

Penpals:

Letters & healings from the edge of severe chronic illness

I've got a city where all of my friends can go...

-from the song "Danielson" by Tigers Jaw

June 5, 2018

Dear Emily,

I hope this finds you doing okay, or at least not as bad as when we saw each other last. It's hard to believe it's been just over two months since the hospital. That time feels like a nightmare that continues to haunt Lauren and me. Your support helped us through that time more than you know.

I remember waiting for Lauren in her small hospital room and seeing a note you had slipped under her door. It was folded and her name was written on the outermost fold next to a hand-drawn picture of a cat. I pointed it out to Lauren as she edged along carefully with her walker returning from the communal bathroom across the hall.

"I get one note a day from her," Lauren wrote on her small writing pad and showed it to me. "Slips them under my door," she wrote next and then smiled at me.

I am not sure if you knew at first why Lauren was unable to talk. It was due to her severe chronic illness, Myalgic Encephalomyelitis. The illness is not well understood in the medical community, and even to this day, patients are being told the debilitating symptoms are "in their head" by too many doctors.

That was how Lauren ended up on the eating disorder unit. Under a court order saying she no longer had the mental capacity to make her own medical decisions for herself. There was no medical explanation the doctors could understand about why eating was causing a sensation of fire in her brain.

Eating was becoming too painful to tolerate for her. It was more comfortable to not eat for her body. So her 5'7' frame had been reduced to 103 pounds just before being admitted to the hospital. A psychiatrist had legally ordered her to go

to the eating disorder unit since she was “failing to thrive.” She was given no choice in the matter.

But you chose her as a friend, Emily. You first saw Lauren struggling to sit up in a chair during communal meals and struggling to eat. With Myalgic Encephalomyelitis, known as ME/CFS for short, the body experiences energy poverty, not producing enough energy for even the simplest of daily activities. You also noticed she was unable to speak at meals and had a written pad next to her she used to communicate with staff. Your heart went out to her as you felt silenced in your own way. Recently, the psychiatrist had asked your family not to take your phone calls if you continued to cry and complain about the treatment protocol.

Feeling alone, you reached out to my wife who you also sensed felt so alone. I am still mailing this letter to your apartment in Youngstown, Ohio even though Lauren and I both know why it will not reach you. It was about a month ago that Lauren saw on your Facebook page that another family member posted about your death. The family member just wrote that “you had lost your battle with anorexia.”

We do not remember you as anorexic. You were our friend. Your bright smile shining up from your wheelchair. The lilt of your soft-spoken British accent since you had moved to Ohio with your family at the age of twelve. Light brown hair with reddish hi-lights resting on your fragile shoulders. You were the only one Lauren and I hugged as Lauren left the eating disorder unit after being there for nine weeks.

Lauren asked me to save all of your notes. The plan was for us to continue to correspond with you by mail and by text. This letter is a way for us to say a ‘goodbye’ we never got a chance to say. Lauren had tried to text you but never heard back after the hospital. Things must have gotten dark quickly for you our friend.

Love Always,
Charley

June 5, 2018

Dear Charley,

Your letter got sent by express mail straight to my heart. There is no time delay in delivery where I am now.

I so very much wish I could deliver Lauren another note right now. I just want to tell her that I am okay , and that a big part of why I am okay is because of the love I experienced with friends like her when I was alive.

Please tell her that I will always remember her smile. Please tell her I am looking out for her and always will. Please let her know she can reach out to me whenever, with words or no words, written or not written, spoken or not spoken.

I just hope she knows I am closer than she could ever imagine. I want to keep being there close to her heart, and I hope she can somehow feel my presence there as much as my absence is also a reality.

Please also let her know there are other loved ones where I am, and all of them are looking out for her. Remaining close to her heart and wishing her well. I just want her to know she is not alone in her suffering and I love her and miss her.

Take good care Charley and I am smiling on both you and Lauren today and every day. You would not believe how many notes I am writing Lauren each day now. I hope that she can feel them as I mail them straight to her heart.

Love Always,
Em

June 10th, 2018
Baltimore, MD, Ram's Head Live!

Dear Tigers Jaw,

I can not mail this letter because I do not have an address for the band. It's not something I would want to e-mail either. I am old-fashioned I guess, preferring to send this as a physical copy. Maybe this is more of a journal entry then. I just know it's important that I write about what happened tonight. Even if I am the only one who reads it.

I just learned about your band earlier this year around early March. My wife was in the hospital then , and I watched your *NPR tiny desk concert* on YouTube at home one evening while I was alone. There were three songs, stripped down versions with Ben on acoustic guitar and Brianna on the keys. I kept hearing the chorus from your song 'window' 'these days it's hard not to feel alone' in my head for days after watching.

In an online interview, Ben was asked if most fans thought their music was 'melancholic'. He replied, " Sure, we have some songs with a sad tone , but I think the overarching sentiment I hear from fans, and that I really appreciate hearing, is that our music helped them through a difficult time."

Last night I saw the band for the first time in Baltimore where I grew up. I went to the concert alone. I got there just as doors opened and before the opening band started. So I perused the band's merch table. I felt so excited to see the band. Also, it had been an incredibly tough start of the year with Lauren just returning from the hospital at the start of May after a two month stay .

Both this sadness and excitement were swirling inside of me and I felt connected , connected to feeling alive in both ways, incredibly sad and happy. The depth of the sadness somehow related to the depth of the joy.

I felt like speaking to the person working the merch table for Tigers Jaw. "The band's music means a lot to me," I offered. "This is my first time seeing them live."

"That's great!" The person smiled back. "Is there anything I could help you find?" The person could tell my eyes were perusing the merch.

"Love this album," I said pointing to their album '*spin*'. This was their latest record at the time and the three songs I had first heard from their *tiny desk* concert were off of it.

"How long have you been a fan of the band?", she asked.

"Just this year actually."

"Oh cool, so was '*spin*' your entry point?"

"Yes, for sure. I don't know their other albums too well. Any suggestions?"

"I personally like '*two worlds*' a lot. It's one of their earlier records."

"Cool, I'll take the CD of that please. Oh, and my name is Charley by the way."

"I'm Lexi, nice chatting with you Charley! Do you want me to keep the CD for you here at the merch table so you can pick it up after the show?"

"That would be great, if you don't mind? "

"No problem. Hope you enjoy the show!"

I noticed Lexi writing my name on a sticky note with a sharpie to put on the CD.

"It's actually spelled with an '-ey' on the end," I said just before Lexi got to the 'I' in my name.

“Thanks for the heads up! I was about to write ‘ie’ .”

I am usually quite shy speaking with new people. I don't know what compelled me to introduce myself and even specify how to spell my name! But it felt friendly and natural. The band's music had been this comforting friend to me while Lauren was in the hospital. That connection I had forged listening to their music at home by myself was ready to become alive with other humans at a show. I chatted a bit longer with Lexi about the band's music and how excited I was for the show. “Nice talking with you Charley and don't forget I've got your CD for you later!”, she smiled.

I even crowd-surfed at the show. I just felt so connected to the music as the band started their song '*chemicals*'. I asked two strangers next to me if they could prop me up to surf from the middle of the crowd. '*We are made from chemicals...but what holds us together...is much more than that,*' the band sang as the hands of the audience passed me along on my back towards the stage.

I lifted my arms up to emphasize the lyric and to celebrate the moment. I felt my worries melt away and I felt in unison with the song and the crowd as they held me up and moved me forward. I felt so much less alone.

Lauren was so happy I was able to go to the show and feel so connected. “But please,” she added, “No more crowd-surfing. I worry if you'll hurt yourself.” “I'm officially retired, I promise. I'm in my late thirties ,” I smiled back. It was a great last run.

Love always,
Charley

September 15th, 2018
Pittsburgh, PA, Slater Funeral Home

Dear Chris,

Yesterday was your funeral and your daughter Lauren was too ill to be able to leave the house to attend.

It feels like grief on top of grief that has been piling up this year..... between Lauren's hospital stay and your death.....and Lauren not being able to mourn with family at your funeral.

You left us suddenly and unexpectedly. It's so hard that we didn't have a chance to be with you or say goodbye just before you passed away.

I feel so very grateful that I had a chance to say our own version of goodbye. The last time Lauren and I saw you was one day before you passed.

You had come to visit Lauren and me in our small, one-bedroom apartment. From the kitchen, I could hear you tell Lauren in the bedroom that you needed to get going to visit Joe and Jaimee. They were in the hospital after Jaimee delivered their third daughter, and your fifth grandchild.

I let you out the front door of the apartment building, and before you left, you looked up to me from the bottom of the steps and smiled, "I'll be back soon to visit and I'll bring some food."

"Sounds good, Chris, thanks," I smiled back.

This was such a different version of goodbye than the one day about a year ago. Lauren had recently become bedbound by the illness, except she was able to walk to the bathroom.

Her hair was in tangles because the illness caused her to feel worse after the slightest exertions, like combing one's hair. She could have debilitating fatigue, insomnia, flu-like symptoms and increased pain in her body for weeks and even months after the slightest exertions or movements.

No one really got the illness at the time, even several doctors and specialists we had seen. Most doctors do not learn about the illness at medical school. Also, it is very common for people with ME/CFS to face disbelief about their illness and symptoms from family and friends as well.

That day about a year ago, I think the pain of seeing your daughter confined to a bed with matted hair and a mysterious illness was too overwhelming. You started yelling at her that "she needs to get up and she can't live like this."

As you passed by me in the kitchen you said with a cold tone of sarcasm, "When is the babysitter coming next?", referring to our paid caregiver who helped cook meals and kept Lauren company when I was at work.

My anger flashed back, "Get the fuck out!"

You slammed the entrance door to our apartment building cursing back at me.

I won't forget the pain and anger in the apartment that day. Also, I won't forget I had yelled at Lauren a few times before over the course of that year, verbally exploding when I could not process or accept the illness and my own pain around it.

I have been learning how to forgive you and to forgive myself so that I don't relate to my pain by blaming Lauren. Or even blaming myself, which I often do. Or blaming you.

Those were two very different goodbyes we had Chris, and I am so grateful that we were able to share a smile on the last day we saw one another. I am so grateful there was no blame, yelling, and anger in our apartment that day.

Love always,
Charley

October 14, 2018
Cleveland, Ohio, The Grog Shop

Dear Lauren,

I had such an amazing night! I just want to write to you before I fall asleep in this hotel to tell you what happened.

I know it has been harder for you to read lately due to the illness so I will try to keep this short.

And I will space out the lines.

Just before the concert, I got an idea to buy a postcard to write a note to the band and to deliver it to their merch table before their set.

Luckily, there was a bookstore right by the venue which is a cool, intimate club called 'The Grog Shop'.

I wrote:

Dear Tigers Jaw,

I just want to say your music has helped me through a very difficult time.

*Thanks so much,
Charley*

I kind of felt like a big dork for writing the postcard. But this residue of shame was much overshadowed by the excitement to write a message I truly meant and share it with the band.

It put me more at ease to find that Lexi was working the merch table again and she remembered me from the Baltimore gig.

As I purchased a poster of a giant anatomical heart, which was a cover for the band's self-titled album, I noticed singer and guitarist Ben chatting with a friend from an opening band who was also selling their merch.

I asked Lexi if Ben could autograph the poster. While Ben wrote his name in sharpie in the middle of the heart, I thought that this may also be my chance to give the postcard to Ben and tell him my message directly.

“Here you go !” Lexi smiled handing me the poster.

“Thank you ...and uh.... I actually have a postcard for the band, could I give it to Ben?”

“Aww that's so nice! Just a second,” Lexi tapped Ben gently on the shoulder and relayed my message.

“Hey, how are you ?,” he smiled as we met at the tigers jaw merch table.

“Hey Ben, I'm Charley. I ...umm...got a postcard for the band...and ...um.. I just wanted to say...”

“Here let me come around, Charley.” Ben came out from behind the merch table to speak to me.

I was still nervous but him moving from behind the table felt like such a kind thing to do.

“Um...the postcard just says that your music means a lot to me...and got me through a really hard time...so thank you.”

I handed the postcard to Ben.

“Thanks so much, Charley. It means a lot to hear that. It's amazing how music can help us through things.....like for me, depression....”

I nodded and my heart just felt full of excitement for connecting with Ben . It felt kind of surreal.

Ben continued, “Music has literally introduced me to some of my closest friends. And I even met my girlfriend through the music community.”

“That’s great,” I smiled and then I paused for a beat. “.....My wife Lauren.....she has been in the hospital this year...and um...she’s been very ill. She’s out of the hospital now and doing a bit better but it’s been a tough year.”

‘Tough year’ was all I could think to say to encapsulate the grief that there are really no words for.

Like what’s the word for a daughter too ill to be able to attend her mom’s funeral?

What’s the word when the doctors don’t understand the illness you have and call it psychiatric and force you to take an anti-psychotic medication against your will?

Ben paused for a second to fully absorb what I was sharing. I could tell his heart was listening.

“Do you mind if I give you a hug?”

I opened my arms and Ben added, “Bring it in, brother.”

“ Thanks...and um... I should let you get going. You probably want to relax before your set...”

“ I’m in no rush. We can keep talking and hang for a bit.”

“Oh cool, but I think I’ll let you get back. I really appreciate your time and just coming out from behind the table and everything.”

“My pleasure, Charley. Oh, and I’m wondering..... is there a song of ours that stood out to you?”

“The song ‘*escape plan*’. It makes me think of my wife..... and also the music video of course with its themes of illness and loss of a partner.”

Ben nodded with compassion in his eyes, and we gave each other another hug.

Later in their set, Ben surprised me by saying, “This next song goes out to Charley,” and played ‘*escape plan*’.

I am crying tears of healing in my hotel room thinking back on the song dedication. There’s nothing like when you feel so seen by a song because it makes you think of your favorite person and then your favorite band sends it out to you.

The lyric for the chorus, repeated twice at first and then four times at the end of the song, especially makes me think of you Lauren, ' *I put it all on the line, would you be my escape plan ?* '

Love always,
Charley

December 1st, 2019
Pittsburgh, PA , Roxian Theatre

Dear Tigers Jaw,

This is a journal entry only I will see, but I am going to pretend it's a letter I could mail to the band.

THANK YOU for existing as a band!

I did not expect such joy and a sense of connection through music.

When Lauren was in the hospital, I was so overwhelmed and scared. I even started to wonder if there was a part of this illness that was in her head. At least that way , we would not always be left without clear answers or treatments. I felt like the forced psychiatric treatment was at least better than just suffering at home with no clear path forward.

In this time of confusion and fear, I discovered the band's music and this helped me not just cope, but start a healing process.

Tunes like '*escape plan*' and '*window*' spoke to my loneliness but in a way that also helped me feel connected to something larger, to something beautiful and melodic.

I could hum the band's melodies and they soothed my heartache. Music is medicine, as the saying goes.

I've seen the band twice this year, the last show was just last night at the Roxian. Lexi was there again working the merch table. She remembered me from the previous show this Spring and the two shows last year.

“Hi Charley!” Lexi smiled. She then took a pause and asked, “.....How is your wife?”

It meant so much she asked how Lauren was doing. She explained that Ben had shared to Lexi and the band about how my wife is ill, and he had shared the postcard I had handed him.

Last night, I brought another postcard. I entrusted it to Lexi since this was a larger venue than the Grog Shop, and the band was probably at a remote backstage area.

In the postcard, I asked Ben if he could dedicate ‘*escape plan*’ to me again. And I reiterated how much the band’s music meant to me.

“This next one goes out to our *friend* Charley,” Ben said a few songs in to their set last night before strumming the opening chords of ‘*escape plan*’.

Lexi had successfully delivered the message, I was so grateful.

And yet, I still insecurely wondered, “Was bringing postcards to the merch table, and requesting a song dedication enough to be called a ‘*friend*’ ? ” And yet I loved being referred to that way.

All I knew was that I was reaching out, in such need of that song to be dedicated to me again. I was in need of being asked how my wife was doing. I was in need of that kind of healing and feeling seen.

Love always,
Charley

February 15th, 2024
Pittsburgh, PA , City Winery

Dear Lauren,

Anywhere I go without you, it feels like half of my heart is missing.

It feels like I am in two places at once. Half of my heart is at home with you and half is wherever I am.

Just two weeks ago, you needed to move to our finished attic to limit your exposure to noise and sound and light.

The illness makes you hypersensitive to all of these things . You needed a nook in the furthest corner of the house to limit your exposure.

Just two weeks ago, you also became hypersensitive to someone sharing the same room with you. There was no energy in your body for even the most minimal of social interaction or tolerating the slightest of gestures or bodily movements from me.

You sent me a social media post written by another person with severe ME/CFS explaining why they could not tolerate having visitors. Even after a friendly and loving visit, there was energy spent that the body could not afford and so symptoms like debilitating fatigue, widespread body pain , insomnia and migraines would increase.

Imagine there is a person you love but they stand face to face with you for four hours , never looking away, never allowing you space and room to easily draw a breath. The comfort of gazing in to their eyes for the first several minutes would naturally turn to bodily pain after several unrelenting hours. With an illness like ME, this pain can develop right away and would then quickly devolve into a fire of worsening symptoms. With ME, even a loving visit means pain.

The past two weeks I have only been able to visit you three times each day for about ten seconds each visit to bring you food and to touch our fingertips together. Touch is another thing that has been so hard for you to tolerate. We have not been able to hug each other for months.

We share the same house, and yet we are missing each other so very much. Since you have become severely ill in 2016, you have not been able to tolerate sharing the same bed with me because of the stimulation of having me so close.

I miss holding you and hearing your voice. The illness has even made talking a form of exertion you can not tolerate without your condition worsening.

It's like the illness is holding so many aspects of your life hostage.

Tonight, at the acoustic Tigers Jaw concert, I called out from the crowd, "Can you dedicate a song to my wife?"

"Sure," Brianna, vocalist and keyboardist, replied from the stage.

"Her name is Lauren."

"Hi, Lauren," Brianna said and some people in the crowd laughed .

"And my name is Charley , and...I love you guys," I said a bit sheepishly but loud enough for them to hear.

“WaitCharley? Charley Pittsburgh !?”

I nodded my head and put my thumbs up in the air. We were seated about twenty feet from the stage so Brianna could see me.

During quarantine in 2020, each band member of Tigers Jaw did a solo online performance from their separate homes. ‘Charley Pittsburgh’ was the username I had chosen for the online platform that hosted these shows, and it appeared in the chats where you could ask a band member questions after a performance or chat with fellow fans during the performance.

“We remember you!” Brianna exclaimed. “I’m so surprised you are here! Well I mean, I guess I’m not that surprised since we’re in Pittsburgh.” The audience laughed a bit again.

“Charley Pittsburgh...Charley...attended every single one of our online shows in 2020. Of course we remember you! ”

“And we remember Lauren too,” Ben added from his mic.

“Yes and Lauren!” Brianna confirmed.

Without specifying the song, Ben knew what to play. He strummed the opening chords to ‘*escape plan*’, the same song he had dedicated to me six years ago after meeting me for the first time before the set at The Grog Shop in Cleveland. The same song that I had told him made me think of you.

At the end of the song, I held up my hands to make the shape of a heart, and I noticed our friend Jennie crying across the table from me.

When the applause died down, Brianna merrily said , “Charley Pittsburgh! We’ll have to meet after the show at the merch table.”

After another slight silence, a voice from an opposite end of the crowd, from a stranger I did not know, joyfully exclaimed, “Chaar—laay!” The crowd clapped and cheered.

I was leaving the restroom after the show and a stranger from the audience greeted me, “ Hey, Charley!” I gave him a high-five and smiled to him from underneath the KN95 mask I was wearing.

Maybe that was the person who yelled out my name, I thought. My heart just opened up, and I felt held by a community of fans like when I crowd-surfed at the Baltimore show.

Our friends Charlie and Jennie were waiting for me by Tigers Jaw's merch table in the lobby of the building.

"What an awesome night. Thanks so much for asking us to join you!" Charlie smiled.

"Yes absolutely, such a special night!," said Jennie.

"Thanks for coming with me. Truly means a lot. Well...are you both ready to head out?" I asked.

"You don't want to stay to see if Brianna will show up?" Charlie asked.

"Oh, I don't know if she plans to be at the merch table," I said.

"She sounded sincere," Jennie smiled.

We stayed and a few minutes later Brianna appeared and two fans approached her and started to chat.

After a few minutes, I approached Brianna who was still talking to the fans and said, "Excuse me Brianna, I'm Charley."

"Charley! So good to meet you!"

We hugged and I shared the postcard I had written that night for the band. Brianna took a minute to read it.

"I'm so glad the music has been a source of joy and connection for you. We couldn't do this without you and all our fans."

"Is this your wife?" Brianna said gesturing toward Jennie.

"That's my friend Jennie. And my friend Charlie, her husband. My wife Lauren is at home. She is too ill to leave our house."

"Nice to meet you both. And I'm so sorry to hear Lauren is unable to come out."

"Thank you. Yeah, she has been really ill for several years now."

"Oh, I'm so sorry..... We have had a close friend who has been very ill..... He actually may die soon."

I nodded empathetically. I didn't know exactly what to say but I appreciated her sharing.

Brianna and I chatted some more and Jennie took a picture of me with Brianna holding up the postcard I had written for the band.

“I hope to meet Lauren one day,” Brianna said just before we left. “And just so you know Charley, we consider you a *friend* of the band , not just a fan.” I had signed the postcard: “Your fan, Charley”.

It turns out Tigers Jaw had to cancel their next show because they posted on their instagram that a close friend had passed away.

I hope whatever healing was generated at the show found it's way back to the bed you spend all your time in, my love. I hope the healing will follow Brianna and the band as they navigate the grief for their friend.

That song was for you my love, and I already have a desire to ask for another song dedication at the next Tigers Jaw show.

Love always,
Charley

