

**ALS Society of British Columbia
2016 Patient Priority Survey**



**AMYOTROPHIC LATERAL SCLEROSIS
SOCIETY OF BRITISH COLUMBIA**

March 2016

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2016 ALS PATIENT PRIORITIES SURVEY

SURVEY STATISTICS

	2016	2014	2013*	2012**	2011	2010	2009
Mailed	302	318	289	296	544	502	516
Returned	109	140	152	138	129	187	201
Undeliverable	2	10	2	0	0	4	?
Incomplete	0	0	3	0	12	10	12
Return Rate	36%	44%	53%	47%	24%	37%	39%

* Both the 'Mailed' and 'Returned' figures for 2013/2014/2016 include individuals who requested and received phone interviews from the independent surveyor, in place of the form.

** The 2012 survey reflected a major change, in that a single survey with room for both the person living with ALS and their caregivers were given an opportunity to respond in the same document. In previous years, the surveys had been separate. This is evident in many of the survey response numbers, where responses are often much larger than previous, separated form years.

GENERAL INFORMATION

1. Which area do you live in?

	2016 (n=102)	2014 (n=136)	2013 (n=142)	2012 (n=131)	2011 (n=115)	2010 (n=175)	2009 (n=189)
GVRD	24%	32%	32%	29%	40%	37%	29%
Fraser Valley	15%	15%	9%	16%	15%	17%	17%
Van. Island – Victoria and South of Nanaimo	15%	13%	11%	7%	12%	11%	10%
Van. Island – Nanaimo & North Island	14%	9%	9%	8%	10%	6%	9%
Sunshine Coast & Sea-to-sky	2%	2%	4%	2%	2%	3%	3%
Northern B.C. and Yukon	8%	7%	6%	8%			
Kootenays	3%	4%	3%	3%	1%	3%	7%
Okanagan	21%	16%	25%	24%	19%	18%	19%
Other	-	-	-	3%	-	-	1%

2. Which of the following **ALS Society of BC Patient Services Programs** are you and your family currently using; if no, please state why:

	2016	2014	2013	2012	2011	2010	2009
Equipment Loan	77%	85%	81%	81%	96%	90%	87%
Transportation Support Program	27%	19%	24%	26%	-	-	-
Mobile Clinics	20%	13%	20%	18%	-	-	-
Care Connections	21%	22%	23%	27%	-	-	-
Psychological Support Services	26%	20%	13%	21%	25%	24%	22%
Support Groups	34%	25%	30%	31%	33%	31%	36%
Caregivers' Days	28%	21%	29%	29%	-	-	-
Camp Alohi Lani	9%	7%	5%	4%	-	-	-

* Historical Data are translated from similar categories in past surveys.

(Please see Appendix A for responses to why particular services are not being used.)

MEDICAL CARE

1. Are you regularly followed up by medical practitioners?

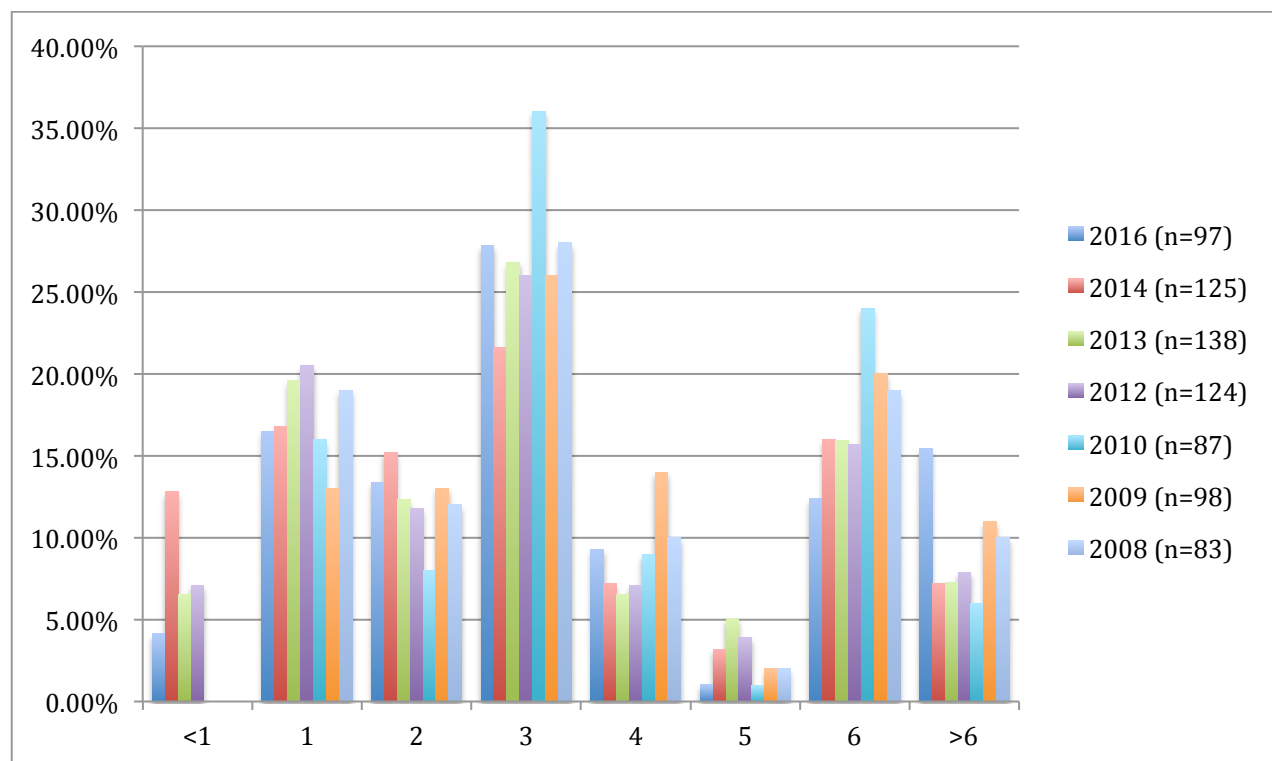
	2016 (n=107)	2014 (n=134)	2013 (n=147)	2012 (n=133)	2011 (n=59)	2010 (n=92)	2009 (n=103)
Yes	90%	94%	97%	93%	90%	91%	83%
No	10%	6%	3%	7%	10%	9%	17%

2. If yes, which medical practitioners do you see regularly? (Check all that apply)

	2016 (n=91)	2014 (n=126)	2013 (n=136)	2012 (n=125)	2011 (n=61)	2010 (n=68)	2009 (n=70)
Family Doctor	74%	83%	84%	82%	79%	74%	67%
ALS Centre Doctors	64%	58%	62%	68%	63%	63%	50%
Physiatrists	-	1%	-	-	36%	10%	7%
Respirologist	10%	10%	-	-	2%	46%	-
Other (e.g. Neurologists, etc.)	42%	27%	26%	34%	-	-	-

* Please see Appendix A for long-form "Other" responses

3. If yes, how often on average do you have contact (i.e. by appointment at clinic or home visit, phone or email)?



4. If followed up, how do you rate the quality of service you received by the ALS Centre Doctors and Team?

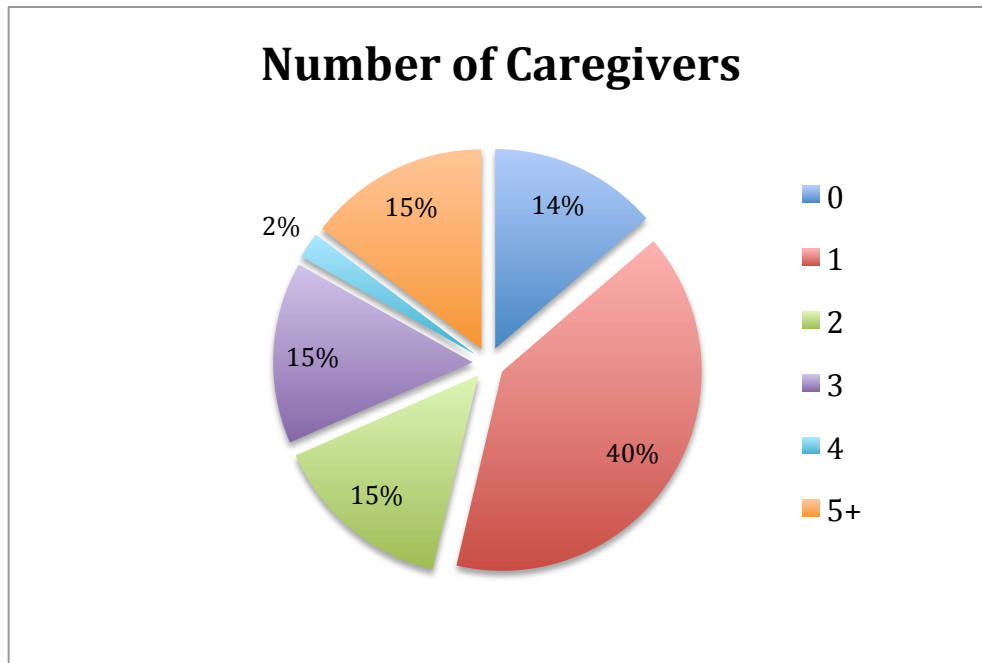
	2016 (n=99)	2014 (n=139)	2013 (n=140)	2012 (n=120)	2011 (n=52)	2010 (n=52)	2009 (n=79)
5 (Excellent)	56%	55%	54%	52%	81%	81%	86%
4	16%	11%	14%	19%	-	-	-
3 (Fair)	7%	2%	1%	7%	17%	17%	14%
2	-	1%	0%	1%	-	-	-
1 (Poor)	-	2%	0%	0%	2%	2%	0%
Not being followed up	20%	29%	31%	21%	-	-	-

* Please see Appendix A for long-form answers to why there is a lack of follow-up

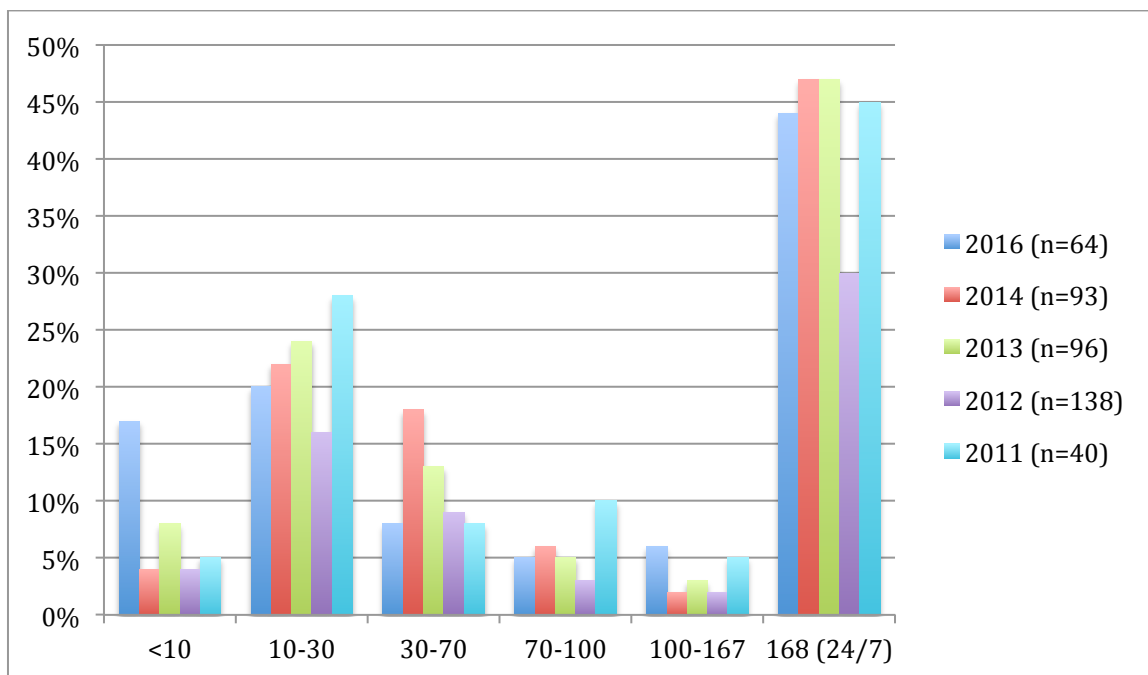
5. What medical services, if any, are missing from your care? *(Please see Appendix A for responses to this long-form question).*

CAREGIVERS

1. How many caregivers do you have?



2. How many hours of care are they providing?



In previous years, averages were taken as oppose to histograms; these data are provided here:

	2010 (n=54)	2009	2008	2007	2006
Per day (average)	17.9	15.4	-	-	-
Per week (average)	18.5	33.9	-	-	-

3. Do you have enough hours of care?

	2016 (n=81)	2014 (n=122)	2013
Yes	88%	82%	88%
No	12%	18%	12%

4. What level of training do your caregivers have?

	2016 (n=74)	2014 (n=114)	2013 (n=109)	2012 (n=114)	2011 (n=42)	2010 (n=66)	2009 (n=48)
Basic	57%	52%	49%	51%	50%	41%	46%
Intermediate	16%	12%	17%	20%	21%	23%	13%
ALS informed	30%	36%	34%	29%	29%	36%	42%

5. Does your primary caregiver get respite care (time for himself/herself)?

	2016 (n=74)	2014 (n=122)	2013
Yes	59%	75%	68%
No	41%	25%	32%

EQUIPMENT SUPPORT

1. Are you aware what equipment is available from the ALS Society of BC?

	2016 (n=102)	2014 (n=135)	2013 (n=140)	2012 (n=136)	2011 (n=60)	2010 (n=89)	2009 (n=98)
Yes	95%	95%	94%	95%	88%	87%	84%
No	5%	5%	6%	5%	12%	13%	16%

2. How are you meeting your equipment needs? (Check all that apply)

	2016 (n=89)	2014 (n=125)	2013 (n=126)	2012 (n=125)	2011 (n=56)	2010 (n=69)	2009 (n=100)
Self-purchased	53%	62%	60%	61%	41%	48%	50%
Self-rented	4%	6%	4%	5%	4%	3%	6%
ALS Society of BC	83%	88%	87%	83%	93%	76%	78%
Extended Benefits Plan	29%	31%	29%	30%	21%	20%	25%

INTERNET SUPPORT

1. Have you visited the ALS BC website?

	2016 (n=99)	2014 (n=132)	2013 (n=139)	2012 (n=128)	2011 (n=60)	2010 (n=88)	2009 (n=97)
Yes	45%	50%	55%	48%	63%	59%	54%
No	55%	50%	45%	52%	37%	41%	46%

2. What would you like to see added to the ALS BC website? (*Please see appendix A for responses to this long-form question*).

COMMENTS AND RECOMMENDATIONS

Please see Appendix B for:

- *Patient long-form responses*
- *Caregiver/Family member long-form responses*

APPENDIX A: Long-form Question Responses

MEDICAL CARE

2. If yes, which medical practitioners do you see regularly? [“Other” responses]

- Respiriologist (11)
- Physiotherapist (5)
- Local Health Authority (4)
- Neurologist (3)
- Nurse (3)
- Rehab Specialist (2)
- Mobile ALS Clinic (2)
- Psychiatrist
- Psychologist
- Cancer monitoring (CLL)
- MS Clinic
- Naturopath
- Gastrologist
- Spasticity Centre
- Dietician
- Local specialist
- Surgeon
- XXX Home Care Services
- ALS XXX

4. If you are not being followed up with, please state why:

- Don't qualify
- I am only being seen by one specialist/not a team, which is too bad
- No point to it
- Location
- Nobody in area can figure out what wrong or will not commit to it
- I do not live in Vancouver
- In care facility
- Good if you get to appointment. Poor regarding support at home. Too far and too difficult to get there. Also really only to monitor my deterioration. Neither do they call to see how I am.
- Family doctor only
- Cannot fly down to Vancouver
- They do not travel to where I live
- The work to get to wherever outweighs any benefit
- Service is always very good
- Not advanced enough
- We are in contact with Family doctor & our health authority

- No treatment, no cure, seeing a doctor is moot point
- My doctor provides comprehensive phone visits including a) nurse, b) physiotherapy, c) medical, d) kinesiology
- Too early after diagnosis
- Not seen; have PLS and not in lower mainland
- We are not sure who to see about ALS here.
- Remote location
- May try mobile clinic

5. What medical services, if any, are missing from your care?

- P.T.
- Physiotherapy. No one seems to know what to do with me. Physio is expensive and not specific for my needs; Orthopedic service. Too far away to travel in winter.
- Just about everything no one will commit to what could be wrong here
- The cure!!!
- A call from ALS / GF Strong would be at least an indication that they are involved and care how I am doing. Sadly they are not. This illness is devastating and leaves the family apart to assist with odd calls and empathetic conversation is a MUST.
- Additional testing to see if you have any GENE issue or nutritional issue such as abnormal DNA or lack of being able to absorb nutrients. Getting into research programs.
- Neurological!
- P.T.
- A cure
- I am frustrated that things like DNA and statistical data isn't being collected should test for viruses and whatever the patient asks for.
- Accessing foot care and dental care privately. Waiting for nurse practitioner for meds renewal/referrals. (They are currently working from avg. referral list, my husband was referred in Nov. so we have a while to go. Presently I have to see his family doctor.)
- A cure!
- Patient goes to a day program on Fridays and a Family Respite Centre every 2 months for 3 days.
- None I am very happy :)
- Maybe a little extended care coverage, i.e. Physical therapy, acupuncture
- Bulbar ALS is so rapid. It would have been better if respite care was initiated sooner but we are on track now.
- Serious need - massage therapy. Transportation from appointments sometimes. Scooter. Access to gym room at the ALS clinic.
- Physio
- Home support is spotty
- None that we are aware of. Over holiday periods / weekends / out of office

hours, who do we contact for concerns?

- Monthly check up and advice. How to get involved with clinical trials.
- Psychological
- Individual physical issues that are unique to patient - i.e. Tongue muscles not strong enough to hold new dentures in place.
- A cure and some good news. Regular doctors do not seem to have much knowledge about this disease. Everybody has a better painkiller.
- Physio in community
- Consistent physio at our home. Advice for future.
- Most especially psychological
- Opportunity to ask questions between visits.

INTERNET SUPPORT

2. What would you like to see added to the ALS BC website?

- NA. No computer
- Is good as it is, maybe more medical facts
- Satisfied
- Care in the area
- Not sure
- Don't know about the website, haven't been on it.
- The support group times are NOT kept up to date.
- Any promising treatments or trials
- Can't think of anything - always interesting to read about research and new possible treatments.
- Progress
- Connection for ALS patients and caregivers to communicate and support each other over similar shared experiences, concerns, etc. Would build camaraderie, friendships when isolated from others.
- Links to support services. New update re: ALS research. Links to ALS clinical trials globally. Links to physio and massage therapists who do home visits.
- Good news!
- Easy link to clinic contact
- Health care guide and information of other references like books, videos, etc.

APPENDIX B: Comments and Recommendations

PATIENT FEEDBACK

- Very satisfied with care
- All of the ALS Centre team at GF Strong are super, great & the best!!!
- I am still within the first year after diagnosis
- I would like to get physiotherapy
- More choice of psychological therapists
- As of now we are satisfied with the help of the ALS society
- Living north and needing special care is hard - travel time is always long and difficult in winter. It would be nice to have more specialists and doctors near by, I feel isolated with PLS/ALS
- I think ALS society is awesome.
- Diagnosed 2004 with ALS. At present have peripheral and motor neuropathy, some cervical dystonia problem & balance, but I manage so far without assistance.
- Lives in a care home
- How many days per week can we get help? Can it be available on weekend?
- I am thankful for all of the offerings from the ALS Society of BC. XXX is a wonderful asset.
- We have received lots of help from ALS BC.
- There is a great need for the team to try and assist in preparing the family and patient for death; to assist with complexities of emotional pain, grief, loss. None of this is available. The family should not have to ask for this. The team should offer direction. We feel abandoned by the ALS team.
- I am not looking for Palliative care such as what we receive at the ALS clinic. I would rather have more proactive care where we are tested and used for research. A database on what helps reduce symptoms and prolong life rather than what to look forward to if you do nothing.
- My hand is cramping up, becoming deformed.
- Thank you for service
- Thanks for the important works you folks are doing. Good to know you are there for me if I need the help!
- A very caring ALS mobile team.
- How about a mobile meet & greet for XXX PALS. There are about 12 PALS XXX. We could then decide if we want to start a support group.
- The services of ALS society were such an appreciated discovery when my husband was diagnosed last summer. Equipment loans have been a life saver. Occasional repairs have been promptly addressed. Three counseling sessions helped with initial coping.
- It is difficult for me to travel to Vancouver from XXX to go to ALS Clinic at GF Strong as a walk on ferry passenger. Would like it if I could get there and back on same day via a car. My family work and are unable to take me. It is physically exhausting for me to stay overnight.
- I have PLS. I am fully satisfied with the ALS society when talking to them they seem so concerned and help in any way they can. Thank you.

- I don't know. I am new to the disease. So far care has been quick to put in place.
- I feel guilty having so little effect from the disease. I was told nothing was available and I was on my own so that was the path I pursued. Deal with the symptoms and get on with life. Drugs to mitigate symptoms are Methacarbomal (Kirkland back + muscle) and Cannabis (dampens seizures)
- My ALS journey this far has been slow progression. I've had good care and resources from ALS team at GF Strong and from the ALS Society. The support and services provided are very much appreciated. Perhaps - looking into the future - ALS "care" via support staff might be very appreciated. Things like respite care so my caregiver husband can have a break. Please continue caregiver days too. Appreciate ALS Society - BC ALS awesome! Please input other initiatives identified by ALS patients who are further than me - they have lived more of the journey.
- Patient is looked after very well by the team, just need to make a phone call :)
- The equipment loan and psychological service are wonderful. The power chair gives me freedom - I love it.
- I have a bipap machine and use mucous suppressing med and have been fairly stable for a while. XXX is following me as required.
- As money is tight the equipment from the ALS society has been very helpful and appreciated. At the moment I am using a chair, walker, alternate TV control and alternate phone. These have added to my quality of life. Many thank yous!
- Condition not advanced enough yet.
- We really appreciate all the society has done for us.
- We really appreciated all the services and rental equipment we have received from ALS - we could not have done it with their help.
- Forms are easier to fill out online, writing is becoming more difficult
- Wife very limited in movement. Just replaced walker for new one and given old one to the ALS Society. I need a scooter but too much for our purse, any help will be helpful but do not want used one, even with partial payment.
- Cannot write
- More support group meetings to hopefully include more ALS patients (none on the North side of the river) XXX to XXX. Can newsletters be emailed to members and patients?
- Maintain contact with the patient, send quarterly or monthly email, ie. Have "Ask Dr. Eisen" on website, newsletter. Although signed up for newsletter online, it is received infrequently, no reminder. Nevertheless the website is comprehensive.
- I'm glad I started attending the XXX Support Group, I quickly learned about many of the services the society provides.
- The ALS Society is awesome. They are always available on either phone or email. The team is excellent. I wish stair lifts were covered.
- The medical, counseling and restorative services that I have received, both through the GF Strong center and my local Home Care, have been knowledgeable and supportive. I appreciate that the ALS Society of BC sends a representative to the XXX for our 'walk' in September; this enhances the support that I receive within my community. It is typical that the diagnosis of ALS comes after months-to-years of testing and elimination of other afflictions, which have similar symptoms (I was encouraged to visit the GF Strong

center coinciding with a visit to Vancouver specialists who confirmed the diagnosis). This 'period of uncertainty' (and hoping that it is not) could be better used by the support services to reach out and demonstrate knowledge and compassion will be available, before they become members of the ALS Society of BC. Invariably the patient is distraught when the suspicion is confirmed. In hindsight of my own case: I wish that counselors had emphasized that although the disease provides time to wind up business affairs, make plans for the end etc., the first and most important objective should be to fulfill ambitions of a physical nature: to travel and experience wild and remote places for example. In the life of any ALS patient, there will never be a future time with as much physical capacity (although many of us have already lost much), as at time of diagnosis. If money and circumstances allow, a newly diagnosed patient should be encouraged to put their career and family on hold for a while, to pursue life-goals that require independence and physical strength. That opportunity will never return. The specialists at GF Strong Centre provide excellent counseling for the mid- and possibly later stages of the disease. However as a newly diagnosed patient, one who had been athletic and vigorous, the personnel (in 2012) could provide little support or relevant ideas. Because active males in their 50s are a significant population of the diagnosed, the GF Strong center ought to provide knowledge of how athletic people succumb, and ideas on what previously active people can do during early stages of the disease.

- I recommend being told of next appointment when being seen. Sometimes it seems I have been forgotten unless I check - doesn't seem right to me!!
- I feel much better after I visit the ALS centre - the staff, all of them, show caring and respect and understanding; it is an emotional feeling for me. The society has been there for me from the beginning. They are wonderful people. They make me feel good.
- Equipment loan service is excellent. Are there alternates to standard medicine, ie. Naturopathic.
- The ALS Society has done a very good job of making equipment and services available. The people doing the installation and service and delivery are very knowledgeable.
- It would be nice to have a scale to weigh me that goes between a lift and a sling as I am unable to stand on a scale by myself.
- Advocacy - dealing with government agencies.
- Excellent support
- I think they are a helpful society. The team is very helpful.
- I appreciate everything you do for me. Thank you thank you thank you thank you and thank you!
- Currently I am still mobile and have low needs - I expect my needs will increase in the future. I take solace in knowing the ALS Society is there when I may need it. Many thanks.
- I have been assessed by my health authority; I will seek caregiving assistance in a month or so.
- It would be helpful if they would call once in a while to see how you are doing
- 1) More information for caregivers. 2) Multidiscipline support and group meetings are recommended but, for me, are impossible due to my remoteness and inability of health care professionals to coordinate. 3) Actually I'm doing quite well directing my own care. It has been XXX years since diagnosis.

- Thank you for the support provided from the ALS.
- Very good services; have been keeping in touch with me all the time, very good people.

CAREGIVER / FAMILY MEMBER FEEDBACK

- So glad that the clinic and society are there or I don't think we could cope. I feel we don't have to look too far ahead as we will be guided as my husband's condition worsens. Thank you all for being there!!
- Days away from any mention of ALS. I believe caregivers want to escape the grip of ALS, they don't want to hear more about ALS.
- My husband is my caregiver 24 hrs.
- I think ALS society is awesome.
- Wife visits - daily
- None - meetings returned to XXX
- Why can't we get more support from local doctors? No one seems to want to commit to the problem.
- I am identifying myself as I have been the principal caregiver for my wife for 27 years. She has been on a ventilator for about 20 years. I have been working from 4pm to 11pm for 27 years and all I want is to know that the money or a large portion of the funds raised by the ALS society goes directly to ALS research. The society does a good job, the fundraising is terrific but before I die I want to know that there is a cure for ALS coming soon otherwise 27 years of my life will have been tainted. BE SURE the RESEARCH is FUNDED and above all REAL.
- More training
- Slow progressing Motor Neuron disease has not required a lot of support
- ALS team at GF Strong only provide service if you go to GF Strong. The only option is for us to call for self directed questions or needs. Would be nice to feel that the occasional call/interface meant they were still aware of us. We feel completely that we are alone.
- Family members are all on board what I need or want. Caregivers are the same.
- No words can express how thankful and grateful we are for ALS Society of BC. Especially of the Equipment loan program that provided almost everything my husband needed. And to the team of Dr. XXX thank you so much!
- Thank you for equipment needed.
- We are very happy with most local professionals since we live so far away from GF Strong we use it more as a resource. The pilot project for caregivers was extraordinary!! My wife was very pleased and grew quite attached to the person. It gave me peace of mind. My only suggestion would be early availability. My wife was already requiring two people to bathe her, which she preferred to bed baths.
- Attended symposium in XXX; other info sessions would be appreciated. Support group meetings at GF Strong have been valuable. PROP has also been excellent resource. Will access care connections in next month or so.
- I rely solely on XXX Homecare at assisted living facility in XXX. The staff are great but are unable to do certain functions - like push my manual wheelchair up ramp when I return from appointments I have to rely on volunteers.

- No caregiver.
- When asked he said he enjoyed the caregiver days - BUT it was only once a year. Future unknown, i.e. Progression needs unknown.
- Access to stair lift loan equipment.
- We appreciate all the support :)
- The only thing is it would be nice to have contact with our local ALS Society. A good friend whose wife passed away from ALS does come for visits.
- The tremendous support from the society - emotionally and with the equipment - has allowed us to use our funds for bathroom renos and a car lift. It was hard for us to believe how quickly ALS would affect our whole lives and staff advice was so valuable.
- My thoughts and feelings are the same as stated above: We really appreciated all the services and rental equipment we have received from ALS - we could not have done it with their help.
- Thank you for all you do and provide.
- I did fill the patient side. She needs a scooter and another appointment for rental but most of them too expensive and not secure. Need electric door opening. Lift/elevator and safety in bathroom and environment.
- Despite XXX having more difficulty with ordinary tasks, she maintains a positive attitude throughout.
- I have home support; is mismanaged. No consistency in care workers. Care workers at times not available. Far night work impacts the most. Props is awesome.
- Does patient services make regular contact with patients to maintain connection and offer support? (Especially new patients?)
- My caregiver has very little contact with ALS Society, busy helping patient. Thank you for doing this survey!
- Both symposiums we've attended have been very good (2014 & 2015). My first caregiver day was also well worth attending (2015). I learn really helpful things from caregivers who are farther down the road of caring for someone with ALS.
- Thank you for your support. Our children are young adults - too old for the camp but could possible benefit from some type of group support as well - peer sharing. It is a scary, emotional experience from them as well to live through ALS. Could there be something for them?
- The professional directives provided by the ALS Vancouver medical team has benefitted us greatly and we very much appreciate the society's ongoing support. As we have a professional team on the island, we would at this time prefer not to travel to our appointments at GF Strong as we find the commute very stressful. However, the ALS Society is a crucial lifeline for us and again we are thankful.
- Great effort to find a cure and cause for ALS. I can't believe that so little is known about this horrible disease. We want to hear that we are winning the "battle" not that it is progressing steadily onward to death.
- Caregiver days are helpful and informative and provide an opportunity to meet and talk with other caregivers.
- Caregiver days exclude working spouses due to weekday event.
- Get along fairly well at this point

- I am at a loss of where to begin, all my requests and questions have been answered fairly quickly and professionally. Thank you!
- I would like to see an online support group for BC/Yukon. I belong to a group on Facebook, but the caregivers are primarily from south of the border. PALS also belongs to one on Facebook. I get a lot out of the caregivers day, but last year it didn't fall on a day off.