John Harnett - My Story

SPINOCEREBELLAR ATAXIA/DEGENERATION (SCA) – MY STORY

Table of Contents

Foreward

Chapter
1. What is Spinocerebellar Ataxia/Degeneration
2. My young Adult Experiences
3. Neurological Evaluation/Doctor's Diagnosis
4. Work/University
5. Applying for Disability Pension
6. Living with Ataxia
7. Exercise for Flexibility
8. Coping with Irritability
9. Walking with a Cane/Walking stick
10. Update from writing in Nov 2004 to 2009

FOREWARD

I was diagnosed as having Spinocerebellar Ataxia/Degeneration but because there was no family history of this disorder in my case it was labeled "sporadic". The word "sporadic" does not tell us anything about the way in which the disorder is inherited. Most adult-onset Spinocerebellar Ataxia/Degeneration is inherited in a dominant fashion, but certainty in my case is not possible. This has been a source of frustration for me and has motivated me to share my story and complete a family tree for both sides of my family.

Ataxia is a rare neurological disorder that can cause a total or partial loss of coordination. In very basic terms, the area of the brain that controls balance and coordination is the cerebellum. Spinocerebellar Ataxia/Degeneration is characterised by progressive ataxia due to degeneration of the cerebellum, brainstem, spinal cord and peripheral nerves. The disorder commences with gait unsteadiness and is followed by upper extremity ataxia and dysarthria. The progression of the disorder is extremely variable and difficulty standing steadily and running progresses to the stage where walking is no longer possible in many instances. Other more severe symptoms associated with the disorder include foot deformity, scoliosis, cardiomyopathy, sensory effect, breathing, speaking and swallowing difficulties.

I was diagnosed with Spinocerebellar Ataxia/Degeneration in about November 1995, at the age of 36 but in retrospect the symptoms probably started some years earlier. After I was diagnosed, I searched unsuccessfully for a book that would give me some idea of what I could expect in the future. Frustrated with the lack of information I could find I decided to document my own situation. I am very fortunate that the severity of the disorder is reasonably mild in my case and that I do not have a family of my own to support. The latter means that financially I have been able to survive well and my accommodation in a SA housing trust house has helped considerably. I have been blessed with a brother and four sisters and some close friends that have been of considerable help, but this cannot make up for having a family of my own. I hope that by writing this book it might help anyone that has a disorder similar to mine to see how it has affected me and to develop positive ways of coping with it.

CHAPTER 1.

WHAT IS SPINOCEREBELLAR ATAXIA/DEGENERATION

Spinocerebellar Ataxia or Degeneration (SCA) is a type of Hereditary Ataxia (HA) which is a debilitating disorder for which there is currently no cure. Ataxia seems to be a word commonly used in the United States while Degeneration is more common in Australia. SCA is a progressively degenerating neurological disorder related to Parkinson’s and Huntington’s disorders, these other disorders affect different parts of the brain. Spinocerebellar Ataxia/Degeneration is characterised by a slow disappearance of nerve cells in the brain. Thankfully, this neurological degeneration began relatively late in my life, (first appearing in my 36th year) and continues to progress slowly.

SCA is a dominantly inherited genetic disorder, which means that only one of my parents needed to have the defective gene for me to have the disorder. I have no known history of the disorder and it is thought that any previous family members with it probably died before manifesting any symptoms. The other alternative is that it is truly ‘sporadic’ and I am the start of the disorder. It is just an accident that I have a damaged gene and as I have no children the disorder will die with me. The area of the brain affected by this disorder is the cerebellum and is evolutionary one of the oldest parts of the brain. The cerebellum is a fist sized round mass located just below the main cerebral hemispheres, at the back of the skull, just behind the ears. It is mainly responsible for balance and coordination. It can give us perfect penmanship or the potential to move like Fred Astaire.

Projecting downward from the brain is the brain stem, here are found some of the oldest brain centers that control life sustaining processes such as; temperature regulation, respiratory rate, heart rate, blood pressure, etc. SCA sufferers have a characteristic of movement known as ataxia. This may be anything from slightly observable clumsiness in walking, to varying degrees of stumbling, lurching, weaving and bobbing. In addition to this physical ataxia, there comes, what is called an emotional ataxia which derives as a result of living with an incurable condition.

In the beginning stages of the condition, the most noticeable symptoms were its physical limitations. For example, I experienced a slowly advancing loss of control over my balance and coordination. In general, I found that I was becoming more clumsy and awkward. I began to bump into things and stumble on steps. I could no longer carry a cup of coffee, or a glass of beer without spilling it. At this time, the simple act of going for a walk became difficult. My body would no longer ‘go’ anywhere in a straight line. For the first time in my life, I had to think about walking and police my movements, making corrections whenever necessary.

I continue to research the medical literature for developments in treatment of my condition. To date, the most exciting things are research in the area of stem cell transplants in the treatment of neurodegenerative disorders such as Parkinson’s or Huntington’s disorders. One day our own stem cells might be harvested to avoid the bodies’ rejection of foreign tissue. While results are promising, it is far too early to assume this technique will be successful in human trials. Nevertheless, it is very comforting to know that breakthroughs are being made all the time in our understanding of the mechanisms behind these neurodegenerative disorders.

CHAPTER 2.

MY YOUNG ADULT EXPERIENCES

The onset of ataxia symptoms may well have occurred during my mid-twenties, although technically I was not medically diagnosed until the age of about 36. Looking back on my childhood and teenage years, I was reasonably average at most things. I did not excel scholastically and while I enjoyed participating in most sports I would not describe myself as being good at any of them. My earliest memories of any hint of this disorder are of clumsily clipping ankles in the action of running while playing sport. Although I was quite a good footballer a lot of this can be attributed to me being tall. In retrospect I was somewhat awkward and while I played football, basketball and water polo, I was not particularly great at them. My younger memories particularly my teens and twenties are all good but I do recall having knee problems in my late twenties that with the benefit of hindsight may well have been related to SCA.

CHAPTER 3.

NEUROLOGICAL EVALUATION/DOCTORS DIAGNOSIS

What started out as a normal Friday night session of drinking at the pub with friends and a close mate who had recently returned to Adelaide after a couple of years interstate. This particular friend noticed and suggested that I appeared more wobbly than I had in the past after a night on the ‘booze’. He made comment that I had always held my drink better and suggested that something might be wrong, and this started me thinking. I had previous knee problems and had always put increasing balance problems to my knees.

I had four minor knee operations (two on each knee) which I thought would prolong my football career.

Anyway my first step was to see the General Practitioner who referred me on to see a Neurologist. After seeing a number of Neurologists I saw one that was very thorough and his investigations meant having numerous blood tests, an EEG (electroencephalogram, which records the electrical activity of the brain, sometimes referred to as a brain wave test) and a VER (visual evoked response). I also had a CAT scan and an MRI scan of both the spinal cord and the brain. All these tests took about 18 months and I was finally diagnosed as having Spinocerebellar Ataxia/Degeneration in late 1996. My Neurologist had referred me to his partner in his practice for a second opinion and this confirmed my diagnosis.

After my evaluation, the review by the Neurologist included tests of my reflexes, strength test by pushing down on my arms, walking heel-to-toe (sometimes with my eyes closed), nose to finger exercise (a test of repetition with increasing speed), taking the heel of my right and sliding it down my left leg, and repeating the same exercise on the opposite leg. All these tests checked my coordination and strength in my arms and legs. Each visit to the Neurologist ended with “you appear to be handling the situation well, as there isn’t a cure I will see you again in another 6- 12 months”. The phrase “there is no cure” always left me feeling a bit depressed and very negative. This combined with the failure to make a more precise diagnosis left me with pessimistic thoughts after my visits, but I was grateful that the speed of my degeneration had been slow. On the research front, my version of the disorder was particularly rare which made it difficult to find others with it, to see what I could expect. In addition, because no one high profile like Muhammad Ali or Michael J Fox had the disorder, not a lot of research went into finding a cure. My basic understanding is that there are about 12 (more are being found all the time) different types of SCA and I have been tested for all known forms of the disorder and have returned normal results. This and the fact that no family history exists means that a more precise diagnosis was unable to be made.

CHAPTER 4.

WORK/UNIVERSITY

I consider myself reasonably well educated. In 1977/78 I left school after benefiting from 12 years at a private college and although I received average marks, I found a job in an accountancy firm. My position was office junior and I soon realised if I wanted to move forward I needed to study Accountancy. I did so part-time finishing in about 1988 which enabled me to join a number of different professional bodies. I climbed the work hierarchy and moved between a number of different accounting firms over my 22 years in the profession. My fields of expertise varied greatly but I mainly concentrated on taxation and auditing. When symptoms started to have an effect on my work, I decided to go back to study an area that interested me. I was told by my doctor that stress from my work probably influenced the pace of progression of the disorder I had. When the symptoms started to become obvious, I decided my health was my most important priority and stopped work. I decided to study full-time at Adelaide University for a Bachelor of International studies. This comprised Asian cultural studies, Asian management, Japanese Society and culture, International Economics, Politics, and Labour studies. I finished and graduated in December 2001. I consider myself a bit of a plodder, not exactly slow but more thorough. I earned good results in my studies because I was willing to spend twice as long as the brighter students to learn the same thing.

CHAPTER 5.

APPLYING FOR DISABILITY PENSION

I was very fortunate with all the help I received from the Muscular Dystrophy Association and the Multiple Sclerosis Society who made me aware of my entitlements and what Government forms I needed to be complete. My accountancy skills assisted greatly with all the forms and all my dealings with the Public Service. Most application forms included medical declarations by Doctors and my Neurologist. This was most important when I was a full-time student and meant applying for a Disability Support Pension (DSP), a Pensioner Education Supplement and the Mobility Allowance. The DSP was the base pension and the Pension Education Supplement was an extra allowance paid to students occupying full-time study. The Mobility Allowance is paid to those in receipt of the DSP who are either working, volunteering, or studying more than eight hours per week. This allowance goes part of the way to compensate for the fact that a person is unable to use public transport and has to maintain a car. These allowances and Pension enabled me to pay all my rent and expenses particularly while I studied. Fortunately, I was able to supplement my income with tax agent duties tax preparation until 2004 when my tax agent license expired. My frugal living expenses, combined with all the benefits of the pension and allowances and my savings and inheritance money has allowed me to live comfortably. All this together with the very reasonable rental paid to the SA Housing Trust has permitted my budget to remain fairly stable.

CHAPTER 6.

LIVING WITH SCA

I would like to have a dollar for every time I have been told to ‘concentrate on what I can do and not what I can’t’ - but it really is true. So is the ‘move it or lose it’ saying. It is for both of these reasons that I have become almost obsessive with my daily exercise routine and remain convinced that my mobility has benefited from this approach. My experience of falling a number of times and losing my balance has taught me to focus on what I am doing at the moment and to avoid hurrying. When I hurry I tend to get very nervous and it takes me twice as long to do anything. It is very hard to explain examples to someone who has never had trouble getting coins quickly out of their pocket at a shop when a line of people are behind you, only to drop all the coins on the floor. Another example is not being able to access a building because it has a flight of stairs in front of it, or a picture theatre. I have learned to make a mental note of things that I should avoid. For example, I tend to lose my balance whenever I walk and turn around in one motion. I have fallen or lost balance often when changing direction too quickly. This is a common problem for those with ataxia but is just taken for granted by those who do not have this disorder. When I walk, I have learnt to really concentrate on walking. If I want to turn around I make a complete stop and slowly make a complete turn. This may sound elementary, but focusing on the task at hand works for me. I am more likely to have an accident when I stop focusing on exactly what I am doing. Fatigue is another common symptom of ataxia. Fatigue can only be controlled by getting plenty of rest. Irritability and slurred speech are indications that I'm tired. I have discovered various ways of coping or living with ataxia that works for me and I have grouped them into various categories.

Personal Grooming

I am very fortunate to have found accommodation in a Housing Trust two bedroom house and the shower in the bathroom has been modified for me. This work was completed in conjunction with occupational therapists. I have three handicap bars placed in the bathroom, two of which are in the shower and one in the toilet. I also have a grab rail at the back door and we have placed another five strategically around the house to assist me to avoid falling. I regularly bounce off walls in the passage way when I get up at night to visit the loo. If I am traveling or visiting friends interstate where there are no handicap bars in the shower, I lean on the wall for support or if there is nothing else to hold onto, I simply wash up using the face bowl until I return home. I always sit down to put on my clothing, shoes or to do anything that requires balance.

Housekeeping

I would like to avoid housekeeping altogether but I can't. I clean the house in moderation. I tend to clean a little and rest as much as I need to. Because I live alone if I do not do the vacuuming and dusting, it does not get done. This can be a both positive and negative. Because I am essentially lazy, I do cleaning when it starts to show, not that the house gets dirty I believe in the approach of doing things as you go. I tend to do things of a morning when I feel energetic. By the afternoon or night I am starting to get tired.

Entertaining

Because I get tired easily when preparing a big meal, I seldom cook to entertain. Anyone who knows me will vouch for my cooking and entertaining skills, so I can’t remember the last time I cooked at home for anyone else, usually I visit others, but who knows what the future hold.

Gardening

I planned ahead a few years ago and put in a very low maintenance garden and have had help with spreading mulch but I still get out and pull out the weeds when the weather conditions are nice and I just do things at a slower pace.

Other ways I have learned to cope with ataxia

The following list includes other things I do to cope with ataxia :

- To avoid spills I drink tea and coffee from a mug with a lid (I am not a big coffee drinker anyway).
- I avoid walking on wet, slippery floors.
- I exercise regularly to maintain flexibility
- I avoid driving in peak hours and use my handicap sticker which allows me to park close to the building when shopping etc.
- I walk up and down steps very carefully.
- I try to take my time when standing or sitting up from either a lying or seated position.
- I try to avoid alcohol (but still manage a couple of light beers on special occasions)

CHAPTER 7.

EXERCISES FOR FLEXABILITY

It’s commonly known and recognized that regular exercise is beneficial to us all. It is especially beneficial to a person with Spinocerebellar Ataxia/Degeneration who is likely to experience muscle weakness and the loss of coordination in their legs and arms, as well as the loss of flexibility in the joints. I also have had speech therapy and while I no longer go to sessions with a speech pathologist, I use the exercises I received every morning. I speak aloud and to a time limit so I know if my speech has deteriorated. For example, each morning while I am doing my twenty minutes on the exercise bike I count to seventy and ensure I do so within a minute, I do this twice. This is difficult as I am usually out of breath from exercising. Taking deep breaths while performing each exercise is very important. When oxygen is inhaled, it enters the bloodstream and flows throughout the body. The muscles are nourished through this inflow of oxygen. I also do volunteer work as an adult literacy tutor, and while it is not rocket science, it probably assists with my vocabulary and articulation. I am convinced that my exercising every morning is the main reason I remain still able to walk, and muscle strength has stopped me from falling a number of times. Principally, exercise improves my self-esteem. I feel that I am helping to improve my mental health while reducing the risk of having serious medical problems such as heart disorder, diabetes, high blood pressure and many other ailments. I exercise each morning while listening to the radio, which serves the dual purpose of keeping me informed and also stops the boredom of exercising for over an hour. Fatigue is one of several symptoms of ataxia. Exercise and rest energize my body. Because I feel tired every day mid-afternoon, I often have a bit of a nap on the couch in front of the TV.

FACIAL STRETCH

Objective: To stretch the muscles in your face and to stimulate the muscles in the tongue.

- Open your mouth as wide as possible
- Move your jaw up and down, round and round
- Stick your tongue out as far as it will go
- Circle your tongue around your mouth
- Stretch your eyes open as wide as you can
- Relax
- Repeat this exercise as often as you like

(This exercise can be done almost anywhere and from a seated position)

HEAD TWIST

Objective: To relieve tension in your neck

- Twist your head to the right, looking over the right shoulder holding stretch for fifteen to twenty seconds
- Relax
- Repeat the same exercise on the left side and repeat the total exercise as often as you like

(This exercise can be done almost anywhere from a seated position)

OVER THE HEAD ARM STRETCH

Objective: A total body stretch

- Sit erect or stand tall
- Pull stomach in for back support
- Slowly raise both arms high above head and pretend you can touch the ceiling
- Hold stretch for fifteen to twenty seconds
- Slowly lower both arms
- Relax
- Repeat exercise three times

BOTH ARMS ROTATIONS

Objective: To gain arm strength

- Sit or erect or stand
- Pull stomach in for back support
- Stretch both arms out (shoulder height), and pretend you can touch the walls on either side of you
- Make small circles, then gradually increase the size of the circle with each rotation
- Relax

- Repeat exercise three times

HAND AND WRIST FLEX

Objective: To exercise both hands and wrist

- Hold both arms out, waist high
- Stretch fingers apart
- Close and open hands
- Flex wrist up and down
- Relax
- Repeat exercise as often as you like

WAIST TWIST

Objective: To exercise hips and back

- Lay down on floor (on back) - I do this on my bed
- Pull stomach in to support back
- Stretch both arms out on either side of body
- Pull both knees up to stomach
- Roll from side to side
- Repeat exercise ten to fifteen times
- Relax

CALVES, ANKLES AND TOES FLEX

Objective: To exercise the calves, ankles and toes

- Sit down
- Take shoes off
- Sit erect
- Pull stomach in to support lower back
- Pull both feet toward you, then point feet away from you
- Hold for ten to fifteen seconds
- Wiggle the toes; stretch toes apart; squeeze toes
- Flex ankles up and down
- Relax
- Repeat exercise three times

THIGH STRETCH

Objective : To stretch the Muscles the thigh muscles

- Lie down on floor (or bed)
- Hold stomach in for lower back support
- Roll over on left side
- Bend right leg backward and grab ankle
- Press foot toward buttock
- Hold for fifteen to twenty seconds
- Repeat exercise for left leg
- Relax
- Repeat exercise three times

STOMACH TO KNEE CRUNCH

Objective : To help flatten stomach

- Lie on back

- Pull stomach in to support lower back
- Raise knees to stomach
- Grab knees with both hands and press knees to stomach
- Hold stretch for fifteen to twenty seconds
- relax
- repeat exercise three times

LEG LIFTS

Objective: To strengthen the leg muscles

- Lie face up on the floor (or bed)
- Roll to the right side
- Take the outer leg (left) and slowly lift it as far as you can to the side
- Slowly lower the leg (do not touch the floor)
- Hold for ten to fifteen seconds
- Relax
- Repeat with right leg
- Repeat exercise three times

DOG EXERCISE

Objective : Improve balance

- Get down on all fours like a dog
- Raise one arm and hold for twenty seconds
- Repeat with other arm
- Stretch one leg out behind for twenty seconds
- Repeat other leg
- Stretch out right arm and left leg hold for twenty seconds
- Reverse and repeat

FOOT EXERCISES – (use a small Volleyball type ball - 6 inch)

Objective : To stretch and control the movements of your feet

- Sit with a ball under you foot and
- Run the ball forward and backward (contacting all parts of your foot)
- Run the ball side to side (watch your knee and hold it if necessary)
- Circle the ball under your foot - change direction
- Rest
- Repeat other leg

BALL EXERCISES (on a larger exercise ball)

Objective : Improve balance

- Sit on ball (I use it up against the lounge to stop it rolling)
- Gently move side to side, back and forward
- Side to side forward and back, circle
- Put arms on knees and then arms out to side
- Transfer weight to right, shift left foot in and out
- Transfer weight to left, shift right foot in and out
- Walk forward and back
- Lift left foot off the ground and hold
- Lift right foot off the ground and hold

I know I have included a lot of exercises above, but I do not necessarily do them all every day. They are exercises that have been given to me by Physiotherapists and Speech Therapists that I have seen. I have a dual action exercise bike (with arms that move) and every morning I do about 20 minutes on it and then about 40 minutes of other strengthening and stretching exercises each morning. My regular routine includes some I have listed plus sit ups, arm curls with a set of 6 kg dumbbells. A lot of the stretching and ball exercises are done in front of the television so I do not find them mind-numbing and I certainly notice the benefits.

CHAPTER 8

COPING WITH IRRITABILITY

I sometimes get depressed with my life, especially when people ask me what I do with my time now that I do not work. To be perfectly honest, I do not have any trouble filling my days. My day starts early at say 7 am every day, I exercise for about an hour, by the time I have had a shower, breakfast, shave etc. it is 9.30am. Often if I have to go somewhere like shopping, I like to beat the rush so this means getting up earlier. I try to schedule my doctor’s, physio, dental, dermatologist and/or neurologist appointments in the late morning but this is not always possible so my days are often filled with seeing various medical specialists. As I no longer work and my tax consulting business has ceased, my spare time allows me to pursue my hobbies of writing this book and creating a family tree for both sides of my family. Ten years ago I was not interested in Politics, but after completing my Bachelor of International Studies Degree at University, I am interested in both international and domestic events. Perhaps the current era has provided us with a lot more events of interest, particularly on a world stage. I have been told that it is very important to exercise both your mind and body and not to dwell too much on what might happen in the future. I also research various websites on the internet in relation to my condition and communicate with a number of email contacts.

The 1990’s, particularly the late 90’s, were pretty tough years for me making the transition from walking to using a walking stick, from full-time employment to full-time study, and eventually not working at all. In retrospect, I was generally upset and an angry person. When I look back at my emotional state at that time, it was pretty plainly a combination of grief and self-pity. When I finished University and realised that full-time work was no longer realistic, I did some volunteer work for the Muscular Dystrophy Association. This was a real eye opener for me and I was amazed with how people a lot more severely affected than me seemed genuinely happy and well adjusted. I imagined what they must have gone through in their lives and compared it to the stuff I had been through in my bad years and saw it that I had no right to adopt a woe-is-me attitude. The more I look into my disorder, I realise how mild it is and how lucky I should consider myself not to be afflicted with something much more serious. I remember having a discussion with the executive director of the Muscular Dystrophy Association who has a condition similarly in severity to mine. He told me of a woman he knew in a wheelchair who had said to him that she had felt sorry for him. Puzzled by this, he asked her why, and she explained that this was because his condition is degenerative (as is mine) whereas she had always been in a wheelchair and had never known anything different, so he had that adjustment to look forward to. I like to think a bit more positively than just accepting this as inevitable for me. When I think about it, Mum bore the brunt of a lot of my frustration. I really regret my irritability which led to many arguments with her. Mum did listen with great empathy to all my problems but I always got the impression that she never really fully understood the technicalities of my diagnosis. This has prompted me to write my story so family and friends are a bit more aware.

CHAPTER 9.

WALKING WITH A CANE/WALKING STICK

It took some time to get over the stigma of using a cane in public, I remember being told by different family members that I should use it if it helped stop me from falling. If I fell as a result of not using it I would be dependent on others and as I live alone this would be a bit stupid. Rather than looking like I was “drunk or on drugs” walking down the street I started using it and now I unfortunately need it. I was once told another way of looking at it was that people would see that you had a genuine medical problem and get out of your way. It is true, often people will give way to you and are much more courteous. I have noticed a different approach when being served in department stores and basically any sort of retail environment.

When I was still working I saw a young woman walking down the hall with a cane. I introduced myself to her and explained that my doctors say I will need a cane one day. She was very nice and endured my clumsy but sincere questions. I asked her how or what she did to prepare herself to walk with a cane. She answered by telling me she has terminal cancer and was pregnant. She continued by saying she also has a bad back and that she wears a back brace and walks with a cane for support. I thanked her and graciously walked back to my office feeling very embarrassed. Suddenly, the concerns I had about the stigma of walking with a cane seemed insignificant.

CHAPTER 10.

UPDATE FROM DATE OF WRITING IN 2004 TO 2009

I am very fortunate that my deterioration has been slow in the last few years. I no longer drive a car and now travel by Gopher. I stopped driving not because I had to but basically because I lost confidence in driving (particularly at night) and just found that I was only driving once a week to go shopping or for special occasions. I decided to sell my car and travel by Taxi or get lifts from family or friends. I have found it is a lot cheaper too. Another reason was that I obtained a dog in September 2006 and walking him became a problem as the walking stick was a dangerous option. The Gopher is ideal and he loves it. The dog (Chad) is a Labrador – and is a companion dog who was specially trained by a Sydney based organisation www.assistancedogs.org.au. A companion dog is placed with individuals who would benefit from the emotional and physical therapy of having a well-trained pet, and would like the companionship of a dog, but cannot raise and train a dog of their own. He performs all the normal commands you would expect from a very well trained dog plus many others.

I am not a fitness freak or Gym junkie but I am convinced and have been told that because of my exercise routine and attitude I have been able to still walk, although aided by a walking stick and sometimes a 4 wheeled walker. I spend 30 minutes each morning on an exercise bike strengthening my leg muscles each morning followed by some exercises that I have learnt over the years. I see a Neuro-physio at least twice each year plus I have a yearly review with my Neurologist. I am determined to remain as mobile as I can for as long as I can so that I am able to take advantage of any advances in medication or ultimately a cure. My personal circumstances (the fact that I live alone) means that I am lucky in that I do what I want when I want (just a little slower these days) but at the same time I do have help. I now have a cleaner each fortnight plus a lot of help from family and friends. Don’t let anyone tell you just because no cure exists for SCA you can’t do things to slow the progression.

Chapter 11: 2004-2014

SAHT - Wheaton St. South Plympton 1999 - 2014

I finished studying at University in 2001 and although I did work from home until about mid 2005 doing a bit of tax work, I was winding down because I could no longer do things as quickly or as easily as in previous years. I still managed to fulfil my days either doing work/various tasks on the computer and when I was bored I always found a movie or TV show. I found myself becoming a bit more politically aware and interested in current affairs and so this took up a lot of my time. I began listening to ABC radio and watching current affairs on TV. Perhaps it was a bit of a hangover from my university days and it helped me to avoid boredom.

I was involved with a past football association but even watching my nephew play football of a Saturday morning became an effort because as my condition deteriorated, the cold weather, and my frequent toileting just made things seem like too much effort. In these years I was still attending Muscular Dystrophy SA’s SCA monthly support group meetings where I would get together with other people living with SCA to learn new things and share experiences. Expatiation

In 2005 I went on a holiday to Phuket. My Neurologist at the time suggested that I make the most of my mobility. Back then, I was managing with a walking stick. I went away with a long time close friend, I was the best man at his wedding, and he had suggested the place.

After that, things deteriorated quite substantially for me. In the mid 2000's, I was still walking with assistance but I was having numerous falls at home. Minor falls were taking a longer time to recover from. The housing trust place I was living in was old-fashioned, with the bedroom at the front of the house and the toilet and shower at the back. It was difficult to heat and cool. I had grab rails strategically placed everywhere so I could avoid falling. I am tall and I did have a fairly wide reach and wingspan but over-reaching was often the cause of my falls. I was slowly increasing my support hours to compensate for my growing fragility. I am very lucky to have a very supportive family and they provided my avenue for a lot of my outings. If I am perfectly honest, family and close friends often took me out screaming and kicking at times.

Going out at the time just involved getting in a regular taxi for me but I could see some a lot worse, requiring an access cab. I didn't want to go down that path so I reduced the amount of times I went out because it was more of an effort and my social activities started to reflect exactly this. I did most of my shopping online and apart from a weekly meal at my sister's place and special occasions, I rarely went out. Attending Doctor's appointments and going to the chemist were the only real exceptions. My condition was slowly deteriorating but it was nowhere near as severe as some of the people I began to meet.

In 2010, 2011 and 2012 after I lost my assistance dog I ran out of excuses not to go to the Grown up's Getaway run by Muscular Dystrophy SA. The Grown up's Getaway is held each year for adults living with a neuromuscular condition. The group goes on a four day holiday to an accessible location in South Australia. I would strongly encourage anyone to go along to things like the Grown up's Getaway. I recall being very apprehensive about going initially. At first, I considered myself more able or more fortunate than a lot of others, but I soon realised I wasn't. Although I was less severely affected by my condition than many people there, I was really inspired by some of those people because they were coping a lot better than I was. I had numerous times when I was able to do things and they weren't, simple things like walking to a pub and holding my own drink. Whenever I felt ordinary about myself, I always looked at the way they coped with things. Seeing people who couldn't do things for themselves, like going to the toilet, bathing etc. made me realise how lucky I was to still be able to do these things for myself. This helped me to cope both physically and mentally. I only wished I had met more people like these, ten or so years ago.

I didn't really handle the difficulties I am now confronted with and frankly I am embarrassed that (perhaps because of my personality and not being much of a people person) I was always looking at things from a selfish perspective. I took a lot of my frustrations out on those close to me who were only trying to help - in particular family. My life changed when I was diagnosed with this condition and it has changed my lifestyle. Not necessarily negatively because I have done a lot of things that I would never have done, achieved and experienced things, met a lot of people I never would have. I have been told many times that I should not let the condition win and it is very true, that you have control of your own life, not your disability. It has taken me years to acknowledge this and I have taken a long time to accept things as they are (and I still haven't completely) I still have times when I feel down and sorry for myself.

In late 2010 I was falling four or five times and this was becoming normal. At one stage, I was told by a doctor that I had osteoporosis after fracturing my knee cap. The Doctor then said I had the bones of an 80 year old woman. I fell over another time and needed stitches in my elbow which was frightening. These are just the ones I remember clearly. Falls resulting in just bumps and bruises I could live with but more serious falls were occurring a bit more often which was concerning. All of these falls were stopping me from doing my exercise.

In about 2010/11, I started using a gopher and a wheelchair more often and moved a little slower and a lot more carefully, but I never foresaw the possibility of where I would end up. I was watching a person I knew with a similar condition start to deteriorate quite severely and although mine was not as bad, I started to see the progression of my condition reflecting some of what he was experiencing.

2014-2015 nursing home

- 2/7/2014 - 16/7/15

This person I knew had moved into a nursing home and said it was like living with all your requirements attended to. So in frustration, I started to think about this. After a lot of consideration about things that were deteriorating with my condition, I went through the process of having an Aged Care Assessment which is a requirement to enter an aged care facility in Australia. They assessed me as requiring High Care. Seeing people I knew and watching their conditions deteriorate hastened my decision. Watching the progression of their conditions, made me think that the nursing home was the best option for what lay in my future. In retrospect, it probably wasn't.

I was assessed by my Doctor and Neurologist who said I needed Independent Living with more support. So, I felt like the right option for me was moving to a Nursing Home where I would have support on hand if and when I needed it. When I spoke to the person I knew in the Nursing Home, they mentioned how much easier things were and how much safer they felt now that they were living there. I saw that as an opportunity to make things better for myself. Thinking that they were happy there made me think I would be happy too. So I moved into the same Nursing Home in the hope it would make things better for me.

Living in the Nursing Home wasn't exactly what I expected. I had to fight the establishment of the Nursing Home, against all of the Occupational Health and Safety requirements to have the rails on my bed taken off, and then the sensor mat removed from my room so that each time I moved, I wouldn't have the Nursing Home staff knocking down the door because I was out of bed. It wasn't for a few months that they allowed me to do some of my exercises on my bed and they wouldn't actually allow me to walk unaided around the place until I'd seen the Physiotherapist. The Physio finally saw my determination and allowed me to do it. Once my exercises were approved, I was up at 6am each morning to do them.

Every day was the same. I was up at 6am doing my exercises and although I was reducing the number of exercises I was doing, these were the exercises I was still doing:

- 100 pushups (on my knees)
- leg yoga rope stretches
- bird/dog lift opposite arm and leg hold 5 secs.
- glute raises - 5 second holds tuck tailbone underneath and consciously squeeze glutes
- lower back stretches holding knees and twisting to sides

Each day was the same, 7am would be showering time and then breakfast was after that at around 8:30am. I would eat breakfast in my room which was always the same thing and then it was a matter of reading and responding to emails in an attempt to find other accommodation. I would spend my days looking on Facebook, reading what was being done by friends and sometimes contributing or just generally sitting around, trying to keep myself busy until lunch time.

Lunch would be at 12 noon always bisected by the morning tea/coffee trolley coming around at about 10.30am. I would eat my lunch in the dining area with everyone else. The rest of the afternoon was generally spent watching programs on ABC Iview or catching up any TV shows that were on the previous night. None of the activities for the nursing home residents really appealed to me.

Dinner would be at around 5pm each night. They did give you a menu choice of either baked beans or toasted sandwiches or something along similar lines. What they tried to do was make breakfast always the same, lunch the main meal of the day, and dinner either sandwiches or salad or something similar, all very nutritional but not exactly tasty. Residents generally went back to their rooms after tea at 5pm watched a bit of TV and then went to bed or got ready for bed by 8pm after a cup of tea and a biscuit.

Each week we would be given a sheet of paper with a timetable of activities for residents. The only activity that I really participated in was group exercise. They had other activities like bingo, flower arranging, or group tea/coffee and a chat, but I wasn’t really interested in joining in on any of those. Group exercises with all the older residents comprised of sitting around in a circle. They were amazed when I would get out of my wheelchair and into a regular chair. The exercises certainly weren’t really strenuous. I noticed that there was a mixture of people, some people with better coordination than mine and some people who were unable to do things like catching a ball. Eventually I gave up on the exercise classes as there wouldn’t be enough carers to help everyone. Many of the residents saw the classes as more of a social benefit than benefits of exercise, and I have no doubt they were, but the benefits of exercise was the focus for me. In the end, I gave up and stopped going because I wanted something a bit more challenging.

I had also stopped doing some of my regular exercises that I was doing in the housing trust home because I no longer had access to my exercise bike or leg/ankle weights. The physiotherapist would come once a week or once a fortnight but there were more than 120 residents and I wasn’t a priority, so once he got to me, it was a matter of him giving me exercises to do that he thought I was capable of doing, walking and doing other exercises in the hallways. I was lucky at that stage that my walking and transferring out of my wheelchair remained quite good, although sitting in a chair all day didn't really help.

Living in the Nursing Home didn't really suit me at all, and in retrospect I should have moved into a smaller housing trust home with more support. The problem was that once I had made the decision to live in the Nursing Home, I could not leave as I pleased as there was nowhere else for me to live. I started to spend my days writing various letters and emails to Ministers, specialists, and advocates, attempting to find other accommodation. I was also trying to organise an interview with the ABC to tell them my story and create a bit of attention. I was very frustrated with my lack of options and began to keep a bit of a diary.

It took months but an interview with the ABC was finally arranged. One of the radio hosts that interviewed me went to school with my older brother, and I listened to the program a lot so I trusted that he would do an accurate coverage of my circumstances. I saw a lot of other people in similar circumstances to myself and knew from my work with Young People in Nursing Homes, that my situation was not too uncommon. I had a lot of emails to and from the head of Young People in Nursing Homes, and that's how a lot of my day would be consumed, writing and sending emails. I was amazed that she would respond to me directly because it is a national body. I would send an email to her and she would respond to me on a personal basis. There was also a student who was doing a study in the field of young people in nursing homes. The student asked me to share my story, and I did. These sort of things took up a lot of my time.

Months had passed but I had successfully arranged an interview on the ABC. So, the Radio interview took place over the phone in July 2015. Below is the transcript of the interview.

ABC 891 Interview with John Harnett

Radio Host: 20 years ago, he had his health, he was an accountant, life must've looked pretty good and then he was diagnosed with Spinocerebella Ataxia. A relatively young man living in a nursing home because that's the only place to put him. You have a rare form of Muscular Dystrophy and your condition's deteriorated. You're now in a nursing home for elderly people. Can you explain your situation John?

John: Well the situation is that, I went from a position where I was in a housing trust place having carers come in the morning and night, but I saw my condition deteriorating. So, as you say, I saw the writing on the wall and I thought this is probably the better place for me. But as it turns out, it's not.

Radio Host: And is that because whilst you're being well cared for, health wise, it's depressing?

John: Yeah, it is, for someone my age. They do their very best but it's a hospital environment. The constant ringing noises and nursing staff and caring staff. It's driving me up the wall.

Radio Host: Did you have an opportunity to stay in the housing trust house, with care in house? You could've stayed there but you thought no, I'll go with the nursing home, is that what has happened?

John: Yes, that's exactly what happened. In retrospect I wish I never left. It's very difficult to leave the nursing home. I've tried my local Member, Federal Member, Young People in Nursing Homes, written umpteen letters and emails to leave, I'm on a waiting list but it's taken six months so far and I'm still here.

Radio Host: Now you have been offered some options to get out of the nursing home into independent care. One in the country, Gawler, and your family I assume, are in Adelaide? Or close by. The other one wasn't wheelchair accessible, so that wasn't great.

John: Yeah accessibility wheelchair wise was a bit difficult

Radio Host: The third option, you'd be sharing with someone who is a heavy smoker and you are not a smoker, is that right?

John: Yes well, initially, that wasn't a problem but after having a look at the place, in second thoughts, I felt it wasn't right. I don't want to make the same mistake I did in coming here, by going with a choice that isn't going to be the best for me.

Radio Host: You must feel extremely vulnerable John.

John: I can’t tell you how bad it is, yeah.

Radio Host: And you’re worried because as you said, you’ve had one move and you regret that and you’re not being critical of the people looking after you, it’s just that…

John: No, certainly not, they’re fantastic here. It’s just that I’m not interested in a lot of the activities that they have for seniors here so I don’t participate basically.

Radio Host: But if you leave and take one of these other options you could find yourself ratcheting downwards in the standard that you want.
John, when did you first come down with SCA?

John: 1995, almost 20 years ago.

Radio Host: Right so when you were 35, you were fighting fit, you were an accountant.

John: Yes, I was working fulltime as an accountant and when I was diagnosed, I went back and did another degree at uni to keep the old mind working.

Radio Host: And has it deteriorated? You’re wheelchair bound, correct?

John: Yes but I can still get up and walk a little bit and move around a bit.

Radio Host: Right, so you’ve tried your local member, you’re a very literate person, you’re able to communicate, a former accountant so you know what you’re doing. You’ve written to the disabilities minister Tony Piccolo, you’ve sent off enough correspondence…

John: I’ve got replies, but not for a while.

Radio Host: Ok, and what you’re telling us is that it’s very hard for someone in their fifties with a debilitating condition to find accommodation where your needs, character and circumstances are met. We just don’t seem to provide it.

John: That’s exactly what I’m saying. If I was twenty years younger, and covered by the National Disability Insurance Scheme things might be a little bit different, or if I had a family to care for me. I do have brothers and sisters but they all have their own families, so I can’t rely on others to do it for me.

Radio Host: Well John Harnett, thank you for sharing your story. We will try and get some answers because it is an issue that has been raised and that is, younger people who need care but also want independence and are in a place that is designed for very old people in many cases. John, thank you for talking with us.

John: Thank you very much for your time and efforts and hopefully something will come up.

Tony Piccolo Minister for Disabilities is on 891 ABC Adelaide:

Radio Host: Minister welcome

Minister Piccolo: Good morning Matt & listeners.

Radio Host: What can you do to do get John out of an Aged Care Facility and into some form of supported Independent Living?

Minister Piccolo: Yes, well it is a sad situation, and unfortunately, there are a number of people in the same situation and even though we are doing better than we have done in the past, there are still a number of people on the waiting list and we are obviously very keen to provide appropriate care.
Can I just correct one point, in terms of care, there are a number of options available to people who require support. So it's not a case of living by yourself or just having institutional care. And institutionalised care I would agree, would be the least desirable option. Irrespective of what age the person is.

Radio Host: How many relatively young people would be living in nursing homes because of a condition like this?

Minister Piccolo: It varies, the exact figure I don't know. It depends on people's conditions. For example, people's conditions do vary over time, in terms of what support they require.

Radio Host: Of course it depends on their condition, but what kind of number would it be, a dozen, two dozen, a hundred?

Minister Piccolo: Look, it probably is over a dozen, but the short answer is, it's too many. And that's why we've signed up to the National Disability Insurance Scheme, and this issue won't be addressed until we've moved 100% to the scheme.

Radio Host: Well Hohn will be waiting years until that's kicked in for his age group.

Minister Piccolo: We're doing what we can with our current resources, we are doing better but we could still do better than this. John's case unfortunately is not unique and we need to make sure people are given a whole range of options and that's why we've signed up to the scheme and that's why we've put money aside to be part of the national scheme.

Radio Host: Are there accommodation options that you can find for John?

Minister Piccolo: I'll talk about people like John. Options range from in home care, to where they share, which sometimes can suit and sometimes doesn't suit, to group house situations. I'm not going to try to defend institutional care because we are trying to transition out of these and into personalised services. We understand and accept that this is better for their quality of life.

Radio Host: Yes, can you get back to us when John has better accommodation?

Minister Piccolo: Sure, I'm happy to do that but what I can say is his case is under constant review like others, and as soon as a place comes available, we'd be very keen to place him in a suitable place. And you're quite right, you can get a place that suits his personal circumstances and that is what the scheme is all about.

Radio Host: Minister, thank you for your time.

I didn't do the interview just to help my own situation, it was more to make the public aware of the situation for other young people in nursing homes which I'd become aware was a lot more common than just my situation. I was happy that Minister Piccolo responded to my interview but I was disappointed that he really didn't offer any concrete alternatives for myself or others. There was then a follow up radio interview with Kelly Vincent MP - Dignity for Disability, where she spoke of how many young people are living in nursing homes and how important it is to get these numbers down. All the likes and encouraging statements prompted me to do some advocating for people who are going through what I was going through, but are unable to speak for themselves.

2015-16

Time at Hill Street 16/7/15 - 1/5/16

In July 2015, after my interview with the ABC I was offered a place outside residential care which looked good. I would be sharing with someone else in community care. Initially this seemed like a much better option than the nursing home but it turned out that the person I was sharing with was incompatible with me. This person had an Acquired Brain Injury that led to severe behavioural problems, which made things very difficult.

The house came with 24/7 care (more for the other resident) and was designed to have two bedrooms down the back and an ensuite toilet for both people to share. Up the front was the carer's room. Sharing a toilet with this person was very problematic. Because of their behavioural problems, they would get up at 2-3am and spend hours in the bathroom. This meant that I was unable to sleep as it was next to my bedroom. I was unable to keep my toiletries, toothbrush, shaver etc. in the bathroom, even though we were supposed to be sharing. At least three or four times this person came into my room in the middle of the night, opened the door turned on the light, confused about which room was his.

One alternative was to move this person to the front room of the house which seemed like a good option. At least three meetings occurred at the house in regards to bedroom arrangements, all of which my brother and sister attended. Unfortunately, nothing was achieved. The carer agency was not prepared to put locks on the front door, but were concerned that if this individual moved to the front bedroom, he would escape without anyone knowing.

I ended up moving to the front room that was smaller but at least I then had my own bathroom. My family, particularly my brother and sister, spent a lot of time with and for me helping to make my situation better. All of my family was very supportive of my situation but very regretfully I let my frustrations out and my behaviour reflected this. I was having a hard time living with this person as nothing was my own. I had to hide my food in my room, and I struggled to even watch TV without this person taking over the remote and changing the channel. The sleepless nights were exacerbating my situation.

Even after moving to the bedroom at the front of the house, his continual ruffling through cupboards and general behaviour was disruptive, along with the carers. So I continued to search for other living arrangements, again writing to various Ministers and as many advocates as I could.

Minister Piccolo,

I respectfully ask the process of my case, I can only assume you have had ample opportunity to examine my case. I have now spent over 12 months in a Nursing Home and been in inappropriate share accommodation since July

this year. I have followed all proper avenues to access single (cluster type) accommodation. Both my brother and sister, as well as my Case Worker from Disability SA have spent countless hours attempting to rectify the situation. We have also had at least three meetings with Calvary Home Care who administer the care where I currently reside but this has amounted to nothing. This has caused extreme stress for both my family members and me. I have had medical reports from my Doctor explaining how detrimental my current housing is to my health - both mentally and physically.
I had acknowledgement of your contact with Kelly Vincent on the 22nd of October but this is not the first contact I have had with you via an interview done with ABC 891 done with you back in June 2015. Please advise what more I need to do because as has been substantiated by my doctor my mental health is not very good. I am sure you will note that I have copied this to Duncan McFetrides office and I will be contacting local media depending on your response.

Yours Sincerely,

John

Many months passed before I heard from anyone regarding any alternative living arrangements. Almost a year had passed until I was contacted by a Disability SA Case Worker with the availability of a place at Woodville West. This place had been vacant for six months which came as a shock to me but I was grateful to be moving in somewhere different.

Current: at Woodville Cara Concierge Apartments 30/5/16 -

It might sound like I am energetic getting up early every morning to exercise but I assure you I am not, after more than twenty years of doing the same routine at 6am every morning I am exhausted. I would like to sleep in and not exercise but I know if I don't I won't be able to self-transfer or go to a disabled toilet without help. I find the thought of having someone help me using various equipment quite uncomfortable and difficult to cope with. I know a lot of people do not have a choice but seeing as I still have a choice, I like to do things myself. I do my exercises on my bed each morning so it is not like I am out in the freezing cold. I also walk as much as I can with a walker, subject to decent weather, so what I do is not as much as some. I personally know people that exercise and walk every morning rain or shine hot or cold – people like that are truly inspiring. I know there are a lot of people who are more severely affected than I am and are totally reliant on wheelchairs, so I am constantly reminded just how fortunate I am. Although, this is also a reminder of what might possibly lie ahead for me. It took me a long time to accept having help to dress and do a lot of very personal things. I might be determined but the reason I do it is because I really believe that if you don't exercise and strengthen your legs and muscles you will end up in a wheelchair sooner. If you do end up in a wheelchair sooner, I know it is not the end of the world. A lot of people do cope quite well with using a wheelchair full-time but I do not, and I wish to keep my mobility for as long as I can. I know I am lucky because there are a lot of people who can't do a lot of things themselves and I continue to be surprised with just how well adjusted they are. I have just not quite adjusted yet.

In saying all of this, the place that I have ended up in is fantastic. It is purpose built for people with disabilities https://www.cara.org.au/accommodation and offers a concierge service and a perfect set-up to allow a balance between independent living in comfort, with privacy, but also help when you need it. I suppose the purpose of me writing this story is to say that although I have had a few very ordinary years, I realise how lucky I am to be in a place like this now and wanted to speak for people that have it a lot worse than me.

Many times I did almost give up on the system, so I am determined to make it known, what people living with a disability have to go through at times. It really is made very hard for people who are disabled. Some stories I have heard range from people having to sleep in their wheelchairs to having to wait hours for an access Taxi in the wet and cold or extreme heat. While I realise the wait and the bureaucracy I had to go through to get here, I thought it might be worth telling my story so that people are aware of the fight. Even if it doesn't achieve much it has been a cathartic exercise for me and might interest or benefit someone.

I want to raise awareness of the need for similar places to Cara’s Concierge Apartments. The last couple of years have been quite difficult for me with no suitable living arrangements. So I just hope that this story can help other people in similar situations to find better options for themselves and perhaps develop and maintain a more positive outlook on things. A more positive outlook would help achieve a better result for both health and long-term.