

# Feeling Fit With FSHD

A person wearing a light-colored hoodie is seen from behind, standing in a field with their arms raised in a 'V' shape. The background is a bright, hazy sunset or sunrise over a landscape with trees and tall grasses. The overall color palette is warm, dominated by oranges, yellows, and soft blues.

Part 1 of 2

## Face, Shoulder Girdle + Arms and Nerve Flossing



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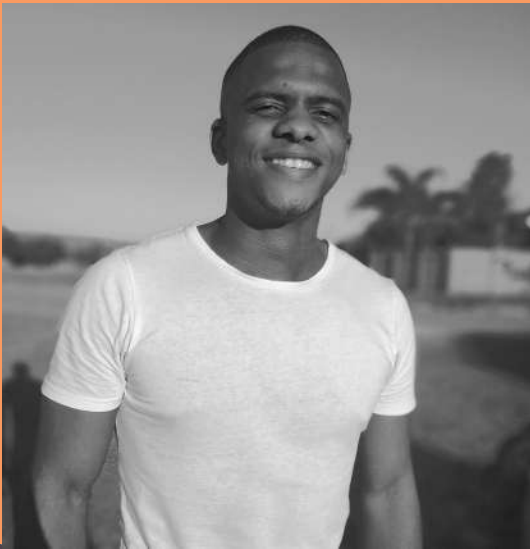
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# A Bit of Background

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My name is Lonwabo Nene. I live in South Africa. In my pre-adolescent years, I started to notice significant weakness and a feeling of 'looseness' all along the right-hand side of my body; from the face - down to the foot.

Subsequent issues of facial weakness symptoms, a 'drooping shoulder', winged scapula, hip pain, cartilage loss as well as footdrop all started to present themselves - unilaterally.

Over the years, I would find myself researching about my condition and all these many symptoms I was experiencing. Trying different exercises and techniques until I was fortunate enough to receive intensive physical rehabilitation.

These are my experiences and I would like to share them with you.

# Before We Continue...

The information supplied in this slide-show presentation is provided as an information resource only.

It is not intended to be relied upon for any diagnostic conclusion or replace any treatment protocol.

Lonwabo Nene is not a medical physician of any kind.

The information provided is mainly from Lonwabo Nene's anecdotal experiences living with muscular dystrophy and the various ways in which he manages the condition.

## A caveat, Contact details and *Medical disclaimer*



FSHD and other forms of muscular dystrophy may vary in degrees of severity between individuals



Should you wish to get in contact with Lonwabo Nene, do so via this email address: [aboutlhn@gmail.com](mailto:aboutlhn@gmail.com)



Please consult your healthcare provider for guidance before undertaking any shown exercise



# “Weakness and a feeling of ‘looseness’ ”

My name is Lonwabo Nene. I live in South Africa. In my pre-adolescent years, I started to notice significant **weakness and a feeling of ‘looseness’** all along the right-hand side of my body; from the face - down to the foot.

|| Weakness and feelings of ‘looseness’ are still two common descriptions I use to describing FSHD ||

**Subsequent issues** of facial weakness symptoms, a ‘drooping shoulder’, winged scapula, hip pain, cartilage loss as well as footdrop all started to present themselves - unilaterally.

|| The more I became aware of my body and what was happening, the more I came to realise these were the knock-on effects of something that would otherwise be seen as unrelatable ||


## Topics of Discussion

FACE

SHOULDER  
GIRDLE + ARMS

Back  
&  
Chest

Hip Girdle  
+  
Legs

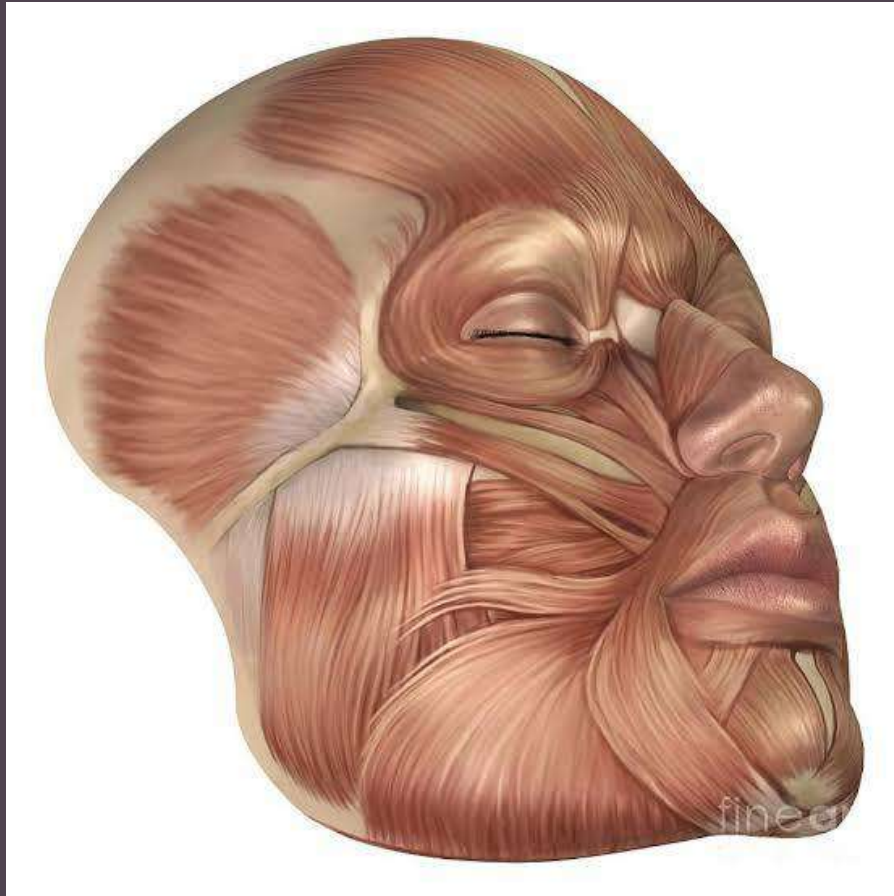
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- Face: Decreased expression and a heaviness on the affected side
  - Shoulder Girdle + arms: Severely internally rotated shoulder and visible atrophy of bicep and tricep
  - Chest & Back: Difficulty with pressing movements, back pain
  - Hip Girdle + Legs: hip drop resulting in unequal leg lengths and compensation patterns

# Face

It felt as though one side of my face had not showered in 3 weeks

It started to feel 'stale'

# Why I started Massaging My Face...



Soon after recognising the first onset symptoms of my MD, I felt a heaviness and a sense that gravity had an extra 'force' on the right side of my face. I would often get numbness and cold skin (features which would later represent themselves unilaterally down the right side of my body)

## Other 'Features'

- Facial weakness in expressions
- Drooping of the eye
- Visibly less sweating from the right side, even during exercise
- Dry eye in the morning

# How To: Face Massage For Improved Blood Circulation

## FINGER PADS

Use your finger pads to press into your temple area, using circular motions.



## INTERMEDIATE PHALANGES

For the cheeks, use this half-fist, with the phalanges massaging the side of your face in a circular motion.



## KNUCKLES

A real problem area for me still remains to be the space of the 'smile lines'.

I like to use my knuckles for this space in a back-and-forth motion.

This allows me to apply deep pressure and stimulate blood flow.



# Shoulder Girdle

I started coming up with creative ways to store my books at school without having to carry anymore than 4 textbooks in my bag

# My Weak Shoulder Girdle and its implications

I assessed Mr. Nene, and established the following:

- R hemiplegic characteristics
- Bi-lateral scapula-humeral dyskinesia
- Right shoulder internally rotated
- Functional scoliosis

general tightness and weakness throughout my right-side

innappropriate scapula stability and strength

all these issues had an obvious, concurrent spillover effect to my posture and greatly affected my walking

From a biomechanical point of view, the following was established:

- Extreme weakness in scapula protraction movement i.e. push up
- Weight bearing is predominantly on the forefoot, with Mr. Nene complaining of wanting to fall/lose balance when on heels
- No pain with full Range of motion in shoulders

resulting in winged scapula

# Accessory Self-Treatments For My Internally Rotated Shoulder



To alleviate the tightness in my chest and bicep, I would rest my arm out to my side on any armrest, really trying to avoid any internal rotation.



When sleeping, I would sleep with my arm outstretched, minimising the amount of elbow flexion and ease the tightness in the front delt.



With the arm to my side, and hand pronated, a good stretch would occur in my bicep. I would replicate this same position, with the arm externally rotated, while sleeping on my back.

Now, obviously, finding the appropriate position to put your arm in while seated or even sleeping will not be the best strategy for addressing a rounded, drooping shoulder.

In the next installment, part 2, I will be sharing the exercises that helped to address my weak scapula stability and improve the strength of my posterior chain.

Arms  
+  
Nerve Flossing



# I DIDN'T EVEN KNOW IT WAS NERVE FLOSSING



After a day spent with my friend who has Duchenne Muscular Dystrophy, a switch suddenly flipped in my head. We had spoken about his extreme muscle contractures and very limited range of motion in his limbs.

That same evening, I forcefully outstretched my arm, something in hindsight, probably wasn't the best of choices. What instantly insued was a sensation like no other I had ever experienced.

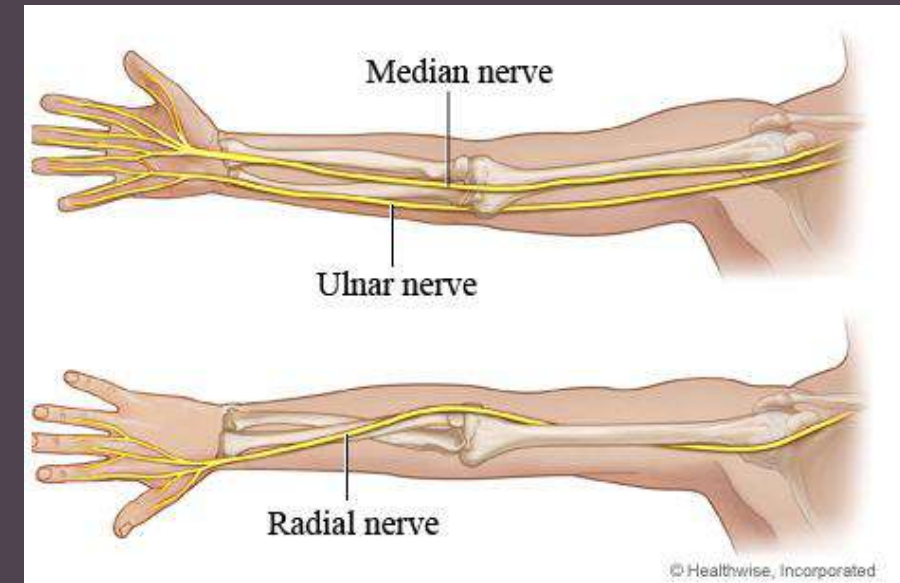
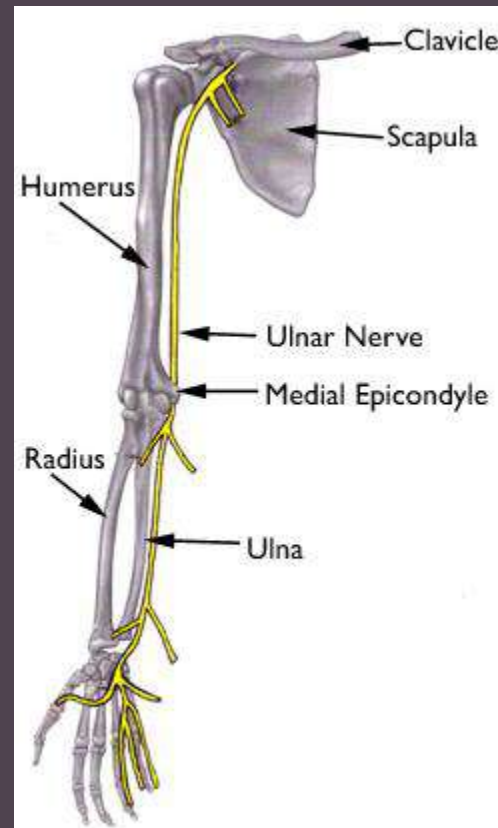
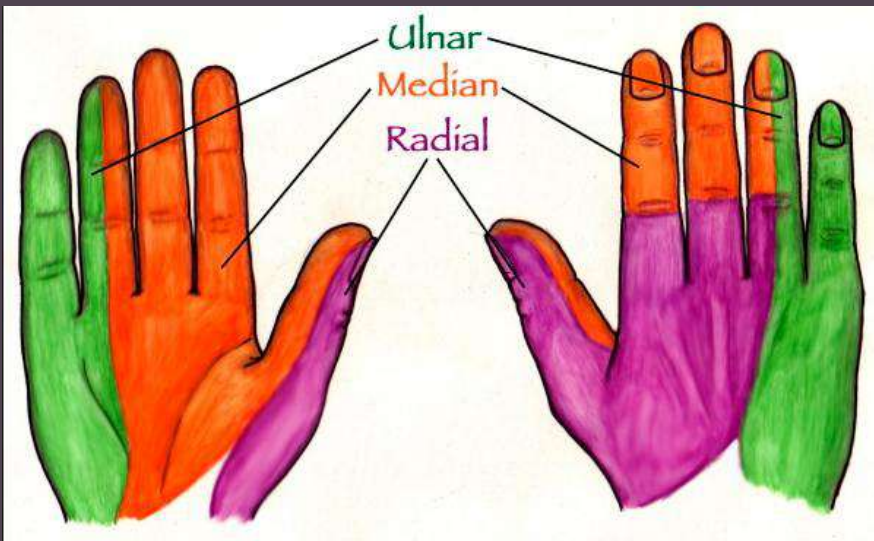
An intense stimulation of the involved nerves that can only be described as **a fiery sensation like the rebirth of my arm.**



# What is Nerve Flossing or Nerve gliding

Similarly to how muscles can get tight and need stretching, so do our nerves. Although, 'stretching' may not be the apt term. The main objective of nerve flossing, as the name suggests, is to help the nerve move back-and-forth, improving its mobility and the range of motion of that affected area. After doing a bit of researching, I came to realise my **Ulnar and Median Nerve** were impinged.

- Sensations of the peripheral nerves on the hand



- Median and Ulnar nerve location

# Nerve Glides that have Greatly Helped Me

## Median Nerve

In an upright position, start off by raising your arm to your side, avoiding any shrugging. Face your palm up, to the ceiling, extending your wrist so your fingertips look at the floor.

At the same time, once feeling the nerve tension, move your neck toward your wrist. Then, bring your wrist towards you and tilt your neck towards the opposite direction.

Repeat alternately throughout the day, doing no more than 5 reps at a time



## Ulnar Nerve

In an upright position, slightly push your hand out to the floor. A good tip; imagine applying pressure in this manner to a yoga ball.

If tension is felt in this stage, you can reset and start the movement again.

Next, you can try going into circular motions, ever so slightly raising your arm and increasing the circumference of the circles.



End of Part 1

Next  
Part 2:

**Back + Chest, Hip-Girdle & Legs**

