

Fifty Years on Insulin - Tino's Story: A Dedication to All Families Living with Diabetes



Tino is presented Joslin's 50 year medal by Dr. Bruce Perkins (Longevity Study Researcher) at Mt. Sinai, Toronto

Feb 9, 2014 will mark 50 years that I have been using insulin. I feel very fortunate and privileged to be able to tell my story. I dedicate this piece to all the families living with Diabetes. Please feel free to send to friends, family or anybody you feel may appreciate this story or find hope and encouragement in reading it.

In the late fall of 1963, when I was 9 years old, I started to drink more fluids and was very tired. I also had to urinate frequently and was losing weight. During the first week of February 1964, my mom took me to see our family doctor. A urine sample showed glucose and a subsequent blood glucose test showed a value of 450mg/dl – equivalent to 25mmol/L, the standard of measurement used today. Type 1 Diabetes (formally called Juvenile Diabetes) was confirmed. My mom cried but I did not fully understand the implications of having diabetes or why she was so upset. I was admitted to Port Colborne General Hospital on February 9th, 1964, the exact date that the Beatles appeared on the Ed Sullivan Show for the very first time! Initially, I was given 20 u NPH insulin and stayed in hospital for a week while they titrated my dose. I recall the staff being very upset with me because I ate some Valentine's Day chocolates which caused a nice spike in my blood glucose while they were trying to regulate me. Feb 16th, I was released and my mother injected my insulin using a glass syringe with a reusable 25 gauge ½ inch (ie 12mm) stainless steel needle which was boiled to sterilize. These needles tended to become dull in time - far from the comfortable 30 gauge short needles we now have.

Our home was attached to the grocery store/fish market that my mom ran. Everybody in the family helped in the store which taught me business and math skills at an early age. However there was always the temptation to indulge at the candy counter.

Over the next 2 summers I was enrolled as a camper at Camp Huronda. In the early years, the camp was located on Beausoliel Island off Honey Harbour. I loved going there because all the campers had diabetes and I did not feel different from the other kids as I did in school. I learned how to inject myself and also learned to use Clinitest tablets in a test tube to measure sugar in my urine. Little did I know that 50 years later I would still be using Clinitest tablets but to test for dryness in wine rather than glucose in urine as I am a serious amateur winemaker!

As a child I was shy and very self-conscious. I tended to keep to myself. My closest friends knew about my diabetes but I did not tell too many people for fear of being rejected. The educational programs and

acceptance that is common place now did not exist back then. Through elementary and high school I was an ordinary student. I stayed away from sports as I was really uncoordinated and I thought my diabetes would be a barrier. I regret not ever being part of a team as I think it would have been good for my self confidence and ego. As a soccer dad for my 2 daughters, I have seen the importance of team sports in terms of confidence and team building.

I was in grade 12 when I thought I might want to be a pharmacist. I wanted to be able to help people like myself who suffered from a chronic medical condition and also I wanted the opportunity to be in business. This appealed to me as I had worked in the family grocery store since I was 6 years old. I was very motivated to do well and in 1973 I was accepted into the Faculty of Pharmacy at the University of Toronto where I met a fellow classmate, Christine Maloley. Upon graduation in 1977, I had an opportunity to work at K-Mart Pharmacy in Peterborough, Chris' hometown and the place where she had taken a position at Sullivan's Pharmacy. A year later we married.

In 1980, I started working at the Medical Centre Pharmacy in Peterborough. It was a very professional practice setting where I started to become involved in diabetes education. I joined the local CDA branch and became their consulting pharmacist and literature chairman.

The first home blood glucose meters appeared on the market in early 80's. As a healthcare professional living with diabetes, I immediately saw the advantages of being able to get a BG reading within minutes, any time any place. The only problem was the price at \$300 per meter!!! How things have changed now that meters are given out free!

Another career change took place in 1983 when I joined Kawartha IDA Pharmacy. Within 2 years I was offered a partnership and eventually became a 50% shareholder. During this time more and more blood glucose meters came to market and prices dropped considerably. It became known in the diabetes community and among the local physicians that I offered hands on training on BG meters and patient diabetes education. I was living my dream of owning a business and helping people manage their diabetes. I was very busy and in good health.

Chris and I talked about having a family. I had concerns about the possibility of having a child with diabetes but the emergence of new technologies in diabetes made me feel optimistic about the future. In January 1986 Chris gave birth to our first born, Reanna, and three and half years later, Chris gave birth to our second daughter Leta. We enrolled both girls into a study at the Hospital for Sick Children where they were tested regularly for Islet Cell Antibodies. These antibodies are precursors to the development of Type 1 Diabetes. The study would try various interventions in an effort to prevent T1D in participants who tested positive. Luckily neither daughter tested positive and when they reached age 18 the study was completed and we were told that Reanna and Leta had the same risk of developing T1D as people in the general population.

In the early nineties my ophthalmologist referred me to a retinal specialist in Toronto as my background retinopathy (which is found in 80% of people with T1D after 15 years) was changing to a more serious form called proliferative retinopathy (PR) which may progress to blindness due to a vitreal hemorrhage. My specialist performed laser treatments on a regular basis in order to reduce the risk of a vitreal hemorrhage.

At the end of September 1994, my partner and I accepted an offer from the Big V chain and sold Kawartha IDA Pharmacy. I stayed to manage the store and within a year Big V was purchased by Shoppers Drug Mart. I was longing to be an independent pharmacist again and in February 1997 Chris and I purchased Stutt's Pharmacy in Orono, just a 30 minute drive from our home in Peterborough. The pharmacy was originally established in 1856 but its décor was more like the sixties. Within 6 months we renovated the pharmacy to bring back the old look with mahogany wood trim and old fashioned lighting in the dispensary. We started to bring in blood glucose meters and other diabetes supplies as the pharmacy had never stocked these items before. Business was good. The people of Orono were very supportive and I loved the challenge of operating a small pharmacy in the small village. Chris had encouraged me to become a Certified Diabetes Educator as this was a specialized area that I was passionate about. I wrote my exam and became certified in May 1997.

In September 1997, I suffered my first vitreal hemorrhage, where blood had entered the vitreous and was blocking my vision. Often the blood is reabsorbed and vision returns. In the following weeks my vision returned to normal and my retinal specialist administered more laser treatments. However, 6 weeks after my first hemorrhage, I suffered another one which was clearing when a third one occurred 2 weeks later. Again it cleared up and I continued to have lasers treatments in the hope that this would stop the hemorrhages from occurring.

Over the next 2 years, I had 2 more bleeds which resolved, but in the fall of 1999 I experienced a hemorrhage which did not clear. On Jan 13, 2000, my specialist performed a vitrectomy, an operation which involves removing vitreous gel and replacing it with a saline like substance to stabilize the retinopathy. I had complications and my retina detached. Gas was introduced in an effort to force the retina to the back of the eye where it belonged. It was successful and my vision was completely restored but I was extremely sensitive to sunlight for a very long time.

In the fall of 2001, I was invited to a leadership forum in Vancouver by Lifescan. I met an endocrinologist who told me that she highly recommended insulin pump therapy for her T1D clients and that I should consider it. While I knew it was the best way to administer insulin, I did not like the idea of being attached to a machine. She said "give a try - you can always go back to your pen if you don't like it". It struck a cord with me and so within a few months I was on pump therapy and loved it!! It allowed me to be spontaneous instead of being tied to a schedule. I would never go back to injections.

After being on an insulin pump for 2 years I was encouraged by Medtronic Canada to become a distributor of Medtronic insulin pump supplies. Having first-hand knowledge of pumping insulin and being a CDE, I had a natural interest in doing so. I realized that no one sold all the different brands of insulin pump supplies in Canada. This gave me the incentive to establish the Diabetes Depot - a place where one could purchase anything required for their insulin pump regardless of the brand they used. AutoControl Medical and Disetronic (now Roche) were also very supportive and before long the website was established and the business grew.

Over the next few years I had regular eye checkups. My right eye was now fine. It seemed strange to me that my left eye had completely escaped the bleeds when on March 5th, 2005, I experienced the first hemorrhage in that eye. After several more bleeds, I had a vitrectomy in September 2007. Ironically on the day of my vitrectomy, Chris was diagnosed with breast cancer. Within a week she had surgery followed by chemotherapy and radiation therapy and is now cancer free.

I had been told 2 decades earlier that I had a bicuspid aortic valve in my heart which resulted in a heart murmur. Normally one has 3 flaps in this valve but I only had two. My cardiologist had warned me that when the valve became stiff and dysfunctional I would need to have it replaced or face certain death. The sign that I needed the surgery was the fact that I was totally exhausted after running for 45 seconds on the treadmill! My cardiogram also showed one coronary artery blocked 80% so a single bypass was done at the same time as my aortic valve replacement at the end of September 2009

Many people have asked: What is my secret for living with Type 1 Diabetes for 50 years? I do not have all the answers. In 1964, the great technologies (BG meters, insulin pumps, continuous glucose monitoring systems), wonderful insulin products and medications that we have today did not exist. I have suffered some long term complications but I am eternally grateful to all the healthcare professionals who have helped me overcome these challenges. There is no magic bullet for living with diabetes a long time. Sometimes diabetes can get you down because it is there 24-7. It never leaves you alone. It never takes a vacation. My best advice is to learn as much as you can about managing your diabetes so that you can tame it. The more you educate yourself the easier it will be to manage it. My advice for young people with T1 Diabetes is to get the best education you can. It does not matter whether it's formal or informal. Never lose sight of your family and friends. Don't be afraid to ask them for help. Follow your heart and passion to do what you want to do. Never let diabetes stop you from following your dreams. I have been blessed as I love being a pharmacist and diabetes educator.

I thoroughly enjoy going to work as I am living my dream.

Tino Montopoli

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