do you rate the quality of service you have received? (n=58)

19% (10%) Excellent	3% (4%) Poor
12% (19%) Fair	66% (66%) None Received

FINANCES, FINANCIAL PLANNING AND ADVICE

1. How are you managing financially? (n=72)

15% (23%) Excellent	76% (71%) Fair	8% (6%) Poor
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2. Have you been receiving financial planning service and advice, for such things as disability insurance, tax claims for equipment, personal planning? (n=72)

28% (24%) Yes	72% (76%) No
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3. How important is this to you? (n=71)

55% (58%) Very important	37% (30%) Somewhat important
8% (12%) Not important	

4. How do you rate the quality of service you have received? (n=61)

18% (16%) Excellent	2% (6%) Poor
30% (27%) Fair	51% (52%) None Received

SUPPORT GROUPS

1. Have you been a member of a support group? (n=75)

36% (36%) Yes	64% (64%) No
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2. If you answered "no" in the previous question, could you please elaborate as to why you have not joined a support group? (n=44)

18% (9%) Not aware of services	2% (0%) Financial cost
32% (44%) No local support group	48% (47%) Other (specify)

3. How important is this to you? (n=72)

25% (18%) Very important 43% (51%) Somewhat important
32% (31%) Not important

4. How do you rate the quality of service you have received? (n=54)

28% (27%) Excellent 2% (8%) Poor
17% (27%) Fair 54% (38%) None Received

REGIONAL CARE

1. What is your general geographical location? (n=73)

34% (35%) GVRD	19% (17%) Lower Fraser Valley
10% (13%) Nanaimo and North Island	7% (7%) Van. I., South of Nanaimo
1% (6%) Sunshine Coast / Sea-to-Sky	3% (2%) Northern B.C.
3% (5%) Kootenays	14% (12%) Okanagan
10% (2%) Other	

2. Where do you have to travel to receive:

a. Medical care? (n=72)

61% (65%) Same town 26% (28%) Same region
13% (7%) Another region

b. Therapy services and outreach care? (n=61)

61% (57%) Same town 33% (36%) Same region
7% (10%) Another region

c. Other services and care? (including financial, counselling, support group) (n=54)

54% (52%) Same town 30% (32%) Same region
17% (17%) Another region

3. How important is this to have such services close to home? (n=70)

77% (82%) Very important 21% (15%) Somewhat important
1% (3%) Not important

4. How do you rate the quality of such services received from your location?

a. Medical care (n=68)

54% (49%) Excellent 4% (9%) Poor
38% (41%) Fair 3% (1%) None available

b. Therapy services and outreach care (n=55)

44% (36%) Excellent 16% (14%) Poor
29% (38%) Fair 11% (13%) None available

c. Other services and care (including financial, counselling, support group) (n=48)

23% (19%) Excellent 15% (25%) Poor
29% (41%) Fair 33% (15%) None available

INTERNET SUPPORT

1. Are you a regular user of the internet? (n=73)

58% (49%) Yes	42% (51%) No
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2. Do you prefer newsletters and information via: (n=72)

35% (30%) Internet/E-mail	64% (70%) Regular Mail
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3. Are you using the Internet to try to find information about ALS? (n=73)

47% (52%) Yes	53% (48%) No
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4. How would you rate the quality of information about ALS that you have found on the Internet? (n=50)

36% (29%) Excellent	4% (5%) Poor
46% (42%) Fair	14% (24%) None found

5. Would you join and participate in an online forum for ALS patients, family members, and caregivers if it were available? (n=66)

47% (50%) Yes	53% (50%) No
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6. How important to you is help and assistance in finding and accessing high-quality information about ALS on the Internet? (n=66)

48% (51%) Very important	21% (26%) Somewhat important
30% (22%) Not important	

7. How do you rate the quality of any help and assistance received? (n=62)

21% (22%) Excellent	0% (3%) Poor
39% (41%) Fair	40% (34%) None received

RESEARCH INTO ALS

1. How aware are you of ALS research being conducted in BC, elsewhere in Canada and around the world, and how and when it might affect you? (n=72)

15% (10%) Very aware	44% (46%) Moderately aware
40% (44%) Not very aware	

2. How important is this to you? (n=70)

61% (74%) Very important	30% (24%) Somewhat important
9% (3%) Not important	

3. How aware do you feel you are of clinical trials underway related to ALS, and how to participate in them? (n=73)

11% (6%) Very aware 21% (20%) Moderately aware
68% (74%) Not very aware

4. How important is this to you? (n=69)

54% (63%) Very important 33% (29%) Somewhat important
13% (8%) Not important

PRIORITIES

Please rank the following in order of priority from 1-9 (with 1 being highest priority, 2 being second highest priority, etc. and 9 as least important)

Rank	2007 (n=54)	2006 (n=60)
1	Medical Care	Medical Care
2	Equipment Support	Equipment Support
3	Therapy Services/Outreach Care	Research into ALS
4	Research into ALS	Therapy Services/Outreach Care
5	Regional Support	Regional Support
6	Finances, Financial Planning	Finances, Financial Planning
7	Counselling	Support Groups
8	Support Groups	Counselling
9	Internet Support	Internet Support