

Dupuytren's and Ledderhose Disease

A Radiotherapy Treatment Experience

Written August 2019 – a patient's review

I am a 68 year old New Zealand male with a long history of Dupuytren's disease (palmar fibromatosis) and Ledderhose disease (plantar fibromatosis). I have detailed my experiences in this article in the hope that it may give other sufferers of these diseases some insight into the use of radiotherapy as a form of treatment. I documented my treatment period (2018/2019) with photos, notes and measurements and have used these as the basis for this report. I have tried to be accurate and practical with my assessments and hope I have struck the right balance in the content. This article reflects my own journey and private opinions, based on my research and experiences.

Dupuytren's overview.

I have a family history of Dupuytren's and I first noticed I had early symptoms of the disease back in the mid 1980's. These symptoms slowly progressed over the years, with signs of thickening skin, followed by nodes, cords and finally contractures of the fingers. During the period 1996 to 2013 I had 4 surgeries (2 on each hand) for Dupuytren's. As my hand surgeon noted, I have quite an aggressive form of the disease. The surgeries addressed the various nodes, cords and contractures in the palms, index and small fingers and in the webs of both hands. One of the procedures was a revision surgery with a large, full thickness skin graft to my right little finger.

In the period 2013 through to 2018 the disease progressed noticeably in both my left and right hands. In both hands there were nodes in some fingers, thickened areas of skin, cords, lumps developing in the webs between thumb and forefinger and also the beginnings of contracture to some fingers. By mid 2018 it was obvious that another operation on my left hand was going to be necessary at sometime in the next couple of years and that the right hand would also need future surgery. Obviously I was not looking forward to the pain, risk, cost, or the 8 to 12 week recovery periods. I will come back to Dupuytren's later in the article.

Ledderhose overview.

I probably noticed the first signs of Ledderhose in my feet about the same time as I noticed the Dupuytren's forming – in the mid 1980's. These signs presented as: a 10mm diameter lump along the arch of each foot, midway between the ball of the foot and heel, and on the left foot there was an additional 10mm lump just below the ball of the foot. Over 30 years these lumps changed very little and caused no problems at all - although I noticed the very slow development of 2 extra lumps along the arch of both feet.

Catalyst for Change.

In early 2018 I noticed that the minor lumps in both feet seemed to be getting bigger. By mid 2018 it was obvious that I had 2 to 3 rapidly increasing lumps in each foot and the increases in size were clearly noticeable with each passing month. These were beginning to cause regular pain when standing or walking and they frequently caused a sharp aching sensation, even when my feet were elevated. These distressing developments, coupled with the ongoing Dupuytren's symptoms I mentioned above, were the catalyst for some serious research. My previous experience and reading indicated that for both Dupuytren's and Ledderhose disease the most common treatments were surgical.

I already had extensive experience with Dupuytren's surgeries - all successfully performed with no complications but with a recurrence of the disease guaranteed.

I discussed the Ledderhose situation with my GP and underwent both ultrasound and then MRI scans to confirm the extent of the condition (and to confirm that the diagnosis was correct). Subsequently I was referred to a specialist orthopaedic foot surgeon for examination and consultation. Essentially the specialist's written assessment was that my only option was to wait until the disease became debilitating and then to have surgery. He specifically noted that there were no proven alternative treatments.

My reading had indicated that this disease is known to reappear aggressively after surgery in approx 80% of cases. The level and degree of recommended surgery to minimise reoccurrence is, in my opinion, horrific. My interpretation of the medical terminology is that it involves removing the skin from the soles of the feet and replacing with a skin graft. I considered the side effects of this procedure would dramatically affect my lifestyle – basically, severely limiting my mobility. This was not a surgery that I was prepared to consider.

Treatment Options.

I began researching alternative treatments for Dupuytren's and Ledderhose disease. Among them I considered collagenase injections, shockwave therapy, steroid injections and radiotherapy. In my opinion the two medical conditions are essentially the same disease, presenting differently in different parts of the body and I was hoping to find a common treatment for both conditions.

Treatment Objectives

My first, and major objective was to halt the progression of the disease - thus avoiding or postponing the need for immediate surgery. The second was to slow or prevent a reoccurrence of symptoms. The third objective was to reduce the effect of these conditions in some practical way - perhaps by reducing the size of lumps, nodes, etc, or perhaps reducing the degree of contraction in fingers or toes, or by simply softening the skin on palms or soles.

Extensive reading and research revealed that radiotherapy would likely achieve my major objective and that the second and third objectives could be considered reasonable as an expected outcome. The internet provided a wealth of information – although it took some months for me to reach my conclusion that radiotherapy was the right option.

In late August 2018 I began an independent search for a treatment provider by directly approaching private radiotherapy clinics and specialists across New Zealand. My situation and prospects were such that I was also prepared to travel to either the UK, Australia or Germany if necessary.

I received a positive response from Dr Ramesh Arunachalam, Consultant Radiation Oncologist at the Auckland Radiation Oncologist Specialist Centre. Dr Arunachalam already had experience in treating Dupuytren's and Ledderhose and he agreed to treat me. He gave me clear guidelines as to the most probable outcomes of the radiotherapy and detailed the procedures along with a few possible minor side effects – seemingly, the worst being the possibility of long term dry skin. He did note that radiotherapy is not normally useful in a situation where contractures have already developed.

The radiotherapy would involve treating the cords and nodules with a 20mm margin to a dose of 30GY in 10 treatments. This would be done via a split course where 15GY is delivered as 3GY each day for 5 consecutive days. This procedure is repeated after a break of 6 – 8 weeks.

The plan was to treat my feet first and to review the results 12 weeks after completion of the radiotherapy, with a plan to then schedule the same treatment for my hands.

Ledderhose Treatment.

Treatment was scheduled to begin in late September 2018. The week before treatment began I visited the hospital for approx 2 hours so that some custom shaped, sheet-lead, shields could be made to protect the areas outside the radiation target zones. At each radiation session these were taped across my hands (total set up time of approx 5 mins per hand). The radiation delivery was 2.5 minutes per hand – the machine was silent and the procedure completely free of any discomfort or sensations. It was actually difficult to believe anything was happening. Each visit took a total of approx 25-30min.

By the start of treatment I had 3 lumps in my left foot measuring 35x45mm, 18mm diameter and 12mm diameter respectively. The largest had developed in just 18 months from approx. 10mm diameter. In the right foot there were 2 lumps measuring 32x38mm and 18x12mm respectively. These had grown at a similar scale and rate as the left foot. Additionally a noticeable tightness had developed in the tendons along the soles - decreasing flexibility on extension.

Ledderhose RT Results

It took about 3 weeks for the effects of the first round of treatment to be clearly noticed and this was generally evidenced as a reduction in size and a softening of the lumps. The skin did become dry and I applied moisturiser twice daily. The effects slowly continued over the 8 weeks leading up to the second round of radiotherapy. I viewed these initial results as very positive.

The second round was completed and within 2 weeks the effects were really beginning to show with a steady reduction in the size of all lumps. The discomfort experienced on walking, standing and at rest was consistently reducing, and the hard cords which had been developing along the soles of both feet had softened and become more flexible, allowing the feet to extend freely when walking.

I cannot express the sense of excitement and relief that I felt by late January 2019. This had been a hugely successful result – far beyond the conservative expectations I had at the beginning of the treatment.

Dr Arunachalam reviewed my situation at the end of January. His observations can be summarised: “Post treatment the patient has had a dramatic response to RT with all his lesions in both feet showing significant reduction in size. In fact, on examination it is very difficult to feel the smaller nodules”.

I had experienced minimal side effects during treatment apart from some mild skin irritation and some tenderness. These symptoms had resolved within 2 weeks of the last RT session – in fact I spent several weeks of last summer barefooted on a boat and at the beach.

It has become apparent to me that the positive effects of the RT continue for several months after the treatments end. As I write this article in August 2019, nearly 9 months since the treatment ended I can summarise my situation.

I do have a single residual lump in each foot, each measuring approx 20x22mm. They are quite flat and not particularly noticeable although they can be felt. There is no discomfort when pressure is applied. The soles of both feet are more flexible and the cords softer and less prominent. Overall I feel that my Ledderhose symptoms have been reduced by approx 85%. I can walk, stand and run without any discomfort and essentially, on a normal daily basis, I am completely unaware of the minor residual indications of the condition. In this sense I can positively rate the RT treatment as a total success.

Whilst the long term efficacy of the RT is not completely known I believe I can optimistically expect to remain untroubled by Ledderhose disease for at least several years – likely even longer. If the condition should reoccur, my specialist advises that a further round of RT treatment is considered both safe and practical.

Dupuytren's Treatment.

The first treatment was at the end of February 2019. At this time, in my right hand, I had a noticeable cord running from the palm to base of the thumb where there were the beginnings of 2 small nodes. These indications were accompanied by the usual thickening in the surrounding skin. There was also a large 10mmx15mm sized lump in the web of the hand. There were early signs of 2 nodes on my little finger (which had been skin grafted in 2000). The Dupuytren's in my left hand was more advanced. The skin around the base of the thumb had thickened and there was a knotted cord running from the palm, up the index finger to a 9mm diameter node just below the first joint. There was a large lump measuring approx 10x15x20mm in the web between thumb and forefinger and this caused some restriction to my ability to fully open the gap between thumb and forefinger, and pain on over extension. At the base of the little finger there was an area of noticeably thickened skin measuring approx 20mmx20mm, and from here were 2 cords running up to an 8mm diameter node just below the second joint. These were causing the early stages of contracture.

The preparations for treatment and the treatment regime for my hands were the same as for the Ledderhose procedure.

Dupuytren's RT Results.

Again it took about 2 weeks for the effects of the first round of treatment to be clearly noticed and this was generally evidenced as a softening of the harder areas of skin. The skin did become dry and I applied moisturiser twice daily which controlled the condition. The effects slowly continued over the 7 weeks leading up to the second round of radiotherapy. By this time some of the lumps had reduced (although not as obviously as with the large Ledderhose lumps) and the restriction between left thumb and forefinger had eased.

I viewed these as very positive initial results.

The second round was completed and within 2 weeks the effects were really beginning to show with a steady reduction in the size of the lumps in the webs of both hands – both were about 30% smaller. There was a further easing in the restriction between thumb and forefinger on my left hand which allowed greater extension with reduced discomfort. The large palm thickening at the base of the small finger was significantly reduced in volume with the surrounding skin becoming soft and flexible to the touch. At this stage the 2 nodes on this hand were little affected but there seemed to be a slight softening of the cords in the little finger (an unexpected benefit – although small).

The changes in my right hand followed a similar course but I was pleased to see that the 2 small early stage nodes on the little finger had noticeably reduced.

At the 5 week point both hands began to dry and the skin deeply peeled in varying degrees over most of the treated areas of both hands but particularly where there had been lumps. This was great as it further reduced the apparent size of the lumps. It took about 3 weeks for this process to complete and after that my hands were generally left softer and the skin more flexible, although still somewhat dry – a condition easily remedied with moisturiser.

As with the Ledderhose experience, the positive effects of the RT continue for several months after the treatments end. As I write this article in August 2019, nearly seven months since the Dupuytren's treatment ended I can summarise my situation.

The lump in the web of my left hand has reduced by 60% in volume and that in the right by 80%. I have no noticeable restriction between thumb and forefinger of the left hand; full extension and lifting a load cause no pain. My little finger is less contracted (it is now almost straight). Nodes in the 2 fingers have reduced by about 20%. Areas of thickened and harder skin are all approx. 50% reduced in size and softer. The cord running from palm to index finger is mainly unchanged but subjectively a little more flexible. The right hand has continued to follow a similar improvement with the cord mainly unchanged but both nodes in the little finger are now visually indistinguishable.

An interesting observation for me now is just how much the Dupuytren's growth seemed to have been more generally spread across the surface layers of the skin on the palms of both hands than I had noticed. The treatment has left the cords in both hands more noticeable to the touch (I guess since the surface layers are now softer and more flexible).

Overall the results were very positive and although not as dramatic as those for the Ledderhose I would say that all 3 of my initial expectations regarding RT were exceeded. My main hope that the disease progression could be slowed or halted appears to have been realistic and there is good evidence that Dupuytren's responds in this way to RT. I would rate treatment as approx 60% successful in terms of a physical reduction in symptoms but since the residual symptoms are essentially untroubling and visually insignificant this success might well be considered around 75%.

I am therefore feeling positive that my Dupuytren's progression has been halted - certainly the symptoms I was experiencing have significantly reduced. Although, as with the Ledderhose, there are still some residual physical indicators, generally on a daily basis I would say that I am now unaffected by the disease.

Summary.

At the start of this article I laid out the objectives I had for any treatment. The first was to halt the progression of the disease - thus avoiding or postponing the need for immediate surgery.

The second was to slow or prevent reoccurrence of symptoms. The third objective was to reduce the effect of these conditions in some practical way - perhaps by reducing the size of lumps, nodes, etc or perhaps reducing the degree of contraction in fingers or toes or by simply softening the skin on palms or soles. The ratings I have given the 2 treatments are based on my original objectives and conservative expectations.

For me, the radiotherapy treatments I underwent in late 2018 and early 2019 have been hugely successful in delivering significant improvements to the physical symptoms of the diseases, and a corresponding reduction in the mental anxiety that is a real part of watching the progression of these distressing conditions. I have no ongoing side effects or skin dryness issues.

This time last year all I could see ahead of me was a round of aggressive foot surgeries which would surely have left me significantly less mobile, if not partially disabled, and a future of more routine surgeries to control the Dupuytren's. As I write this report I feel a great sense of excitement at the very real and positive results of RT and look forward to the strong probability this has halted the progression of the diseases – maybe not forever, but I've read a lot of articles and reports which record no noticeable reoccurrence of symptoms for periods of more than 6-8 years.

My understanding is that RT is acknowledged to work best if treatment is given when either Dupuytren's or Ledderhose are in the active growing phase, rather than after cords and contractures have formed. To me this implies that treatment is better sooner than later and that allowing the conditions to progress to advanced stages of growth and contracture (ie to the degree where surgical intervention is normally considered and recommended) would negate the very real benefits that early RT could bring.

I was advised that there is no risk of damage to underlying tendons or bone and studies have suggested no increased complications with surgery after RT delivered to this dose – if future surgery is needed.

From my experience I would urge those who suffer from Dupuytren's disease (palmar fibromatosis) or Ledderhose disease (plantar fibromatosis) to seriously consider the early intervention of Radiotherapy ahead of regular surgical procedures. If your regular GP or surgical specialist is unfamiliar with, or unsupportive of, the use of RT for these conditions I would urge you to “start the conversation” and, if possible, gain their support. If this is not forthcoming then “self refer” to a Radiotherapy Specialist.

I hope there are readers who have found this article useful – good luck with your quest.

Thanks to Dr Ramesh Arunachalam and to the kind, talented RT team who treated me at Auckland Hospital.

Disclaimer: This article is the result of my private research and personal experiences – I do not have a medical background. Readers should form their own opinions about RT treatment and ultimately seek advice from a suitable medical professional.

