



Navigating the System After Discharge: A Family's Perspective

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We are the parents of Liv, who was born at 25+1 weeks, on March 24 2014, after Shannon was medivaced by plane to Edmonton from our home in Yellowknife, Northwest Territories, almost 1500 km away. Our journey in the Royal Alex NICU lasted 143 days, during which time we gained a huge appreciation for the family-centred and NIDCAP models of care. When Liv was discharged in mid-August, we expected that the hard days were behind us.

Soon after discharge, Liv was diagnosed with profound hearing loss, which meant she would be followed both by practitioners at home in Yellowknife and by specialists in Edmonton.

When we returned to Yellowknife, six months to the day after being medivaced to Edmonton, we anticipated life becoming “normal” and Dan returning to work full-time. However, Shannon was quickly overwhelmed trying to manage scheduling, information flow and follow up for all of Liv’s appointments both in Yellowknife and in Edmonton, navigating the Northwest Territories’ medical travel system, and caring for Liv. Dan felt guilty because of pressure to return to work and the need to spend more time at home to play larger role in Liv’s daily care.

There were benefits and challenges of being immersed in two streams of care for audiology and speech. The specialists in Edmonton provided us with a perspective that was based on years of experience with kids similar to Liv. We also had frequent access to the Yellowknife practitioners who developed lovely relationships with Liv and us, and were always available to answer our many questions. However, we found it challenging when Edmonton and Yellowknife practitioners provided conflicting advice about treatment options. We did not feel like there was an adequate communications or support structure in place to manage information flow and relationships between the two streams of care. Neither did we feel qualified to be the ones to determine which information or option was best.

However, within a couple of months, Liv required fewer appointments and we settled into a routine, including Dan reducing his work hours to 80% so he could be more involved at home. Although we continued to have the odd challenge with medical travel and being in two streams of care, we also grew very fond of all of Liv’s practitioners, are grateful to have benefited from their expertise and support, and for the partnership approach we did end up forging with them.

We recently moved from Yellowknife to Victoria. We were sad to be discharged from the care of all the practitioners who’d helped Liv, and also us. With their support, we transitioned from being parents of a chronically ill kid with a scary hearing diagnosis to being empowered and confident parents of a funny, vibrant little girl who just happens to be small for her age and wears hearing aids.