

2007 ALS PATIENT PRIORITIES SURVEY (For Caregivers)

261 surveys mailed; 4 undeliverable; 70 returned

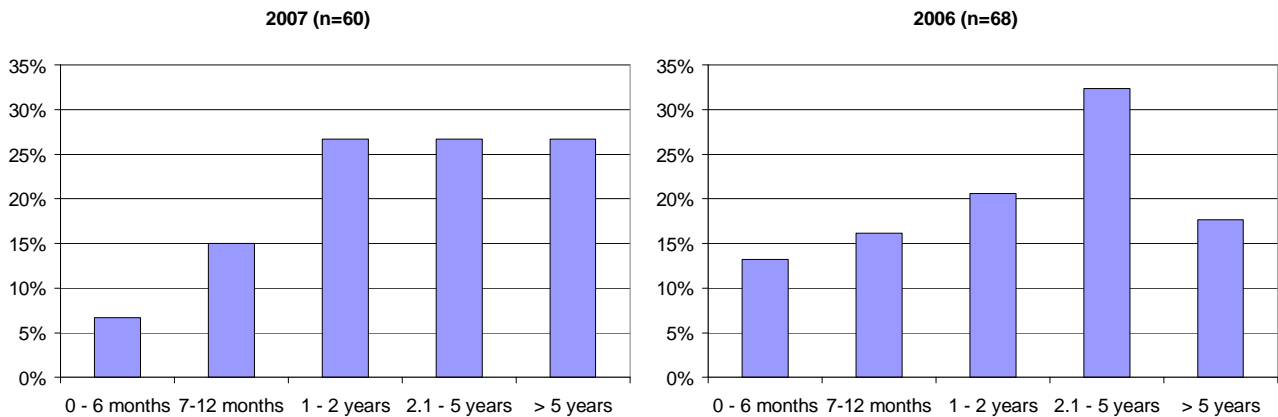
GENERAL INFORMATION

We would like to obtain some general information about you without identifying who you are. This will allow us to better understand the survey results.

1. You are responding as a: (n=62)

48% (39%) Primary Caregiver **52% (61%) Family Member**

2. How long have you cared for the ALS patient?



3. Have you joined the ALS Society of BC? (n=62)

69% (74%) Yes **21% (26%) No** **10% (n/a) Don't know**

4. Did you participate in last year's 2006 ALS Patient Priorities Survey? (n=63)

46% (n/a) Yes **51% (n/a) No** **3% (n/a) Don't know**

SURVEY INFORMATION

MEDICAL CARE

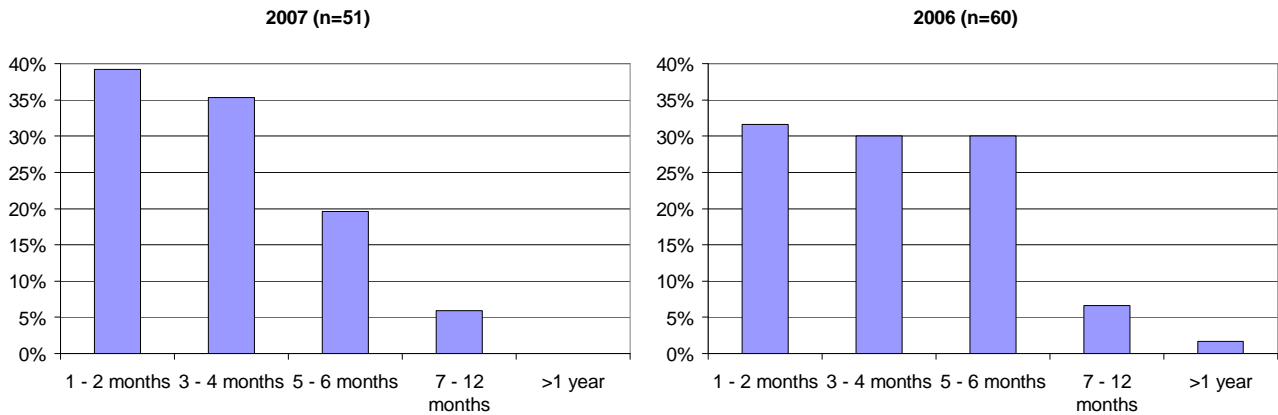
1. Do you regularly attend medical care appointments with the ALS patient? (n=62)

89% (90%) Yes **11% (10%) No**

2. If yes, which medical practitioners are regularly seen? [check all that apply] (n=54)

87% (74%) Family Doctor **52% (47%) ALS Centre Doctors**
7% (1%) Psychiatrists **69% (55%) Other Doctors elsewhere**
 (such as Neurologists, Respiratory Specialists, etc.)

3. How often, on average, do you attend these appointments?

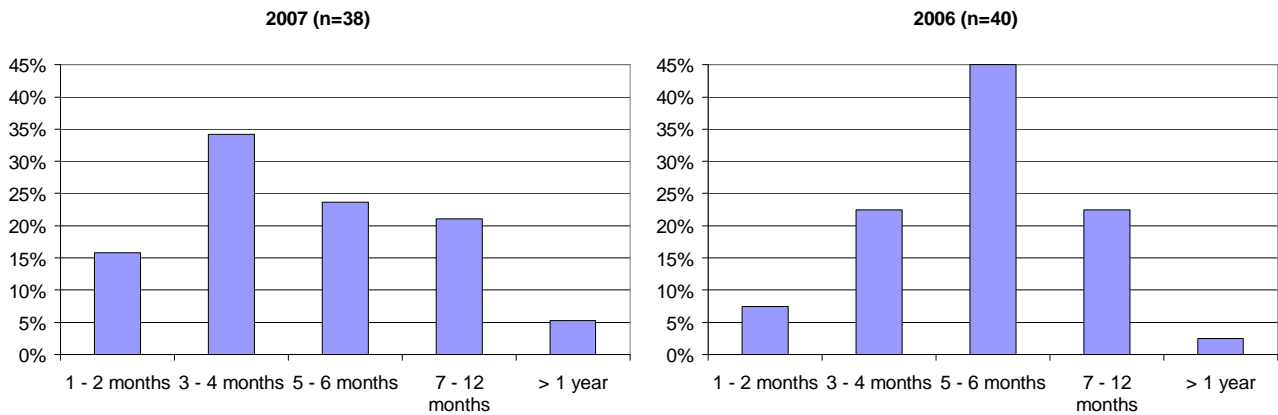


4. How informed do you feel the family doctor is about ALS? (n=61)

33% (28%) Well informed
11% (19%) Not informed

56% (53%) Somewhat informed

5. How often, on average, would you attend an appointment with an ALS Specialist?



6. Has the patient been assessed by the ALS Care Team at GF Strong, and if yes, about how many times has he or she met with any Team member, including the neurologists? (n=62)

13% (n/a) No

87% (n/a) Yes, about [4.3] times

7. Do you feel you are well-informed about the patient's condition, prognosis, etc. by the family doctor and/or ALS Specialist(s)? (n=61)

51% (49%) Well informed
11% (7%) Not informed

38% (44%) Somewhat informed

8. Would you like to know more or less about the patient's condition, prognosis, etc. from the family doctor and/or ALS Specialist(s)? (n=61)

52% (65%) More information
0% (0%) Less information

48% (35%) Same level of information

EQUIPMENT SUPPORT

1. How are you and the patient satisfying equipment needs? [check all that apply] (n=59)

| | |
|---------------------------------|---|
| 56% (49%) Self-Purchased | 7% (21%) Self-Rented |
| 88% (80%) ALS Society | 31% (32%) Extended Benefits Plan |

2. How important is meeting these equipment needs, to you? (n=59)

| | |
|---------------------------------|-----------------------------------|
| 98% (96%) Very important | 2% (4%) 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=59)

| | |
|----------------------------|------------------------------|
| 78% (77%) Excellent | 0% (5%) Poor |
| 15% (15%) Fair | 7% (3%) None received |

COUNSELLING

1. Have you been receiving professional counselling? (n=62)

| | |
|----------------------|---------------------|
| 10% (15%) Yes | 90% (85%) No |
|----------------------|---------------------|

2. If you answered "no" in the previous question, could you please elaborate as to why professional counselling was not sought? (n=51)

| | |
|--|------------------------|
| 6% (13%) Financial cost | 0% (9%) Too far |
| 41% (43%) Not aware of services | 53% (36%) Other |

3. How important is professional counselling to you? (n=55)

| | |
|---------------------------------|-------------------------------------|
| 15% (32%) Very Important | 51% (53%) Somewhat Important |
| 35% (15%) Not Important | |

4. How do you rate the quality of service you have received? (n=44)

| | |
|---------------------------|--------------------------------|
| 9% (17%) Excellent | 2% (2%) Poor |
| 9% (23%) Fair | 80% (58%) None Received |

FINANCES, FINANCIAL PLANNING AND ADVICE

1. How are you managing financially? (n=62)

| | | |
|----------------------------|-----------------------|---------------------|
| 13% (20%) Excellent | 82% (77%) Fair | 5% (3%) Poor |
|----------------------------|-----------------------|---------------------|

2. Have you been receiving financial planning service and advice, for such things as disability insurance, tax claims for equipment, personal planning? (n=62)

| | |
|----------------------|---------------------|
| 24% (31%) Yes | 76% (69%) No |
|----------------------|---------------------|

3. How important is this to you? (n=58)

57% (60%) Very important 29% (28%) Somewhat important
14% (11%) Not important

4. How do you rate the quality of service you have received? (n=53)

13% (17%) Excellent 4% (6%) Poor
23% (30%) Fair 60% (47%) None Received

SUPPORT GROUPS

1. Have you been a member of a support group? (n=61)

44% (32%) Yes 56% (68%) No

2. If you answered "no" in the previous question, could you please elaborate as to why you have not joined a support group? (n=34)

9% (10%) Not aware of services 0% (2%) Financial cost
30% (51%) No local support group 61% (37%) Other

3. How important are support groups to you? (n=59)

27% (22%) Very important 49% (52%) Somewhat important
24% (27%) Not important

4. How do you rate the quality of service you have received? (n=46)

33% (21%) Excellent 2% (7%) Poor
22% (23%) Fair 43% (48%) None Received

REGIONAL CARE

1. What is your general geographical location? (n=60)

35% (35%) GVRD 22% (23%) Lower Fraser Valley
12% (11%) Nanaimo and North Island 7% (9%) Van. I., South of Nanaimo
0% (4%) Sunshine Coast and Sea-to-Sky 3% (3%) Northern B.C.
2% (4%) Kootenays 8% (10%) Okanagan
12% (1%) Other

2. Where do you have to travel to:

a. Receive medical care? (n=60)

60% (66%) Same town 35% (28%) Same region
5% (6%) Another region

b. Receive therapy services and outreach care? (n=49)

51% (48%) Same town 41% (33%) Same region
8% (19%) Another region

- c. Receive financial planning advice? (n=32)
 50% (63%) Same town 47% (30%) Same region
 3% (7%) Another region
- d. Receive counselling? (n=29)
 48% (62%) Same town 52% (31%) Same region
 0% (7%) Another region
- e. Participate in a support group? (n=44)
 48% (47%) Same town 48% (36%) Same region
 5% (17%) Another region
3. How important is this to have such services close to home? (n=57)
- 79% (75%) Very important 18% (23%) Somewhat important
 4% (2%) Not important
4. How do you rate the quality of such services received from your location?
- a. Medical care (n=57)
 49% (48%) Excellent 0% (10%) Poor
 51% (42%) Fair 0% (0%) None available
- b. Therapy services and outreach care (n=45)
 40% (40%) Excellent 7% (15%) Poor
 49% (38%) Fair 4% (8%) None available
- c. Financial planning advice (n=30)
 3% (18%) Excellent 10% (18%) Poor
 67% (46%) Fair 20% (18%) None available
- d. Counselling (n=24)
 21% (34%) Excellent 13% (26%) Poor
 50% (21%) Fair 17% (18%) None available
- e. Support group (n=33)
 48% (29%) Excellent 3% (24%) Poor
 30% (26%) Fair 18% (21%) None available

INTERNET SUPPORT

1. Are you a regular user of the internet? (n=59)
- 63% (59%) Yes 37% (41%) No
2. Do you prefer newsletters and information via: (n=59)
- 36% (31%) Internet/E-mail 64% (69%) Regular Mail
3. Are you using the Internet to try to find information about ALS? (n=60)
- 62% (64%) Yes 38% (36%) No

4. How would you rate the quality of information about ALS that you have found on the Internet? (n=47)

36% (41%) Excellent 2% (2%) Poor
47% (46%) Fair 15% (11%) None found

5. Would you join and participate in an online forum for ALS patients, family members, and caregivers if it were available? (n=53)

51% (52%) Yes 49% (48%) No

6. How important to you is help and assistance in finding and accessing high-quality information about ALS on the Internet? (n=48)

48% (54%) Very important 38% (35%) Somewhat important
15% (11%) Not important

7. How do you rate the quality of any help and assistance received? (n=47)

26% (36%) Excellent 0% (4%) Poor
47% (33%) Fair 28% (27%) 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=60)

10% (13%) Very aware 62% (53%) Moderately aware
28% (35%) Not very aware

2. How important is this to you? (n=60)

60% (63%) Very important 38% (34%) Somewhat important
2% (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=61)

8% (7%) Very aware 38% (32%) Moderately aware
54% (61%) Not very aware

4. How important is this to you? (n=59)

41% (55%) Very important 56% (39%) Somewhat important
3% (6%) 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=46) | 2006 (n=56) |
|------|--------------------------------|--------------------------------|
| 1 | Medical Care | Medical Care |
| 2 | Equipment Support | Equipment Support |
| 3 | Therapy Services/Outreach Care | Therapy Services/Outreach Care |
| 4 | Research into ALS | Regional Support (4T) |
| 5 | Regional Support | Research into ALS (4T) |
| 6 | Finances, Financial Planning | Counseling |
| 7 | Support Groups | Finances, Financial Planning |
| 8 | Counseling | Support Groups |
| 9 | Internet Support | Internet Support |