

This is an email conversation chain that took place between Sean Tagert and VCH administration about the possibility of moving to The VCH Evergreen extended care facility in North Vancouver, British Columbia, Canada. There had already been some back and forth with family, but this is where I came in. Names and addresses have been removed.

Email #1, my introduction.

SEAN:

I have to admit this is an interesting option. The details are what will be the catalyst. So we haven't met, my name is Sean Tagert, I was diagnosed with ALS in 2014. I am a full paraplegic mute, unable to speak at all, but completely aware and in full control of my cognitive abilities. So I differ from most long term residents in that I feel and understand everything around me. Ie ; I'm not 85 and I don't have dementia.

I have an 11 year old son whom I'm very close with, so the private room is key, I will list a bunch of questions at the end of this email, after I explain my needs more. I am the most advanced case of ALS in Canada, verified. I have an oral catheter in my mouth 24/7, it never comes out due to extreme excessive saliva, so the rooms have to have permanent suction outlets, not the portable kind. I also value my autonomy above all else, so my communication equipment is vital to my well being. I have current doctor ordered one to one care. I understand staffing is an issue at evergreen, but maybe we have a solution to that.

So just to get the ball rolling, a few questions:

1. Size of room. Enough for a cot for my son to stay some nights? A spot on the walls for my monitor and computer?
2. Internet. I need high quality internet. My life requires high bandwidth. If you can't provide it, can I have it installed at my own expense?
3. overhead lifts? Obvious but have to ask. I use slings for all transfers.

Staffing - I believe this is going to be the biggest issue. I will be your highest needs client. Having spent three months in the Lions gate ICU and nccu, I am speaking from experience.

1. If you're unable to provide one to one care, can we combine my csil program with the facility? Obviously some conversations needed, but with open minds it's doable. We could set boundaries as to who does what, etc...
2. Ventilation trained people. In ICU and nccu all vent stuff was handled by RT's. A year and a half ago evergreen did not have 24/7 Respiratory Therapists. Do they now?

Email #2 – VCH reply

Please excuse my delay in responding to your e-mail. Nice to hear from you.

As I said to Erica and you in the last e-mail, the clinical contact for you will be ---, who is the Resident Care Coordinator (RCC) on the unit as well as -----, the Operational Initiatives Lead responsible for

clinical issues that are escalated. I am not usually involved in introducing potential residents to Evergreen House so I anticipate they will lead the discussion and assist in answering many questions you may have. Although I am an RN, this is a big place (284 beds with a staff of over 300) so my main role is operations (non-clinical). I worked for over 30 years in Emergency and ICU before becoming a manager in Fraser Health (Residential and Acute). After 5 years there I moved 2 years ago to Evergreen House. Residential Care (or Long Term Care as the name has recently changed to) has been an interesting change from acute care. We are continually striving here to reinforce a person centred approach in care and programs offered and we function under a leisure/non-medical model. This can be challenging given our resident mix (age, ability, cognition etc).

SEAN:

1. Size of room.

VCH:

You will have a private room. We don't have one available right now so that needs to happen before anything else.

SEAN :

Enough for a cot for my son to stay some nights?

VCH:

We haven't allowed anyone staying overnight previously but I won't say an absolute no to this request. We can explore how this might work. A cot would fit in the room if need be. We would have to discuss a risk management plan in regards to your son staying overnight. Further discussion would be needed.

This was the first positive response I'd ever gotten about a place for my boy.

SEAN:

A spot on the walls for my monitor and computer?

VCH :

This is not a problem.

Remember this for next email.

SEAN:

2. Internet. I need high quality internet. My life requires high bandwidth. If you can't provide it, can I have it installed at my own expense?

VCH :

Residents have the option of having internet installed at their own expense. Telus or Shaw. We don't supply this and are not responsible for any computer equipment. Residents bring valuables and any IT equipment in at their own expense. VCH is not responsible for resident valuables that are lost, stolen or damaged.

Good news about the Internet. I had already read their theft disclaimer and had an idea for that.

SEAN:

3.overhead lifts? Obvious but have to ask. I use slings for all transfers.

VCH :

Oh yes. We have ceiling lifts. This is not a problem.

Another check box ticked.

SEAN:

Staffing - I believe this is going to be the biggest issue.

VCH :

Probably right.

No translation needed. They know and agree staffing is a problem. Easy solution.

SEAN:

I will be your highest needs client. Having spent three months in the Lions gate icu and nccu, I am speaking from experience.

VCH :

Understood....you know best.

So they agree I'm a high needs client.

SEAN:

1. If you're unable to provide one to one care, can we combine my csil program with the facility?

VCH :

I have checked and this is not an option. The Medically Enhanced Care Unit where you would live is a 5 bed unit (currently expanded to 7 beds) staffed with round the clock RN's. While I don't think 1:1 care is doable (current staffing would not permit this), we would assess your needs and provide care as necessary for safety. Since we don't have the most up to date assessment regarding your needs, staffing would be assessed when we have a full picture.

"This is not an option." This is where the VCH God complex starts to peek out a bit. There is ZERO legal reasons why this is not an option. Corporate policy. Keep in mind that both programs are administered by VCH.

SEAN:

Obviously some conversations needed, but with open minds it's doable. We could set boundaries as to who does what, etc...

SEAN:

2. Ventilation trained people.

VCH :

RN's at Evergreen House would be trained in ventilator care. They currently have some training however the only other resident we have on a vent is not ventilator dependent. The RN's are proficient in deep suctioning. There is wall oxygen and suction available at each bedside. In ICU and NCCU all vent stuff was handled by RT's.

Did I read that right? They are not currently trained on vents but have someone on one there? Not ventilator dependent... So why does that client need one? Blowing bubbles? Something off...

SEAN:

A year and a half ago Evergreen did not have 24/7 Respiratory Therapists. Do they now?

VCH :

While we do not have an in house RT, we utilize the RT's from Acute (LGH) 24/7. If needed, they come from the hospital.

So untrained RN's and no RT.

SEAN:

I have many more questions, but I'm open to this idea, so let's start with these and move forward from here.

VCH :

We are happy to answer anything we can and yes I am sure other questions

Email #3 – Sean reply

SEAN:

Great reply -----, I truly appreciate the honesty. I've got a few things on my plate right now, so I think I'll wait till my sister does the tour. I have instructed her to video the room, or a room like I would be in, as I know exactly what equipment I need and visually seeing the room will allow me to figure it out. Truthfully I don't care too much about the rest of the facility, even here at home I don't leave my room. We can talk about staffing and my boy after I see the room, it's the first thing we need to look at. Happy to hear about the Internet, I have Telus high speed, so I could just transfer it. Thanks again and talk to you soon.

Email #4 - VCH reply

VCH :

Just minor correction :

Two RCAs will have another assignments beside of MECU residents during day and evening shifts. This ratio will not increase at night . There is one RCA at night for MECU.

Minor correction? So you have a single care aide for the " Medically Enhanced Care Unit" at night for how many clients?

Hi Sean:

Thank you for forwarding the areas which you want further clarification on. I will do my best to answer. Please see below....

SEAN:

Hi Guys,

Thank you for the tour, I appreciate it. Sounds like the room is viable. So that is two hurdles cleared that Pearson couldn't, a private room and a place for my son. There are more hurdles however, and as previously stated, staffing is a massive problem. I am not interested in going anywhere that increases my suffering, being a quadrapalegic mute with full sensory and cognitive function under constant threat of drowning is enough suffering for me. I value my autonomy very highly. I will not give up my basic human rights like decision making under any circumstances. So here is just a few of the guarantees I need, in writing, legally binding, from any facility I would live in. Please read to the end and hear me out.

VCH :

I am sorry but we cannot provide legally binding agreements in writing regarding residents residing at Evergreen House.

Cannot? You mean will not. Wonder why...

SEAN:

1. I have no set bedtime, or wake up time, like any adult. Need to be able to go to bed and get up when I want.

VCH :

Care routines are made in conjunction with your wishes and to the best of our ability. We will do our best to meet your requests however we need to keep in mind that there are a number of residents living here, all whom have specific requests that we cannot always meet due to our ability to safely manage care for all. The team would negotiate with you in regards to your care plan with an equitable solution.

Another problem that could be solved with my combination CSIL program idea.

SEAN:

2. A place in my room for my son to sleep, with unrestricted visiting hours.

VCH :

Further discussion will be needed in this area.

Change in tone from first email. I was very clear that this was a key point.

SEAN:

3. I have daily BMs, necessary. I do not use diapers or catheters, nor will I as ALS does not affect bowels or bladder. I also go at different times.

VCH :

The care plan, including bowel care routines, will be made between you and the team. You don't need to use briefs or have a catheter if you have control.

After some research I found out scheduled BM's are every three days. If you have to go between, they put you in bed with a bed pan and come back when they can. Some residents have had to sit in feces for 24 hours.

SEAN:

4. Privacy. This could be my home for many years. I'd need a private address for mail, deliveries, utilities, etc... Visitors, intimacy, movies, etc.... It needs to be 100% clear that this is my home, no different than if I was renting an apartment.

VCH takes 80% of your TOTAL income, not just your pension. That would get you a pretty apartment.

VCH :

You are correct this is your home and as for all residents, deliveries are delivered to the site then dispersed to the residents. There is no specific room delivery system in place. There are no specific visiting hours. You are entitled to privacy in your room. This is a health care facility however and is different than renting an apartment. Residents living here are the responsibility of Vancouver Coastal. Rooms are not treated as rental units.

How hard is it to put a room number in front of an address? Dispersed by a non postal carrier? Are they bonded? No specific visiting hours? So you can just say no visitors? You take the majority of my income but I can't have the most basic freedoms of my own home? Doesn't seem to match up with "this is your home" or "entitled to privacy"

SEAN:

5. Security. You have stated you cannot guard against theft. I can. I would have a security system complete with cameras installed At my cost. I have tens of thousands of dollars worth of electronics and disability equipment.

VCH :

Security systems including the use of camera surveillance is not allowed in resident rooms or on the premises.

So you publish in your own literature warnings against rampant theft, no insurance company will insure in a VCH facility, yet I am not allowed to put in my own cameras? NOTHING to hide? I'm pretty sure that isn't even legal. Police are wearing body cams for a reason. It's called truth.

SEAN:

6. Diet and food prep. I eat a mostly vegan home blenderized diet. I'll need a fridge, counter and sink. I have all the prep equipment, and can set up a counter after I see some pics of the room. We are not able to accommodate this.

VCH :

Organic vegan prepared diets are what we use. We do not have the manpower to prepare home diets. Fridges are not allowed in rooms as this is an infection control concern.....we do not clean resident fridges so the resident would have to do so which in most cases is not possible. The only sink in the room is in the bathroom.

Another problem solved by my CSIL combination program idea.

SEAN

7. I have my own wheelchair van, will need a secure parking space.

VCH :

This cannot be provided by VCH. The only parking is the public park aide parking (daily).

So you want a person that travels with two ventilators, two suction machines, a feed pump and an eyegaze tablet to use public transit? Does public transit have 1000+ watt inverters? Am I allowed to leave?

SEAN:

8. Room alterations. Paint, tv mounts etc... again, this will be my home for years, needs to feel like a home. Of course nothing crazy and I'd consult with management before making any alterations.

VCH :

Residents are not allowed to paint or alter rooms. TV mounts are installed according to VCH standards at our expense. Additionally, you should note that although we have showed you a 4 bed room which we will convert to a private should you decide to accept the bed, in the case that a private room does come available you may be asked to relocate to that room. The relocation would be done at our expense if you have internet etc that has to be moved.

Couple 180's here. They originally said I would have a spot for my computer and monitor station. Now it's a TV mounted by them. Originally it was a room verified by my family as big enough for my equipment and son. Now they are saying oh by the way we're going to cram you into a small room asap. I can't even paint? Seriously?

SEAN:

The staffing will be the biggest hurdle. There is an easy solution however. Evergreen house has a companion policy. This will be my personal apartment so it doesn't exclude the CSIL program.

VCH has a policy, already in place, that allows residents to hire third-party employees. Called the companion policy. This is literally how my home care works. So they already have the legal paperwork

done. Translation : they would not have to change a single thing with my current program besides the address.

VCH :

This is not a personal apartment. It is a room within the facility. Evergreen House is not an apartment building but a facility to provide care for residents. Yes it is their home, but residency here comes with liabilities for VCH so thus not just an apartment. CSIL program cannot be accessed by residents in Evergreen House or any other owned and operated health care facility.

Again, take all my money but not even the most basic rights that come with a home? Liabilities? Straight up lie – Companion policy already in place. CSIL program “cannot” be accessed? Another lie. Corporate policy. Not allowed by VCH would be the appropriate statement.

SEAN:

The only actual barriers to this solution exist in the mind. Keep me on the CSIL program, under the Evergreen house companion policy.

VCH :

Third party care providers (companions) can be hired. There are guidelines for what they can and cannot do as VCH still remains the primary care provider for residents in VCH facilities. The resident/family is the employer in these situations and agreements are signed waiving responsibility for care rendered within the scope of what is allowable for companions.

Woop there it is. Straight from VCH administration. Read that three times and think about everything they said they “ cannot” do.

SEAN:

We can easily set union trades demarcation lines (Ie; my Csil workers could alert evergreen staff if I need trache suction while taking the load off the Evergreen staff by dealing with BMs, meal prep, washing and cleaning, etc...) The only thing needed on the CSIL side would be a change of address. I see potential in Evergreen house, with a progressive attitude it could shine. Please consider these requests with an open mind, think about if it were you. No system is perfect but we don't stop trying.

VCH :

The option of having CSIL attend to residents in Evergreen House is not a decision of me or anyone here at Evergreen House. This is provincially mandated. You would have to talk to someone higher than me, but at this point I am told it is not an option.

Please feel free to share this. No one seems to be listening in the government.