

ORAL QUESTION—JULIE GREEN, MLA YELLOWKNIFE CENTRE

**QUESTION 399-18(3):
SPECIFIED CONDITION FUNDING ELIGIBILITY FOR AMYOTROPHIC LATERAL
SCLEROSIS (ALS)**

October 16, 2018

MS. GREEN: Mr. Speaker, now that the Minister of Health has recovered from all his questions, I have a few more. He is well-informed about the situation of a constituent of mine who has ALS, or Lou Gehrig's disease. Recently, people in Yellowknife held a major fundraiser to meet his expenses, now that his disease has progressed where he needs a lot of different kinds of support.

He is not eligible for public support for his condition because it's not listed in our medical health insurance program. My question for the Minister is whether he can explain how it's possible that such a serious and not completely uncommon condition could not be eligible for treatment?

HON. GLEN ABERNETHY: Yes, the Member is correct. ALS is not one of the conditions covered under our specified disease conditions under our supplemental health program, but I do want to make it clear that, unlike many other jurisdictions, things like homecare are part of our services that we do provide. We are working with clients and residents who have different specified diseases such as ALS, providing them with things like homecare and other services that they wouldn't get, or they would have to pay for in other jurisdictions. Having said that, the specified disease condition is just one of our programs that focus on things like prescription drugs and sometimes medical supplies and these types of things.

Currently, most of our programs are tied to the non-insured health benefits program, and ALS is not something that's covered by NIHB. We are trying to move away from having a specified disease condition program here in the Northwest Territories. I agree with the Member. It doesn't seem to capture some of our residents who are in the highest level of need, and it should be based on condition or on individual's ability needs, rather than a specified condition.

We are doing some work to modify our supplemental health programs. Much of the work is going to occur in the life of this Assembly, but it probably won't be until the next Assembly that some decisions need to be made around that. I do hear the Member's frustration. I share that frustration. We will certainly work with individuals to ensure that they are getting as much support as they can.

MS. GREEN: There is lots of good news in that answer. The fact is that, if I had the misfortune to walk out of here and get hit by a truck and I needed a wheelchair, no one would question my eligibility for that, but my constituent who has this terrible progressive disease has to make a case for it.

Having said that, the Minister and his staff have been helpful coordinating with the ALS Society of Alberta in providing services to this person. As an alternative to the specified

condition, is it possible to create something like a catastrophic disease fund where somebody who has a progressive disease that has very high needs over a short period of time might be able to access help?

HON. GLEN ABERNETHY: In reviewing what has been provided by other jurisdictions across this country, it has been clear to us that no other jurisdiction actually has coverage for ALS, either. Fortunately, in other jurisdictions, they do have ALS societies that have done incredible work to support people with ALS by getting them the equipment they need, often on a loaner basis. We don't have an ALS society here in the Northwest Territories, but the Alberta ALS Society has been a significant partner for individuals in the Northwest Territories who are struggling with ALS.

Having said that, I take the Member's point, and we have had conversations about upgrading our supplementary health programs, modifying and changing them. We are doing that work. I think the Member's suggestion is certainly one that we have to consider, and it will be incorporated in discussions around the future of supplemental health programs.

MS. GREEN: Thank you to the Minister for that response. As the Minister may know, this is a disease without a cure. The debilitation continues to progress, sometimes quickly and sometimes not. Both of my paternal aunts died of this disease. I've seen it up close. What is the Minister's plan for this individual going forward in terms of providing him with the care he needs so that he has the best quality of life for his time remaining?

HON. GLEN ABERNETHY: I'm not prepared to discuss an individual's plan of care in the House of this Assembly. I don't think it is the appropriate place. The Member and I, as well as other Members who have been provided consent by the family, have had some discussions. I am certainly happy to sit down with any of the Members who have received consent from the family, and I am happy to meet with the family again to discuss where we are. We have had a discussion with the family previously, but I am definitely not about to start talking about an individual's plan of care in the House before this Assembly.

MR. SPEAKER: Oral questions. Member for Yellowknife Centre.

MS. GREEN: I appreciate the Minister's response. My final question is whether the Minister can give us an indication of how many people in the NWT have been diagnosed with ALS? Mahsi.

HON. GLEN ABERNETHY: I know the current number in the Northwest Territories. I can't tell the Member how many people over time have had ALS. The number is quite small, and given the fact that it's small, it might be statistically inappropriate for me to throw that number out, but I am happy to have a sit-down with the Member and let her know how many individuals are currently living with ALS in the Northwest Territories.

I say that recognizing that the media has already interviewed both the individuals or their families, so we know how many individuals there are out there, but I'm not prepared to say at this time, except I did just say "both." Whatever, two.