Dupuytren's Tale of Woe and Intrigue Another Update by Dougster October 21, 2022

This is my personal tale and is directed to those who have discovered they have Dupuytren's disease and have an opportunity for early intervention. Below are some additional and more current thoughts on my experience as a follow-up to a post I made to the International Dupuytren Society's Forum.

A full year has elapsed since my successful treatment. I have no signs of Dupuytren's disease re-emerging. I will gladly accept treatment again if my Dupuytren's disease reappears.

The first step is to get a diagnosis if you haven't already done so. Don't get a biopsy if there's a chance of Dupuytren's disease, because that might make it worse. If the diagnosis is unclear, get a second opinion.

Dupuytren's disease is highly variable, and lamentably for most of us, incurable. That doesn't mean giving up.

Sometimes Dupuytren's will go away or go into a quiescent state on it's own, with or without the help from changes in physical activity, diet, medications, personal habits, or home remedies. So there's an argument for watchful waiting. But once it stops being quiescent, then you must act.

References at the bottom of this discussion will be helpful for those who want more information. I took the liberty of copying material I found on the web.

Dupuytren's disease is a benign fibroproliferative disorder. Roughly speaking, it is caused by maladaptive gene expression at the cellular signaling level where the body is responding to a perceived injury. If your Dupuytren's disease is active, it may grow and proliferate if left unattended, but having surgery (an "injury") can introduce its own set of problems. You're stuck between a rock and a hard place. An early but minimal "Goldilocks" intervention is your best bet.

Two options are available for early medical intervention: radiotherapy and steroid shots. They both work as long as the nodules are growing and the fingers have no or a minimal contracture. They are both low-risk, with few side effects. There's a difference of opinion as to which approach is better. From what I gather, radiotherapy is more popular in Europe. Steroid shots have the advantage of not requiring sophisticated equipment, the associated training, or cost. Steroid shots involve fewer treatment visits. And from my own personal experience, steroid shots can alleviate fibroproliferative disease in other parts of the body through the incidental leakage of steroids out of injected tissue.

One caveat with both radiotherapy and steroid shots is that they are not appropriate for people with specific health concerns. You need to do your own research just to be sure.

Start with one of the two low-risk options described above first. There's little to lose if, for some reason, they fail to work. I now have complete use of my hand after successful treatment. It is pain free, with nodules/cords having shrunk 50-70%. Once you are on the path to more invasive treatment, there is no turning back.

I was interested in getting steroid shots, so I thought it would be best to have a skilled hand surgeon perform the procedure. I went to five different hand surgeons with a combined total of nearly 100 years in clinical practice. It did not go well. The entire tale of woe is posted on the International Dupuytren Society's Forum, listed in the references section below.

As it turned out, a resident (in-training) doctor supervised by a MD in family medicine was responsible for my successful treatment. This was her first time, and she did a brilliant job. She performed the procedure the way it was described in the AFP Journal (link below), except she used 40 mg Depo-Medrol as directed by the MD supervising her. The nodules from Dupuytren's disease are on the surface, so they are easy to locate; and as long as the nodules are injected from the side, as outlined in the procedure, there's little chance of something going amiss. Be forewarned that it takes some strength to inject directly into a nodule. The resident doctor had a genuine, but temporary, indent in the palm of her hand from the plunger of the syringe as she forced Depo-Medrol into the nodules. I did not need to go back for a repeat treatment.

This is a terrific article with a detailed description of the experience of steroid injections, with lots of pictures: https://kineoptics.com/stuff.html

Sometime in the future, Depo-Medrol could in turn be substituted with Humira once Humira has completed the requisite regulatory approval for treatment of Dupuytren's disease. Depo-Medrol is quite a bit less expensive, so it might continue to be useful in some cases. Conceivably, one could start with Depo-Medrol first and follow-up with Humira when needed or available.

Conclusion:

Once you have discovered that you have Dupuytren's disease, don't wait for a contracture to develop. If your Dupuytren's disease is active, then get an early start with a low-risk approach. The sooner the better. You will risk little by trying steroid shots or radiotherapy, and have a better chance of normal use of your hands for the future.

For steroid shots, adhere to the procedure as specified online by the AFP Journal: https://www.aafp.org/pubs/afp/issues/2007/0701/p86.html

Do not deviate from this procedure EXCEPT for injecting a total of 40 mg Depo-Medrol as a substitute. This is what was used on me. Similar to antibiotic usage, you want the maximal systemic impact of a FULL DOSE, with as much of it going into the nodules as possible. A lower dose could be insufficient and aggravate the disease. Repeat injections may be necessary after three months. It just so happens that 40 mg of Depo-Medrol is used in needle aponeurotomy procedures. An intriguing coincidence, if you think about it.

Afterword:

For those who are actively seeking medical treatment, set time aside to read, understand, and prepare. When meeting with a medical professional, don't be pressured into compromising your health. Be aware and act when something doesn't seem right. You may not know it at the time, but your future health and quality of life are at risk when treatment is inadequate or inappropriate. Dupuytren's disease is called "fibroproliferative" for a reason.

For steroid injections, make sure the medical professional completely understands and clearly agrees to the procedure as described in this article before starting. I got up and walked out after a hand surgeon had first agreed but then later changed his mind. And I'm glad I did, as it turned out to be one of the best decisions I've ever made. Truly life-changing. Not only for me, but maybe for you too.

"Full Medrol" Steroid Injection Procedure Summary For Dupuytren's Disease

- Follow the AFP Journal procedure, except use a <u>full dose</u> of 40 mg Depo-Medrol with as much of it going into nodules as possible.
- With considerable effort, force the syringe needle and steroid <u>fully into</u> nodules.
- Steroid injections are in a <u>full star</u> pattern around the nodules.
- Steroid injections are <u>fully from the side</u> and not perpendicular to the palm. Keep clear of injecting steroids under nodules.
- The syringe is <u>full of Depo-Medrol</u> and is not diluted.
- A separate syringe full of Lidocaine (or some other local or topical anesthetic).

There's a reason for each step above. Don't take short cuts. If there ever was a saying that applied to Dupuytren's, it would surely be "Give it an inch and it'll take a mile". Don't give it an inch. Follow the procedure.

If you find that Full Medrol shots have helped you, pay it forward by helping a fellow sufferer of Dupuytren's disease. Please do your part and spread the word.

And pay attention to the references below!

References:

"Dupuytren's Tale of Woe and Intrigue" post on International Dupuytren Society Forum; This is the original Jun 27, 2022 post containing <u>additional comments and information</u>; https://www.dupuytren-online.info/Forum_English/board/other-therapies/steroid-injection-2 36.html#3

Ketchum, Lynn; "The Rationale for Treating the Nodule in Dupuytren's Disease"; A must-read for anyone who wants to delve deeper into Dupuytren's and steroid shots. "The smaller the nodule when first treated, the more satisfactory the response."; https://dupuytrens.org/DupPDFs/2014_Ketchum.pdf

Ketchum, Lynn and Donahue, Terrence; "The Injection of Nodules of Dupuytren's Disease With Triamcinolone Acetonide";

This early study found "97% of the hands showed regression of disease", although it took several rounds and did not use the Full Medrol procedure mentioned above; https://dupuytrens.org/DupPDFs/2000_Ketchum_1463.pdf

Syed, Farhatullah and Bayat, Ardeshir; "Superior Effect of Combination Versus Single Steroid Therapy in Keloid Disease: A Comparative In Vitro Analysis of Glucocorticoids"; Comparative study of fibroblast response to different steroids. "Medrol was twice as effective as [Triamcinolone Acetonide] at a similar (25 mg/mL) concentration (Figure 2A)". However, extending the trend lines of Figure 2A shows that Depo-Medrol was almost 2.5 times more effective when extrapolated for two more hours; https://pubmed.ncbi.nlm.nih.gov/23126666/

Pess, Gary with Eaton, Charles and Denkler, Keith; "Advanced Techniques in Needle Aponeurotomy and Collagenase - Going Beyond the MP Joint"; This paper cites the use of 40 mg of Depo-Medrol.

[Opinion: To prevent fibroproliferation, crippling pain and injury, and the undeserved, heartbreaking devastation to one's life, use Depo-Medrol <u>before a contracture has started</u>. The Full Medrol procedure is a simple, economical, and accessible treatment with few complications. Patients from all walks of life would benefit from it. The Full Medrol procedure should be the universal first choice of treatment during the early active phase of the disease when treatment is most effective.]

https://www.assh.org/annualmeeting/servlet/servlet.FileDownload?file=00P0a00000mMoDBEA0

Trojian, Thomas and Chu, Stephanie; "Dupuytren's Disease: Diagnosis and Treatment"; The original 2007 AFP Journal procedure for steroid injections, using Triamcinolone Acetonide (instead of Depo-Medrol);

https://www.aafp.org/pubs/afp/issues/2007/0701/p86.html

Dupuytren Research Group; "Dupuytren Literature: Corticosteriods"; An excellent compendium of research articles; https://dupuytrens.org/dupuytren-literature-corticosteroids/ Nanchahal, Jagdeep et al; "Anti-tumour necrosis factor therapy for early-stage Dupuytren's disease (RIDD): a phase 2b, randomised, double-blind, placebo-controlled trial"; A trial using Humira injections;

https://www.thelancet.com/journals/lanrhe/article/PIIS2665-9913(22)00093-5/fulltext

LaCour, Joe; Online commentary with pictures of personal experience with steroid injections; https://kineoptics.com/stuff.html

Wikipedia page for Methylprednisolone (Depo-Medrol) https://en.wikipedia.org/wiki/Methylprednisolone