

SOCIAL SECURITY DISABILITY DETERMINATION SERVICES

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PERSONAL PAIN QUESTIONNAIRE

Applicant's Name: (YOUR FULLNAME)

1. Please describe the location, severity and nature (sharp, dull, aching, etc. of your pain.

I have pain all over. The main locations are fingers, hands, arms and shoulders, hips, legs knees and ankles. Some dull and aching when not moving but mostly sharp when performing any movement. My fingers are so crippled and contracted with ulcers and calcinosis, that if they get touched or bumped it basically feels like someone hit them with a hammer.

My skin is so tight and hard that any reaching or bending is painful, sometimes even just being touched. The tendons in my wrists, elbows, shoulders, knees and ankles are so hard and tight that they even squeak when I move and are very painful. If they stay in one position too long or one of my limbs do, they get so tight or locked up trying to get them to move or forcing them causes extreme pain especially if they snap.

2. What makes your pain worse? (movement, cold weather, etc)

Cold is terrible. Causes everything to be stiffer and harder. For me indoor or outdoor temperatures under 75 degrees is too cold. Right now at work I rarely remove my winter parka. Movement and not moving are both trouble. I have to try and balance them. I can't stand or walk for very long time or distance, yet if I sit too long or hold a phone in a position too long, it causes pain and then trying to move again causes severe pain. Too much handling of paperwork, writing, folding paper to put in envelopes, trying to remove a staple etc causes a lot of pain and cramping to my hands and fingers, which can extend to the next day with them basically being unusable and causing the calcinosis to flare up.

3. How many times do you experience pain? Per day? Per week?

All day, every day.

4. How long does the pain last?

Since I have it all day every day, lets consider the severe pain for this question.

If my fingers get bumped, broken open or caught and pulled the severe pain will last for a minimum of 20 minutes, but can cause implications that can last days or a week. Severe pain when standing up or moving the joints usually lasts 10 or 15 minutes, then goes back to a moderate pain.

5. Is your pain worse in the morning, afternoon or evening?

The mornings are real bad after being in bed all night. Knowing that, I just have to get ready for it when I try to get out of bed, then try to get to a standing position and walk. Besides the joints the feet are very painful to walk or stand on in the morning. Late morning and early afternoon usually gets better. We'll just consider the afternoon after 4 hours at work, by then my hips, back and legs are in severe pain that I can hardly stand it and I when I get home it is straight to the heated lift chair with massage. Scleroderma come with a great deal of fatigue. If I push it too long at work or activities I can almost end up at the point of collapse. After getting to rest, then stretch or do a little light movement exercise - sometimes the evenings are better except for being extremely tired.

6. Is your pain located in a specific area or does it radiate (move) into other areas?

My pain is in many areas. The main locations stay pretty steady, though it can move around.

The scleroderma decides to activate in a new area too.

7. Has your pain changed over the last 12 months? If so, how?

Yes. It has become more severe. The scleroderma after 10 years of struggle has become even more active. My doctor is trying new medications as my prior medications have no effect in controlling it any longer. In my situation now, medications that are not FDA approved for scleroderma but have shown improvement over standard treatments are now my best option for trying to keep from becoming unable to move. Our goal is to get me on actemra.

8. Please list your pain medication(s) and dosage(s). How effective are they in relieving your pain? Tell us any side effects you have from each medication.

MEDICATION NAME	DOSAGE	EFFECTIVENESS	SIDE EFFECTS
leflunomide	20 MG	Have only been on it for two weeks. Most patients start to feel the positive effects of leflunomide at 4-8 weeks. I discontinued methotrexate when I started taking this.	Common side effects are Diarrhea headache etc. Can cause liver and kidney damage or disease. In a small amount of cases has caused lung damage.
Folic Acid	1 MG tablets-2 per day	Helps to counteract side effects of leflunomide	None

9. Describe any treatments that you use to relieve pain. (Hot baths, therapy, exercise, etc.) How well do they work?

Heated Lift chair with massage. Gazelle low impact exercise machine, and treadmill. Stretching. Also resting and performing no movement at all and not touching anything. I was in physical therapy, but insurance won't pay for additional sessions. I can't get in and out of a regular tub even with assistance, I have walk in shower. Hoping to get a walk in tub, but they are expensive plus renovations to the bathroom. Don't know if it will be financially possible.

10. Are you involved in rehabilitation with the goal of returning to work either part time or full time?

I went into physical therapy because I was afraid I wouldn't have been able to walk in a month. Also to try and continue working.

11. Tell us how pain limits your activities.

I'm struggling to make 4 hours 4 days a week at work. I hardly go anywhere but work and home. I try to get out with someone to go shopping once in a while but it can't be for very long. I haven't been driving lately - so hard and painful to get in and out of the car, turn the steering wheel, even turn the key. I can't clean my own house or do the dishes. I don't commit to any activities with friends or family until the day of because I don't know if I will be in too much pain to go. Also, if travel is required, an hour or more in the car locks my legs up tight and I can hardly stand to stay sitting. Can't go for walks.

12. Describe the activities that you have had to restrict or stop because of pain.

All my athletic activities (golfing, skiing, running), but I had to discontinue them years ago. Cleaning my house. Working full time. Going for walks (other than around the block). Opening mail. Driving. Going on trips. Going to events with friends. Anything that can cause my hands to be bumped. Cooking or preparing meals. Thank goodness for microwaveable mac & cheese!

13. Has pain affected the amount of time you sleep? No Yes

If yes, please explain how your sleeping habits have changed.

I try to sleep more sometimes to get away from the pain, but now when I move at night it causes such extreme pain and wakes me up. A lot of times I scream. I can only sleep on my back. Sometimes the pain is so bad especially in my legs that I can't stay in bed.

14. Since your pain began, have your eating habits changed due to the pain?

No Yes If YES, by how much?

The scleroderma tightens my face and mouth. I basically have no lips and my mouth has become so small it has pushed my teeth in and they are a crooked mess and painful. It is hard to keep my mouth open and chew because the big ligament/tendon in the jaw has been so affected by the scleroderma it causes extreme pain Plus the fact that I can hardly get my mouth open enough to get a spoon in it. Scleroderma affects the internal organs as well as the skin, tendons, muscles. I have tried to gain some weight with no success. I am 5'4" and now at 95 lbs. It isn't just the mouth and teeth that affects it - every movement takes so much energy, my stomach feels full very quickly and can't digest much hearty food like meat, which I can hardly chew, and the digestive organs are affected so the food nutrients do not absorb into my system as they should.

If there has been a change in either direction, were you trying to change your weight?

15. Has your ability to think and concentrate been affected by pain? No Yes

Sadly yes. When the pain is bad, there is no way to concentrate, solve anything, even try to do calculations, or remember facts names, work with software that requires skill etc. Have to go to easy tasks that take little mental effort.

16. Are you able to take care of yourself as far as day-to-day needs are concerned?

No.

I can no longer dress myself. I cannot shower myself/ completely and effectively on my own. I can't bend enough to pick up anything that is not at least 2 feet off the floor. I have a grabber, but with my hands it is hard to use, and I can only pick up light items. I can't cut food by myself, remove cold items from the fridge, very limited on food preparation. Can't open bottles or jars, boxes, basically anything. Can hardly reach to the top of my head. I need assistance get up from most chairs and to get out of bed. Driving/riding: very difficult to get in and out of vehicles. Since I can't grasp the steering wheel and my arms and shoulders are weak and have such limited movement, it is hard to turn the steering wheel. I no longer drive on the highway, only in town, and lately have not been driving at all. I can't clean my house or do laundry. At home have high toilets installed with assistance chair bars - not just a handicap accessible bar. Work put up a handicap accessible bar which worked for a while, but the toilet is normal height not high and I can't get down or off it. My dad installed the chair bars, but I still can't get down and off, so if absolutely necessary I use the arms to support myself and stand and lower a little. Mostly I try to not use the facilities at work.

17. Please describe your activities for a typical 24-hour day. Please comment on things such as: cooking, laundry, cleaning (vacuuming dusting, scrubbing), car repairs, yard work, exercise, etc.

Wake up hopefully laying flat. Try to break knees free with extreme pain, then shoulders and elbows. Do movement exercises in bed till falling back to sleep from pain and exhaustion. Hopefully be able to get to a sitting position on the bed without assistance. Hold on to the stool and the bed and try to stand up and straighten the knees. Regain balance and try to walk on the extremely painful feet. Get the sketchers and robe on and try to walk back and forth. Hydrate and take medications-getting them out of the bottle and into the mouth takes time. Go to the computer, have milk, coffee and toast, check work email if there are any emergencies. Check government, medical, insurance etc requirements in personal email. Try to get off the chair, take robe off and head to the dreaded shower. After shower, make it to lift chair before collapse. Up and off to dressing wounds. (I should own stock in bandaids and curad. Call to see who can dress me & take me to work, hopefully with enough time to do exercises if I am able so I can last longer at work. Get dressed, make it in an out of the car to work now exhausted. Get in the office, in my chair, on the computer and engage. Try to accomplish as much as possible till I can't take it. Get picked up by somebody and make it home so I can use the bathroom and hit the lift chair - hopefully getting to watch Judge Judy. Actually, best thing getting to see my loving puppy dog who knows I can't get down to hug or pet him and doesn't think my hands are creepy, runs in to the bedroom on the bed to I can pet him and get hugs and kisses. Have crackers an olives or mac and cheese. Wait for Jeff to cook supper if his schedule allows. Back to the computer for research, reading, trying to learn new things. Back to the adjustable bed, watch a little tv, go to sleep and start the next day. That's if nothing happens which requires doctors visits, wound clinic etc.

If needed, you may use additional paper to answer any of the questions.

Signature: _____ Phone Number: _____ Date: _____