

From caregiver to dependant

Arlene Underdown and her husband Jerry are the parents of nine children (with six being adopted) and grandparents of fourteen grandchildren. As well, they were foster parents for numerous children for over thirty-five years with their speciality being babies.

The process of diagnosis of Amyotrophic Lateral Sclerosis (ALS or sometimes called Lou Gehrig's disease) for Arlene began in early 2014 when she noticed that her foot was dragging a bit. This was originally thought to be an effect of her diabetes but she was diagnosed in June 2014 with ALS. This came as a surprise to Arlene and her family as there was no family history and they had no idea of what ALS was or how it was to drastically affect not just Arlene but the family as well.

The past year has seen a dramatic change in Arlene's life due to ALS. She no longer has use of her arms and legs and is confined to her wheelchair. She requires oxygen as her breathing becomes more and more difficult. She can no longer swallow and needs to receive nourishment by a PEG feeding tube. Speech is difficult for her. Arlene now relies on the help of her family and caregivers for all her basic needs.

Arlene's main caregivers have been her husband Jerry, who cut back his working hours in order to be home with Arlene and their daughter Sarah, who provides daily support while being an amazing mom to her own four kids. Two other children; Richelle and Ben have provided support especially



The Underdown Family

when crisis arise. Other members of the family have stepped up from the grandchildren who love to do their Grammie's nails and help her update her Facebook ; to children that drop by to just be with their Mom even when words can't be exchanged.

Arlene's main support has been the Vancouver Island Health Authority and the ALS Society of B.C. which has provided the equipment that enables Arlene to live comfortably in her own home. As well the ALS Society of B.C. Victoria Chapter has been a good support for the family especially in helping with emotional support as they deal with seeing their mom/grandmother's health decline every week.

The Underdown family has become actively involved with various fundraising and awareness activities with the ALS Society of B.C. such as the Walk for ALS and Flower Day. As well, hosting a dinner fundraiser to raise awareness among their many family and friends and

to raise funds for both the ALS Society and for Arlene's bucket list.

Being involved with these activities also allow for the grandchildren to take part in helping their Grammie out when there are so many things that they can't do with her anymore.

One item on Arlene's bucket list was a trip to Winnipeg to visit her hometown before her mobility was totally limited. Arlene and Jerry were able to take this special trip via train last Fall. This was a special time for the both of them as they were able to travel together before the limitations of ALS took over.

Holidays and family events like birthdays take on a new meaning as no one knows if each one will be the last one with mom/Grammie.

Arlene is amazed by how much effort it takes for people to care for her. How difficult such simple tasks have become....how each day brings a new challenge. She says that it has been very frustrating not knowing what will happen

What is ALS or Lou Gehrig's Disease?

Amyotrophic Lateral Sclerosis (ALS) is a rapidly progressive, neuromuscular disease. It attacks the motor neurons that transmit electrical impulses from the brain to the voluntary muscles in the body. When they fail to receive messages, the muscles lose strength, atrophy and die.

ALS can strike anyone at anytime, regardless of age, gender, or ethnic origin. It does not affect the senses, and only rarely does it affect the mind. The equipment costs for each patient average \$137,000, while nursing and home care costs can be up to 10 times this amount.

The ALS Society of B.C. is dedicated to providing direct support to ALS patients, their families and caregivers, to ensure the best quality of life possible living with ALS. Through assisting research, we are committed to find the cause of, and cure for ALS.

next with your body or when.

Arlene had been an independent person, the main caregiver and organizer of the family. Having to learn to depend on others has been a struggle. There are moments when her mind struggles with the limitations of her body. She has gone from being independent to being dependent.

Even with these limitations Arlene has not let her spirit be overcome by ALS. She has taken up the challenge of learning how to use her iPad and provide her family and friends with updates regarding her ALS journey even though she had never used a computer before.

Jerry says that their living has come down to "being" vis-a-vis "doing". His coping strategy in being a caregiver is to take mental and physical breaks to do the things he enjoys, engaging family members

and friends to provide assistance where they can. Both he and Arlene have learned to be open and accepting of the assistance provided by others as they've realized that they can't fight ALS all on their own.

Their oldest daughter Shannon says "that you have to make memories from every moment. These are the foundation that build the memories for when someone is gone. Even the smallest things are what will bring the smiles when the tears come."

Arlene says that the reality and her outlook on life is; "we are given one day at a time to continue to live our lives to the fullest with the help of family and friends"

To reach the Underdown Family you can email TeamGrammie@gmail.com

- Underdown Family



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