



February's Windows: Emily

Written by Emily's Mom, Lindsey

Originally "published" on Facebook as a series of interesting and informative daily postings throughout the month of February 2017, providing a unique window each day into the current life of our own Emily Yeskoo, the palliative client after whom Emily's House is named.



Day One: Feb 1, 2017



Today we are launching "**FEBRUARY'S WINDOWS: EMILY,**" a series of interesting and informative daily postings throughout this month, giving you a unique window each day into the current life of our own Emily Yeskoo, the palliative client after whom Emily's House is named.

The background story of Emily's life can be found on our website. However, "**FEBRUARY'S WINDOWS: EMILY**" will share photos and significant aspects of her personal journey and adventures as they unfold from day-to-day this month.

You can be sure that there will be twists and turns and joys and surprises that you might never imagine possible under the circumstances. We look forward to meeting you here throughout her "purple month." It could turn out to be a very life-enriching experience!

~ *Written by Emily's mom, Lindsey.*

Day Two: Feb 2, 2017



While Emily was still able to speak, soon after she was diagnosed with MLD, her Daddy wanted to do something extra special for her, while it was still possible that she could enjoy it. She was a pre-teen at the time and she had been told the longest that she could possibly live would be until age thirteen.

"What would you like me to do?" he asked her. Her instant answer frankly surprised him. **"Dad, please buy a house with big windows so lots of light can come in."**

Our family had never owned a home up until that point. Due to the job situation, we were privileged to move in and out of overseas so often that we had only ever lived in rented homes in each location. With this new twist in her life, and a race for time, Emily expressed a yearning for something more. A place to call home, in a new sort of way. It was the only request she made before suddenly losing her capacity to talk at age eleven. It involved a rather adventurous process. Her father, in time, was grateful to be able to make that dream of hers come true. And this is where she lives now, at the hub of our household, in the very room which has the most expansive windows of all. So that the light can shine through. If you were to peer through one of those windows right now, you would see our now twenty-three year old Emily propped up so comfortably in her hospital bed, smiling and occasionally dissolving into peals of laughter at the film she is watching. One of her wonderful nurses is at her side, attending to everything she needs for the next few hours.

For years now the trajectory of our Emily's neuro-degenerative condition has rendered her incapable of doing anything for herself. Her mind is still completely intact, as it was in all the years before this disease ever started interfering with her every attempt to send messages to the rest of her body.

The constant care she requires day and night is complicated. She is in a very real sense fighting harder than ever to survive, yet one good look at her countenance today would reveal some likely surprises. Her skin is seamless. Her big brown eyes are bright. There is a radiant flush on her cheeks. What is going on in her spirit as I write is far outweighing what is happening to her body.

She is loved. She is nurtured. She is at peace. She is content. **In spite of unfathomable odds, she is thoroughly enjoying this day. Of how many people in your life do you know this to be true?**

The winds are picking up. More snow is falling. There is a distinct chill in the air outside. Indoors, though, we are cozy and warm. Still together. As long as I myself have breath, I shall never stop giving thanks for our Emily.

~ *Written by Emily's mom, Lindsey.*

Day Three: Feb 3, 2017



Today's "window" has everything to do with seeing RED! This will come as quite a surprise to those of you who have known for years that Emily's favourite colour is purple. Don't worry, she has not changed her mind. She is simply on a new quest. Let me explain....

According to the Chinese calendar, this is the Year of the Rooster. As it turns out, Emily herself was born in the Year of the Rooster. A friend who recently came to visit said, "Emily, now you must get your mom to find a little bit of RED to enhance your every day this year. That's the Rooster tradition!"

How interesting that Emily already has a real affinity for combining purple and red! Not only is she finding so much pleasure in the freshness of this new idea, but she and I are also digging a bit through our memories and discovering that RED has actually been intercepting our lives in significant ways through the years. Perhaps we needed the Rooster to wake us up out of our drowsiness in order to notice it!

We invite you to stay tuned in the coming days as we explore this topic a little more! For now, here is a photo of Emily, taken this morning ... decked out today in RED!

~ Written by Emily's mom, Lindsey.

Day Four: Feb 4, 2017



It has become a game. As it was this morning.

Emily's rigorous routine kicks off each day [at 5 a.m.](#) The goal is to have her clean and fresh, pain-free, sitting up comfortably in her hospital bed, happily awaiting the arrival of the nurse. Some days we are more successful than others.

Daybreak comes. Emily settles down. I water the many plants around the circumference of her room. Then pour myself a coffee. Every single day, in every single season, no matter what the weather, something then transpires outside Emily's windows. A familiar voice is heard. I instantly detect it, recognizing the sound arising from that throat. I stand up, and Emily smiles. She is totally familiar with the habit. She knows a certain Mr. Elusive is out there, somewhere.

"Where are you? Where are you?" I ask, scouring the back yard with my eyes, inclining my ear to discern the direction of his chatter. He eventually grants me a clue; there is a visible flurry.

A sudden flash of RED confirms it! Mr. Cardinal makes himself known. He rises to the top ledge of the cedar hedge, calling out, calling out. Often his female counterpoint will then join him.

He knows Emily is there, just beyond the glass which separates them. I am convinced of it. She is not forgotten. He has come to welcome her to yet another day. She hears him, and laughs. Just as she did today.

A marvellous sign of life. His daily presence has become a source of such significant comfort.

~ Written by Emily's mom, Lindsey.

Day Five: Feb 5, 2017



It is a curious observation, in retrospect. There turned out to be a most unlikely surprise in store, once we began to recover from the massive initial shock of Emily's terminal diagnosis almost 14 years ago. We were asked to begin facing a rapid loss of all of her incredible abilities followed by losing her completely within those next three years. Imagine, then, how startling it was to wake up to the fact that all the talk of death actually underscored just how alive life really can be!

The most commonly acknowledged trait of roosters is their habit of awakening people. People who are born in the Year of the Rooster, it is said, happen to somehow demonstrate this trait in a significant way during the course of their lives. I am looking at Emily this morning through this "window", and a myriad of thoughts are rushing into my mind. Roosters notoriously wake people up with a jolt, in a timely way, prodding them out of slumber to get up and get on with their day. This role is not always welcome! Emily's Dad recently had a series of rooster encounters overseas and found them quite annoying!

However, I see the lights going on as I take a closer look through this "window." Why did I never notice it before? **Emily, of course, has been awakening us all. And I confess that in both literal and figurative ways, there is actually no-one who has experienced this more than I have.**

"Wake up!" she is crying, in her wordless way, "Wake up from your sleep, your stupor, your drowsiness, your sluggishness and complacency! Wake up not just from your sleep, but from the death that has made you more dead each day than death itself! Wake up, and get a move on with that gift of LIFE that is yours for today!!"

~ Written by Emily's mom, Lindsey.

Day Six: Feb 6, 2017



Emily had dreams for her future, long before this MLD ever set in. She went to pre-school in Virginia and then to kindergarten on an island off the port of Kobe in Japan, and she declared, "I am going to be a Teacher!"

The following year, in Grade 1, also on Rokko Island off the coast of Japan, her teacher held a Literary Afternoon Tea for parents, during which each student made a wonderful presentation. A lot of time had been spent preparing for this occasion, as each child had to choose their own preferred topic of interest, write about it and design artwork to correspond to it. What an impressive afternoon it turned out to be! A highlight of her school experiences. When it was over, Emily declared, "I am also going to be an Author and an Illustrator!"

It was settled in her mind, at such a tender age.

If you were to peer through her window on this winter Monday, what would you see? I suspect we all have a perception, perhaps, of what an aspiring Teacher, Author and Illustrator might look like. Today, I venture to suggest that what you would find might in no way represent what you might have had in mind. You might even feel uncomfortable, disarmed. Oh, she is beautiful and has an aura about her which is compelling. However she is immensely more fragile than you may have imagined. She can no longer stand up; she can only even sit up for very brief chunks of time, and even then she has to be fully propped up so as not to fall over. She can no longer utter one word. She can no longer hold a pen or a pencil between her fingers, let alone write. Her hands no longer receive the messages she longs to send to them so that she can draw and paint as she once did.

Don't just look. Come in and sit with her for a while. Linger, and observe thoughtfully. She has a way of slowing us down, to get us to really listen, not just with our ears but with our hearts too. Such an unconventional way of creating an opportunity to learn something that really matters. A Teacher? An Author? An Illustrator? There are hundreds of people ~ or more ~ who would unhesitatingly vouch for the fact that her dream has already been coming true for years. Just not quite in the way anyone would have expected.

~ *Written by Emily's mom, Lindsey.*

Day Seven: Feb 7, 2017



February's
Windows:
EMILY



emily's house
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What a very special day this is turning out to be, for Emily. Today is her beloved Grandmother Yeskoo's birthday. We are celebrating her life this afternoon in an entirely different way than ever before. Emily is 23 years old. Just imagine: from birth up until the age of 23 she has had all four of her amazing grandparents very lovingly involved and playing precious roles in her life, through thick and thin, even though they all lived far away. What makes today so very different from any other day in her life is that her Grandma Yeskoo's birthday has come, but she herself has gone. She passed away eleven months ago. We are celebrating her life today, together, but there is definitely some sadness and not a few tears. You see, we miss her so very much. Not only was Emily her Grandma Yeskoo's 7th grandchild, Emily was also the first GIRL born in two generations! Emily has her Grandmother's winsome smile! She also has the very best of her Grandmother's strong, sweet, hopeful, determined disposition! Here is the poem which was read at her grandmother's memorial service, on behalf of Emily:

*"You had a voice; You had a song;
You had a hand that held mine as the years moved along.
And I know you loved me, and I know you prayed,
And it brings tears to my eyes to think that you have slipped away.
The singer's gone, but not the song,
And you'll be there to welcome me when I come along.
Yes, you'll be there to welcome me when I come along."*

~ Written by Emily's mom, Lindsey.

Day Eight: Feb 8, 2017



It's mid-day already! Time for the fun part of this Wednesday to begin as more snow blows about outside. There is no day nurse today, but Emily is looking forward to her personal spa!

This will be the reward for all her patience this morning as I tended to all things medical: sterilizing and re-setting her PICC line site (tube through her right arm which delivers all her daily nutrition in liquid form to her heart); cleaning and checking her mic-Key button site (through which all her medications are syringed, also in liquid form); taking her off her TPN nutrition (which looks like a large hanging bag of white IV solution) to give her a five-hour break before the nineteen-hour daily cycle starts up again; changing her often and propping her up constantly to keep her comfortable; exchanging all her bedding for clean, fresh linens; sanitizing the outer rim of her bed and the medical pole beside her bed; doing a general clean-up in her room; double-checking to make sure we have all necessary supplies in stock; and even trying to "bring her back" from a rather long-lasting seizure.

Now for the hair-washing, massage and heat therapy to hopefully relieve all her nerve pain and settle her for the rest of the day!

~ *Written by Emily's mom, Lindsey.*

Day Nine: Feb 9, 2017



Let's mark the calendar! There is a generous supply of winter-white sunlight beaming into Emily's window this morning. Those of you who share this part of the world with us know this is cause for hearty celebration! May light not just reach us today but filter through us as well.

The phone rang. It was Emily's palliative doctor. "I am doing home visits today and am in your area right now. Is there any chance I can swing by to spend a few minutes with Emily? I have not seen her for a few weeks and really want to see how she is doing."

Tears rose immediately to my eyes. The two of us just happened to be here alone at the time. His spontaneous thoughtfulness and genuine care for her struck a chord with me. In how many other places in the world can one receive this kind of personal consideration and follow-up? "Of course," I replied without hesitation. Within a few minutes his vehicle rolled up the driveway. He came in.

"How are you today, beautiful Emily?" he asked as he drew near to her bedside. Things were peaceful in the room at that moment, and she identified his voice with a rather dazzling smile, before moving her head to fix her brown-eyed gaze on him. **Her wordless welcome somehow stilled any hurry he was feeling, to the point that she soon had him seated comfortably in the armchair next to her, content to simply BE with her, sometimes in complete quietness, other times speaking to her.**

Looking through her window, you would have had no problem observing that the heartfelt affection between them was apparently quite mutual... and illustrates one face of pure palliative care in the community.

~ Written by Emily's mom, Lindsey.

Day Ten: Feb 10, 2017

February's
Windows:
EMILY

Emily has a mind of her own! This may come as a surprise. You see, she lived some pretty healthy, adventurous years before this neuro-degenerative MLD disease crept into her life, and she was used to making many decisions for herself. For example, did you know she was beginning to learn her fourth language by the time she was eight years old? Yes! English, Japanese, Spanish, and Mandarin Chinese. Not just speaking, but reading and writing too.

Anyway, **she still has a lot of opinions, even though she cannot voice them.** We are committed to granting her dignity and respect at every turn, so an important portion of every day is not medical at all but rather spent in trying to determine how she would like to pass the hours, seeing that she is too weak just now to go out. This afternoon is no exception, as lots of snow is tumbling to earth outside her window. What does Emily want to do just now? There are options. She has a massive world map on the wall near her bed; does she want to keep on memorizing the countries and capital cities of each continent? She cannot speak, but she can retain it in her head, and when I quiz her in our unique way I can tell by her response whether she actually knows - or not - the correct answer to each question. Makes her feel so good, to have this ability recognized. Or, does she want to paint? We are trying to help her to hold a paint brush again. Or does she want me (Mom) to keep practicing a new musical instrument, something which can cause her to erupt into laughter? Maybe she wants to call her older brother, Chris, and his fiancée. Or maybe she just has to hear her younger sister's voice on the phone. Perhaps a story or some music is what she is longing for, or maybe she just wants to relax by watching a film, which removes from her any pressure to perform.

I have a hunch this afternoon that she wants the two of us to start making plans to surprise some special people on Valentine's Day!

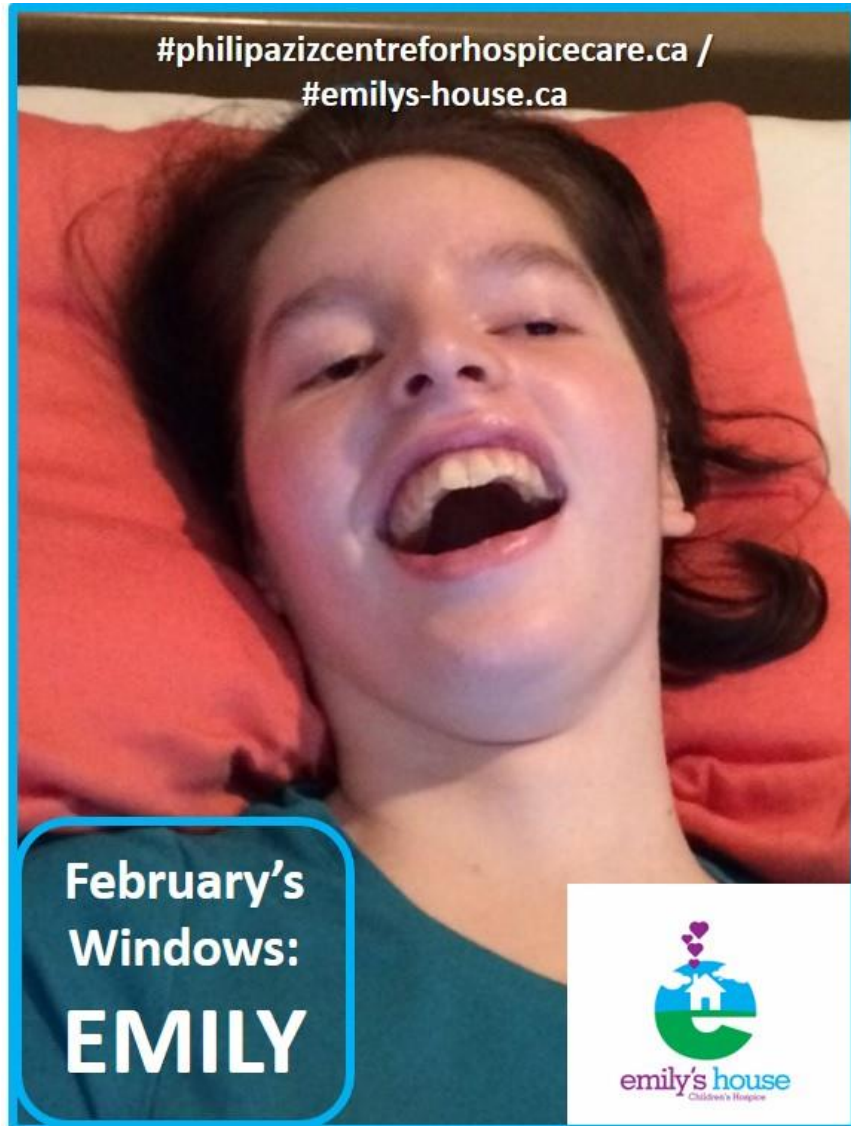
~ *Written by Emily's mom, Lindsey.*



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Day Eleven: Feb 11, 2017



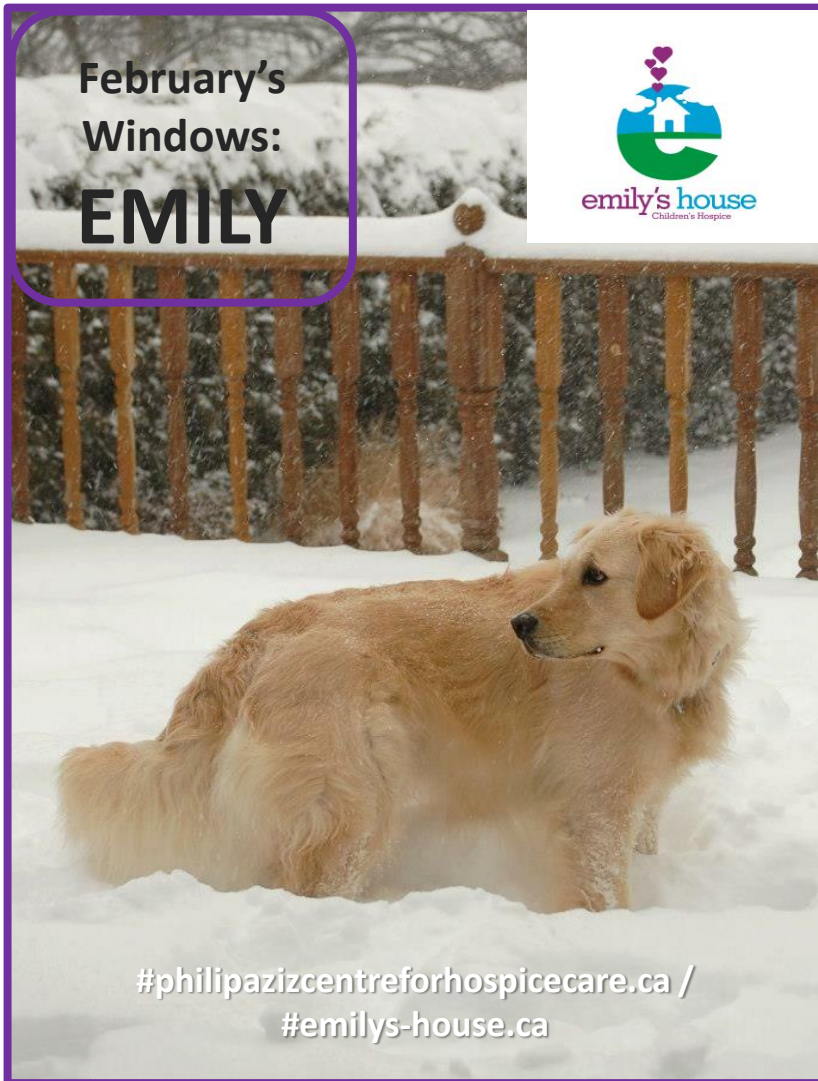
Laughter. Who could have ever imagined? There has been so much to learn at Emily's side, and one of the most unanticipated aspects of the whole palliative journey has been that she has never relinquished her desire to laugh.

When one considers all the types of pain that need to be addressed during the course of a day - some of which include nerve, muscle, heart, abdominal, kidney stone pain, emotional and mental grief, as well as the pain of some of her spiritual questions... - it confounds me that **there are pockets of time when humour does actually override all the above and she bursts into peals of laughter!**

It has been that kind of a Saturday for her today, and you can catch a glimpse of it in this photo which was just taken right now. Her youngest nurse was on duty today for a few hours, and they had such a HAPPY time together. The nursing shift eventually came to an end but the belly laughs did not, in fact it seems to me that they even lit up the entire sky for a while between Toronto and Paris where Emily's Daddy happens to be ever so briefly.

~ Written by Emily's mom, Lindsey.

Day Twelve: Feb 12, 2017



This afternoon, we are doing what Emily is doing.

Instead of looking into her window, we are taking a peek outside it. It has been snowing fast and furious since 7 o'clock this morning. A few minutes ago it took a slight break, but the minute I started to write, down it started coming again!

Meet Chuck. He is our tried and true Golden Retriever. The first day he came into our home, his breeders had driven him in from a farm near Hamilton. It was two days before Christmas, just over seven years ago. He was tiny and white, just six weeks old. Would he be a good fit? We brought him though to Emily and placed him on her hospital bed here in her room. He was curious. He crawled all around her, sniffing, sniffing, sniffing. He licked and licked her, but amazingly never interfered with any of her tubes. He actually started to cry and cry. **Emily was taking all of this in, in wonder!** Her left arm was stretched out wide. Chuckles crept up into the crook of that arm, buried his head into her side, and fell asleep.

Our hearts were won over instantly.

Here he is right now, just outside Emily's window in all the snow!

~ *Written by Emily's mom, Lindsey.*

Day Thirteen: Feb 13, 2017



Emily is not the only child in her family! Today we look through a window that sheds some light on her very important relationship with her siblings. She has a brother who is just a little bit older, and a sister who is four and a half years younger.

After amazing years together before Emily became so ill, and afterwards, once the disease set in and required so many changes, they have both grown up and moved on with their lives.

Her brother has happily settled 1,500 miles away, south of the border, and is now planning a beautiful wedding with the love of his life!

Emily's sister is still in university some 2,700 miles away on the west coast of Canada where she is studying to become an engineer!

Emily, with all her limitations, has demonstrated such a remarkably generous spirit to them whether in presence or in absence. **She, of course, misses them more than words can say! However, she takes great delight in hearing from them as they go about pursuing their dreams, and even more so when they make their way back home from time to time to see her. The bond is very, very strong!**

~ Written by Emily's mom, Lindsey.

Day Fourteen: Feb 14, 2017



Happy Valentine's Day! Or so the saying goes. It is a day that stirs a lot of emotion, because the theme of the day strikes such a chord deep inside us. Does my life matter? Am I loved? Will anyone show it to me today in a meaningful way? If I convey my special appreciation to someone else, will they be able to receive it in the spirit in which it is given? Emily herself is still quite the incurable romantic. She has never lost the thrill of the possibility of True Love.

I doubt if anyone gets more excitement out of the prospect of a Knight in Shining Armour riding in on a Noble Steed to whisk a Young Woman off her feet and carry her away to a life of Never Ending Love! And who would deprive her of that active imagination?

Of course, the truth today is that there is no Handsome Prince on the horizon. The way things are going, there may never be. But she is full of zest this morning to celebrate another very real kind of love in her life, and it is that of a most extraordinary Friendship.

Emily and Erica have been friends since they were two years old. They met in Arlington, Virginia where Erica lives. In and out of all the moving around Emily has done, in health and then in illness, Erica has been the most remarkable friend a girl could ever wish for... even coming to visit Emily here in Toronto twice a year at least!! The twists and turns of Emily's journey have sadly made it difficult to keep genuine peer relationships... but Erica's steadfast devotion to her is such an exception and has affected and inspired hundreds of people all around the world. She knows the real Emily. Emily knows and cherishes her. The two of them have become vibrant reminders to each other of The Love That Will Not Let Them Go. Something to wholeheartedly celebrate on a day like today!

~ Written by Emily's mom, Lindsey.

Day Fifteen: Feb 15, 2017



How Emily wishes that you could peer through her window today! Her room looks as if she held a little party, with beautiful red and purple flower arrangements, presents and meaningful little remembrances and messages for her.

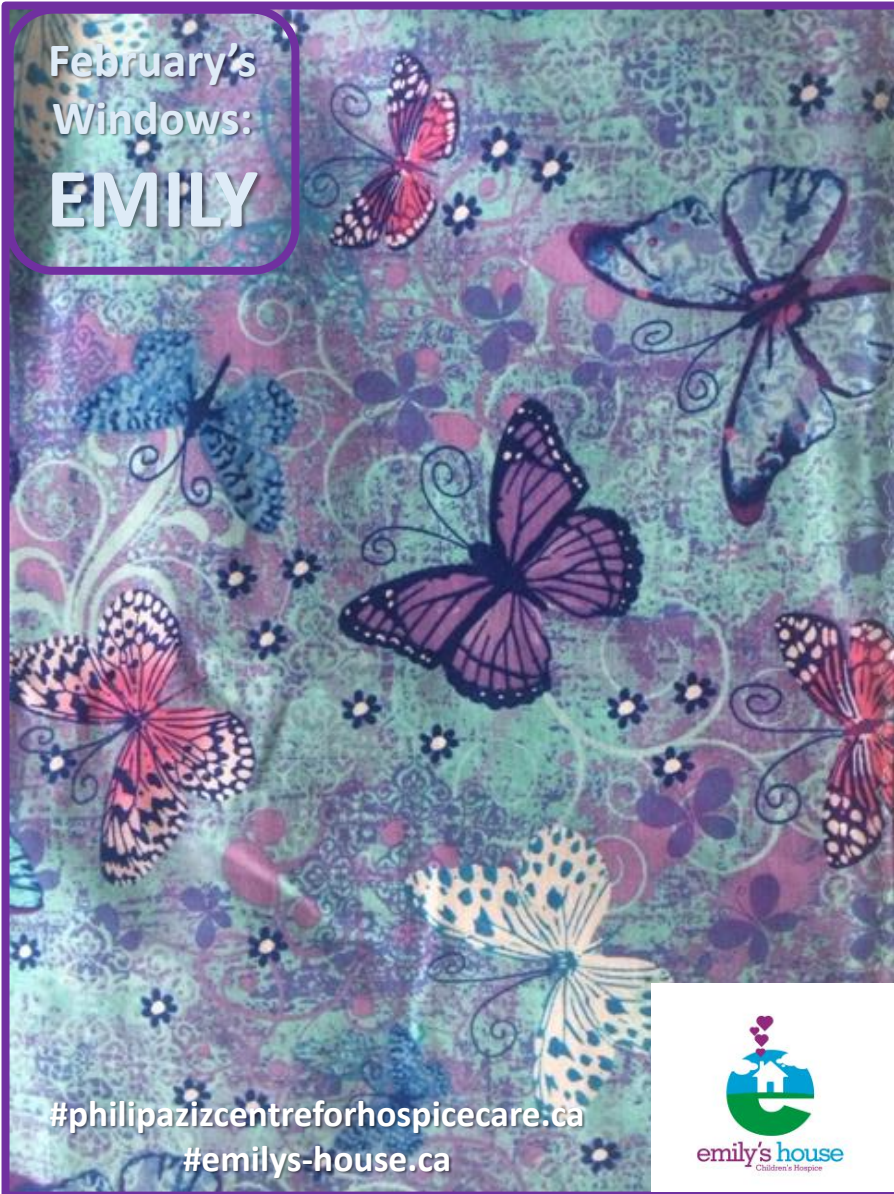
Much to her surprise, her devoted and caring friends from her very special Friendship Class at church spent some time last Sunday making Valentine's cards for her! **No opportunity to feel lonely at all.**

The two of us are here by ourselves and Emily is surrounded by all the gestures of love, quietly enjoying them after her long, heated spa-like bath in bed with her fantastic new relaxing foam bath scent called "eucalyptus tea." Normally scents or fragrances are difficult for Emily, but not this one! Its aroma is so natural and delicate and spirit-lifting that she is basking in it this morning with sleepy, smiley delight. What gentle ways to be welcomed to another day!

Her heart is filled with gratitude.


~ Written by Emily's mom, Lindsey.

Day Sixteen: Feb 16, 2017



February's
Windows:
EMILY

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emily's house
Children's Hospice

Pale blue winter skies. A few scuttling feather-soft clouds. White winter sunshine reflecting off the thick ice-crusting snow. Wind shaking up the barren tree branches.

It is that kind of a morning. And the view through the window looks slightly different because Emily has been entirely in the care of a steady rotation of three of her wonderful nurses, without any trace of mom around last night or so far this morning.

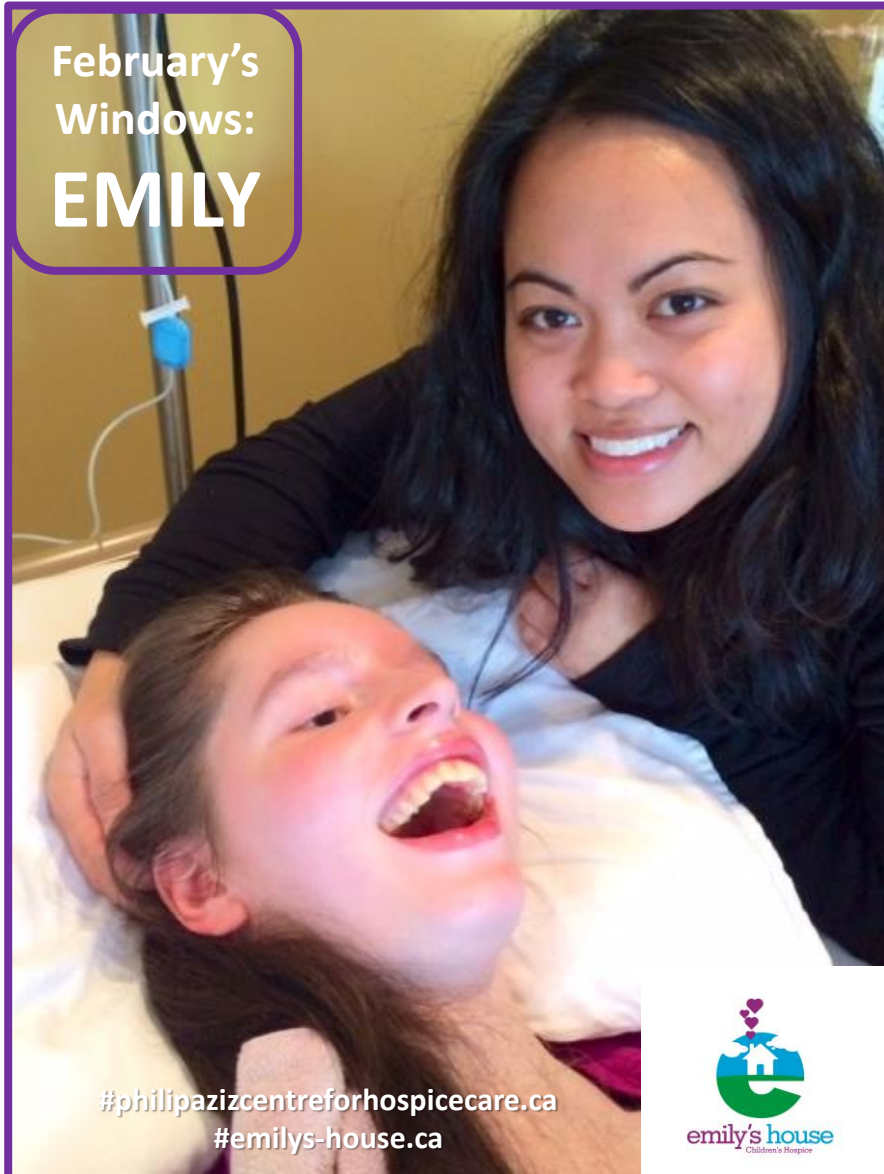
There are rhythms in life, and routines to be selected which best complement them, and one of the corresponding dilemmas left on the lap of many mothers of palliative children is that of deciding when it is best to be close at hand, and when a little bit of space might be in everyone's best interest instead.

Taking a break is not easy when a child's dance with life has become so fragile. Time may be of the essence, however, so may be the need for primary caregiver rest. We, at this end, have been trying to implement a better balance, especially as Emily's Dad is so often overseas.

Yesterday, with a bit of thoughtful tweaking, some back-to-back nursing shifts were finally put in place to allow Emily's mom to slip away for 24 hours overnight to a quiet, local convent guesthouse... for some very necessary, unbroken sleep. And according to all reports, Emily's spirits have been seamlessly peaceful and content so far through all of the hours apart! The nurse says she is happily watching a film this very moment, beaming from ear to ear!

~ Written by Emily's mom, Lindsey.

Day Seventeen: Feb 17, 2017



Meet Edelyn! Edelyn is Emily's newest nurse. They are just about the same age. The two of them have been having a great time this morning, as you can see by this photo which was just taken. Edelyn has had so much to learn to take care of Emily, but she has mastered it already over these past seven weeks of 2017. She has not only developed her skills while dealing with the two tubes, the pump, the TPN, the equipment, the rigorous schedule of medicines, keeping Emily clean and comfortable... she is also such a fun-loving, thoughtful, sensitive presence at Emily's bedside.

It matters how every client is treated, in every setting. It is so important for every client to be seen as a whole person, not to be blown off or diminished or dismissed. But it takes an openness to learn to see beyond the surface of things, to have courage to recognize the real beauty in a person which may not be instantly, immediately visible.

One of the greatest wonders of Emily's journey, against the backdrop of the serious ravages of her disease, is the way that some people, in their genuine interactions with her, succeed in 'calling out' her sometimes hidden essence just by the way they interact with her. Edelyn has this natural gift! It makes such a difference.

We are immensely grateful to the nursing agency for choosing her and adding her to Emily's already-amazing team of nurses who preceded her. Yet another gem of the palliative care system here in Ontario!

~ Written by Emily's mom, Lindsey.

Day Eighteen: Feb 18, 2017



The way of BEING at Emily's bedside is crucially important. It needs to be emphasized, because if caring for individuals who are ill solely focuses on what needs to be DONE for them, then only one part of the responsibility is being addressed. **Emily might struggle in ways which defy imagination, yet she is a 23-year-old young woman ... a whole person.** In spite of all the ravaging losses of physical abilities, you can be sure her hearing, and powers of observation, and remarkable intuition are all quite intact.

Conversations around her bed, and within earshot, affect her profoundly, whether in helpful or detrimental ways. Assumptions and attitudes and moods also have their impact. Even the spirit of a person who has entered her personal space makes its indelible imprint on her, before any word is spoken. You see, she knows that she lives very close to That Thin Line between life and death. Things are terribly fragile. By virtue of that fact, everyone who draws near to her makes their mark. Everyone. Each one ends up either being a comfort to her (somehow encouraging and celebrating the life she still has), or a disrupter of her peace (bringing conflict, or discussing her situation or others in dismissive, diminishing ways which leave her sad and anxious and with a sinking heart).

I am often asked for specific advice by new volunteers at PAC and Emily's House, during their amazing training program, and one of the very few things I urge them to always consider is to make sure they BRING THEIR OWN INNER PEACE as they come alongside each client.

Emily and I have had plenty of occasion to personally experience that they end up doing this extraordinarily effectively!

~ Written by Emily's mom, Lindsey.

Day Twenty: Feb 20, 2017



Yes! Out for a walk! A number of things had to be in place, in order for this to happen, beginning with a significant rise in winter temperatures. Quite a production, to get ready! But **Emily made it clear she was feeling strong enough to tackle this little endeavour.**

So, bundled up warmly and decked out in her purple with accents of red, she headed outdoors for the first time this year with nurse Edelyn, Mom and Chuck at her side.

The delight she conveys in the photo speaks for itself. Such a wonderful memory to make on this Family Day Weekend! We are especially thankful for this encouraging development, because it may just allow her to follow through with some very special plans this coming week... including the huge excitement of a stay at her very favourite Emily's House!!

~ Written by Emily's mom, Lindsey.

Day Twenty: Feb 20, 2017

February's
Windows:
EMILY



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This morning is quiet, cold, sunny, still. It is Family Day! The sunlight is shimmering through, and Emily is watching squirrel after squirrel in premature spring fever chasing each other on the fence, on the heavy overhead wires, up in the barren branches of very high trees nearby. She is having some struggles since our lovely outdoor stroll this weekend, so this morning has been spent trying to manage some pain and discomfort.

Her lovely Persian nurse, Sheila, has come to help for a few hours. All the rest of our family are so far away right now, enjoying the holiday weekend in their various corners of the globe.

Emily, of course, misses each one of them more than anyone will ever be able to express, but since they are very close to our hearts today in a concentrated way, she thought it would be a good idea to share this last photo taken, very spontaneously on January 3rd, of all of us together.

~ Written by Emily's mom, Lindsey.

Day Twenty One: Feb 21, 2017

February's
Windows:
EMILY



Things with a palliative patient can quickly take a nose-dive. This is the case right now with Emily.

She had so much fun being outside on Saturday in the sun and the snow! We knew that there would be a possible risk involved, getting her up and out, but decided to go for it anyway, just for the **sheer joy of helping her break free from the house. You saw the photo. Her face radiated with absolute delight.**

I still maintain we made the right decision. However, there has been a price to pay, including a persistent cough and congestion and diarrhea which developed immediately afterwards. Our friendly and familiar technician from Life Labs arrived early this morning, and we should get various test results in a day or two.

In the meantime, she had a very restless night last night, and we were obliged to cancel all plans for today in order to try and keep her as stable as possible, and in order not to spread germs to anyone else. This has honestly been quite disappointing. We had hoped to be able to relay some happy and unexpected news to you of another very special outing today. Instead we had to learn yet again to remain cool, calm, collect ... flexible! And grant her what was most needful on this rainy Tuesday: REST.

~ Written by Emily's mom, Lindsey.

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Day Twenty Two: Feb 22, 2017

February's
Windows:
EMILY



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house.ca

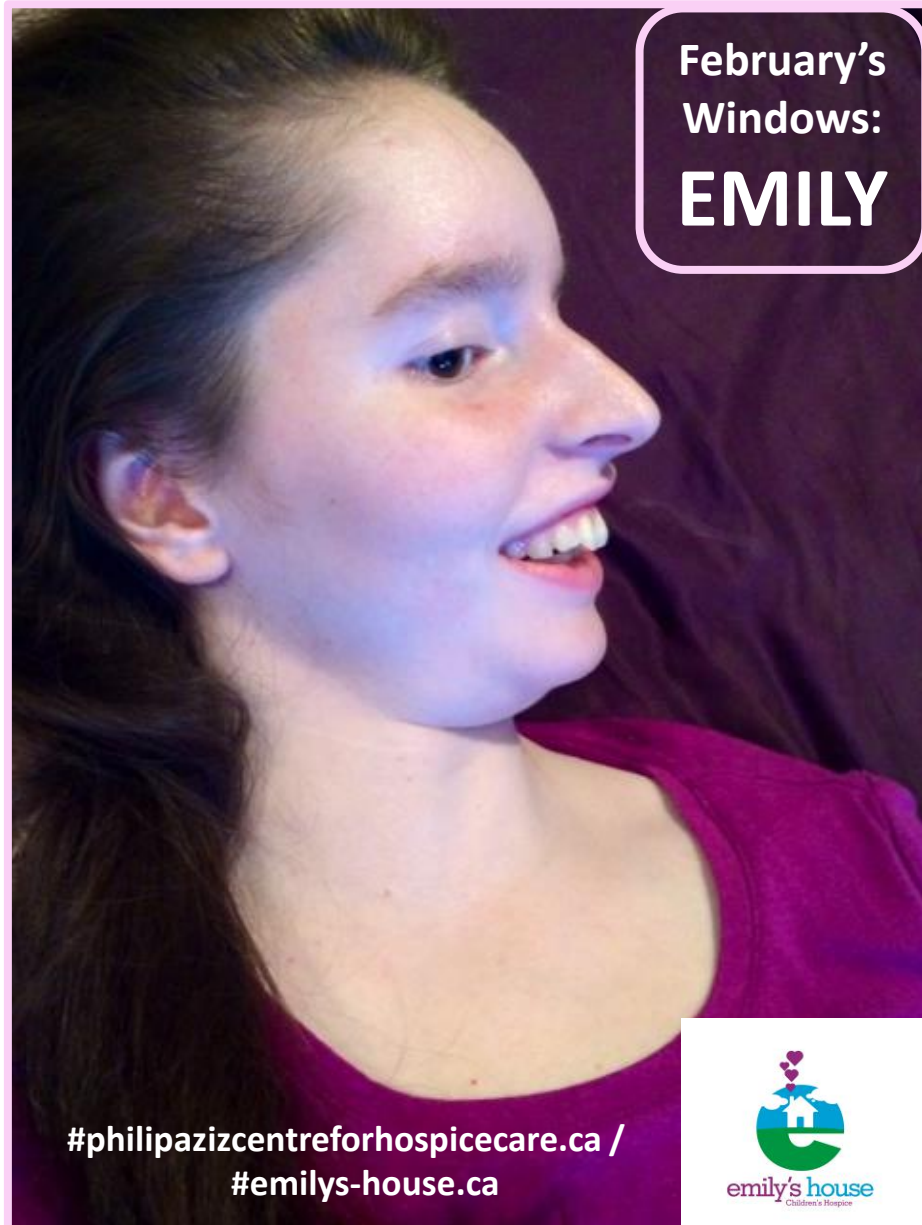
There was no chance today to write until now. Emily has toughed it out since about 2 a.m. this morning and a few minutes ago (4 p.m.) the first nurse of the day arrived for a five-hour shift. If you had stopped by her window today, you would have seen that Emily has had a challenge with alternate fevers and chills, let alone side effects from all the issues we mentioned yesterday. We are still waiting for test results. What I can tell you is that we somehow both emerged from all these hours together with our serenity and sanity intact. This is no small feat.

Burnout rate is exceedingly high among mothers of children with life-limiting diseases! Many of us live very close to that line. Take our situation, as a case in point. Emily is entirely dependent on help. She can no longer do one single thing for herself. She cannot lift her hand, or roll over, or stand up, or walk, or tell us what she is thinking, or explain why she is uncomfortable... or scratch her nose if it is itchy, or move away a strand of hair from her eye... or let us know if she is cold, or thirsty, or lonely, or afraid, or if her ears or nose are bothering her. Day and night, total vigilance is required in monitoring her.

Now here is the point. There are 168 hours in her week. As her mother, I am solely responsible for 108 of them. Entirely my own. Until a few weeks ago, it was many more hours than that, for almost sixteen years! Running a mini-hospital in our home. While I absolutely consider it a privilege to be able to keep doing this for Emily, and am grateful to the moon and back that she is so alive and I have been strong enough and healthy enough to keep up with the pace all these years, you can maybe start to get an inkling of why Emily's House ~ her ONLY other option for complete care and quality of life under these circumstances ~ is such a critical part of our lives!! The excellence with which it carries out its mission to countless families unfailingly astounds me. We are blessed beyond measure to have access to it!! Its presence and viability means the children and their primary caregivers are NOT ALONE.

~ Written by Emily's mom, Lindsey.

Day Twenty Three: Feb 23, 2017



Good news! The palliative doctor called last night with conclusive test results. Emily is on the upswing and she does not have C-Diff!

He gave me the go ahead; she might just be up for celebrating her birthday on Saturday. Wow! The news cheered her up, as you can see in this photo I just took. She is, after all, a bit of a “Celebrating kind of Gal.” She has been resting up today, under the wonderful care of three consecutive nurses, as well as a visit from Marlene this afternoon, who came again to read to her.

In this late afternoon, her smile is as **sunny and carefree** as the extraordinarily mild February 23rd outside! I love this girl!!

~ Written by Emily's mom, Lindsey.

Day Twenty Four: Feb 24, 2017

February's
Windows:
EMILY



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For those of you following FEBRUARY'S WINDOWS: EMILY, there were no updates from Lindsey today. I believe it is because she is preparing something special for tomorrow.... 😊

Day 25: Feb 25, 2017

February's
Windows:
EMILY



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#emilys-house.ca

Spring bouquets. Big, beautiful balloons. Myriads of lovely cards and some delightful presents. Quite a spread for lunch. Scrumptious birthday cake. Champagne! Yes, Saturday did finally arrive. Emily's 24th birthday! But what meant the most to Emily, in all her frailty, was the loving kindness expressed by so very many family members and friends. Her face and eyes shone when her Daddy phoned from his business trip to sing "Happy Birthday" to her in the morning. Lots and lots of people came to see her here at home in the afternoon. Others also called from long distances away, or wrote, conveying cheery messages of various sorts.

It was so moving for Emily, to see tangible proof once again that her life matters. The fact that she keeps on living against so many odds is profoundly meaningful to a great number of people, not just here in Canada but around the world.

Afterwards, in the evening when we were alone again and all the activity had spiralled down to a whisper, the snow was swirling around outside. Her body completely relaxed and she looked up at me, as if to say, "This really has been such a special day, Mom. In the end, it is so good that we had a party. I cannot receive others in the way I want to, and sometimes feel very vulnerable and helpless when they come near. But I realized today that lots of people do care! There is a reason for me to keep on living. I cannot believe how many came and told me that my life has purpose even if it is so difficult because it somehow gives them courage to face their own challenging circumstances, to keep going, and to trust that there is a bigger picture than all the pain."

YES, Emily, YES. Our world would not have been the same if you had not been born.

~ *Written by Emily's mom, Lindsey.*

Day 26: Feb 26, 2017

February's
Windows:
EMILY



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There was one extra special gift still waiting to be opened this morning. I brought the little "ADORE" gift bag to her bedside and began to tell her the background story of this present. "Emily, your Daddy is still away on his business trip and is so sad that he could not be here for you on your birthday. However, he asked Mommy to buy you something you would like, just from him. So I went out last Tuesday to hunt for it. I searched high and low and then found just what I was looking for. The sales lady was very thrilled about my choice and excited at the thought of how happy you would be when you saw it. I left with the package, stopped in a couple of other shops, then went to my hair appointment. Later when I got home, I called Daddy and he asked me to take a picture of your gift and email it to him, so that he could see it. Emily, I went to get it. But to my horror I could not find it anywhere! It was missing! Oh no! I called the hair salon, and they searched but could find nothing. **My heart sank because I knew I would be alone with you for the next more than 24 hours (no nursing) and would not be able to get back to the mall to hunt for it as quickly as I wanted.** I waited and waited and kept it a secret from you, but you can imagine how terrible I was feeling with every passing hour. The next evening, the nurse arrived and I jumped in the car. I was desperate to find out if I could locate the missing parcel. I went back to the store where I had bought it. No-one had handed it in. I went to the beauty salon. It still had not shown up there. I went to a department store where I had tried on clothes. Nothing. Had someone stolen it? I could not bear the thought! I then found myself passing a bookstore and suddenly remembered that I had also gone in there. I went straight up to the cashier and asked if they had a Lost and Found. The young, kind woman seemed amused and replied, 'Why do you ask?' I told her the story, revealing that there was a piece of jewelry in the bag. 'What kind of jewelry?' she asked. 'A ring.' I described it. She suddenly smiled and clapped her hands. 'I was praying all day long that whoever dropped this package here would think to come back and check with us!' She reached back onto the shelf behind her... and there it was! Your Daddy's beautiful present to you was completely intact! Wow!!!"

~ Written by Emily's mom, Lindsey.

Day Twenty Seven: Feb 27, 2017

February's Windows: **EMILY**



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Come and have a look through Emily's window this morning. It is hard to tell which is shining the most, the flawless blue sky and sunshine we have enjoyed so far today, or the bright array of all these recent greeting cards right next to her bed! **Emily is lighter and brighter in spirit, eager to move forward.** All the birthday evidences of love and care have filled her cup to overflowing. It is actually a lot for her to take in, the wonderful people who came face-to-face and engaged with her, along with the seemingly never-ending trail of simple acts of kindness. Her THANK YOU seems to be oozing from every pore of her body!

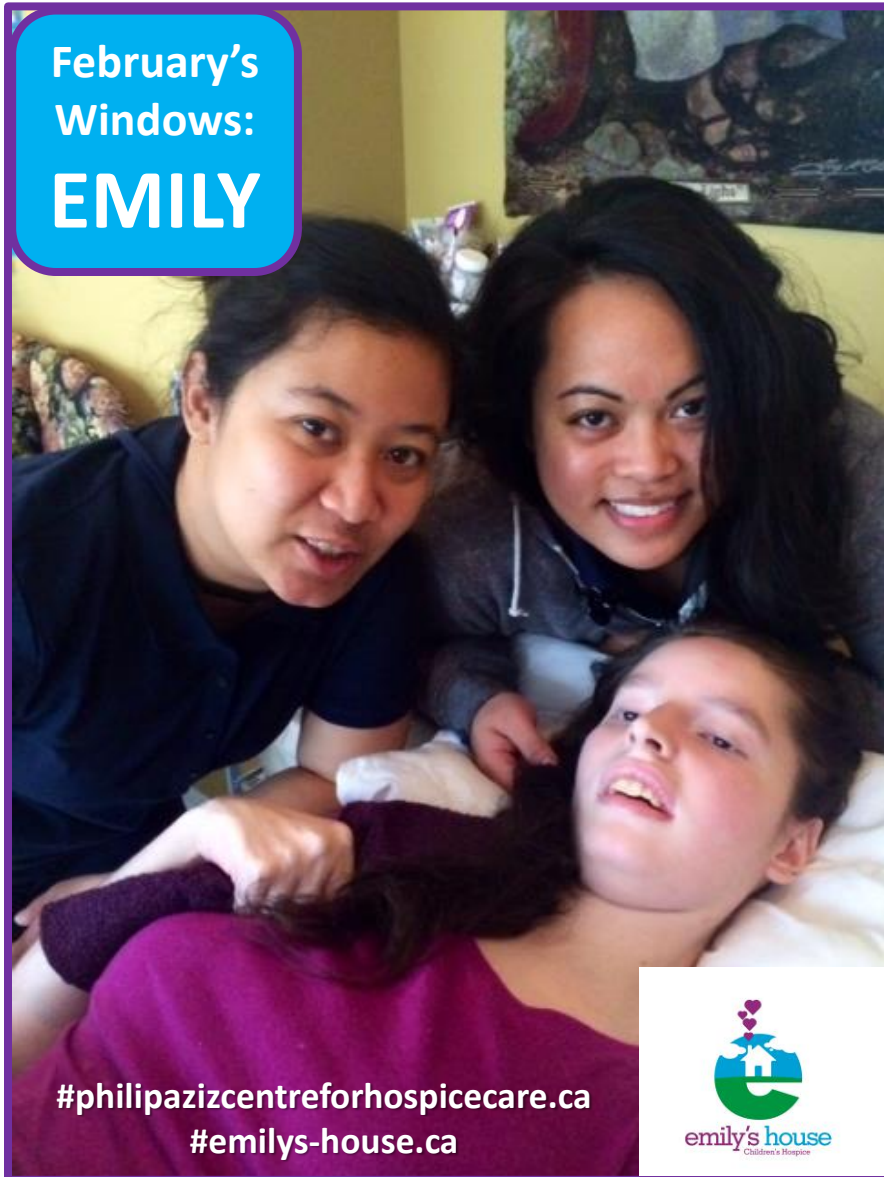
Emily has a formidable desire not just to be on the receiving end but also to continue the flow of encouragement by finding meaningful ways to extend generosity to others, especially others who for one reason or another are living right now with a broken heart and loneliness.

Some very kind souls know this and brought along with them a hefty provision to empower her to fill this dream of wanting to do something completely unexpected for others.

To spread the joy. This is how she is starting off this next year of her life: making a little personal plan of disbursement and putting it into action. She is excited!

~ Written by Emily's mom, Lindsey.

Day Twenty Eight: Feb 28, 2017



Emily suddenly became very ill overnight. The nursing agency actually called in TWO nurses to share the shift today. It has taken the three of us to help Emily to deal with the effects of seizure after seizure and the residual assortment of distressing complications. So sorry to relay this news, but when we took on this little writing project, we were committed to sharing the truth of our days, no matter what transpired. It was a bit of a risk from the start! This is also the last instalment of this particular mini-series, "February Windows." By no means does it fit the 'high note' on which we had hoped we might end! Plans were all in place to have Emily staying at Emily's House today so that you could finally see her there! How do we make our peace with the letdown? I

It is disappointing. But maybe it underscores a very important point. **What we are left with, after all, is an all-too-familiar heart-sinking scenario in the palliative world. In the snap of the fingers, without warning, everything can change. Just like that. Nothing can be taken for granted.**

Today also happens to be Rare Disease Awareness Day, which most certainly includes Emily's Metachromatic Leukodystrophy (MLD), and the outcome we have been experiencing at our end through the course of the past twelve hours is actually highly indicative of rare diseases as well. Who knows what will transpire in the coming days?

All I can say to you is, **"Thank you for allowing yourself to catch a month of daily glimpses into the not-so-normal life of one of too many children and adults living with a life-limiting disease. May you never forget the small indication it gives of this particular realm of our society, and its families, which the Philip Aziz Centre and Emily's House serves and cares for so skillfully, insightfully, wholeheartedly and compassionately!"**

Meanwhile we shall not give up on Emily's dream, to get back to her beloved Emily's House, for it is the ONLY option other than home where she can go and receive all the care she requires for body, mind, heart and soul. This state-of-the-art facility and all the top-notch people who work there deserve our unswerving support!!

~ Written by Emily's mom, Lindsey.



Thank you, for visiting

Emily's House and the **Philip Aziz Centre for Hospice Care** provide respite, practical, emotional, spiritual and bereavement support to people living with life-limiting illnesses in the comfort of their own home, or in Toronto's first paediatric residential hospice. Our programs support children, adults, caregivers, siblings and survivors at no cost to them. Our residential and community hospice programs make more celebratory, therapeutic and memorable moments available, and provide reprieve and supports for caregivers.

