

Feeling Fit w/FSHD_Lonwabo Nene

Session for: 13 February 2025

An Interactive Discussion of Possible Exercises For All Levels of FSH

Excerpts and life testimonials from my emails and DM's

Greetings from South Africa to all Feeling Fit members and moderators

As the title suggests, this Feeling fit session may be different from others that I have been a part of. Over the years, I have received a number of emails from FSH patients from all over the world and I have interacted with many more through my DM's.

These are heartfelt and sincere messages - often from the patient themselves. However, I do also receive the email from the concerned parent and caregiver who was moved by my experience and exercises shared. They often seek for more information and further suitable movements that they can introduce to their child or loved one who they observe is losing mobility and strength by the day. I offer my support where I can but always direct them to the FSHD Society website, YouTube channel and link to request to be part of the Feeling Fit sessions. I have also connected others to fellow FSH members here in South Africa who I knew had gone through similar experiences and would be able to offer a more tailored approach to their requests.

Therefore, I decided to use this opportunity of hosting the FF session to ask for your assistance in better understanding the different scenarios that these FSH patients and members may find themselves in. I am able to answer the distressed mother who is worried about her 16 y/o son's mental health after his diagnosis, a lot better, than the mid 60's y/o patient who is now considering scapulothoracic fusion surgery. That is because I too was once sixteen and an athlete and was going through this entire journey with my mother as well. So, the exercises and regiments that I offer will be more relevant to the sixteen year old and his general fitness levels relative to his early diagnosis of FSHD. Juxtapose this with the patient who is in her mid 60's and has lost almost all of her overhead mobility and scapular protraction abilities; I soon find myself in a very unique predicament. I do wish to help, but the exercises will not be the same. Perhaps even the low-impact exercises may not be suitable. So, I refer them to another FSH member who had gone through similar scenarios, and they are extremely grateful.

I hope I have provided enough of a prelude to my unorthodox session. I wished to keep this agenda document to one page, alas, 2 will do. I kindly ask that you read each of the following 4 cases of FSH patients and their caregivers that have contacted me through email or DM's over the years and help me curate a suitable exercise regiment that may be beneficial for their circumstances.

* No email identities will be shared. The information will be listed in bullet point form with verbatim extracts in quotation (" ") marks.

* Suggestions and exercise discussions will be held in the Feeling Fit session on the 13 of February, 2025.

Case 1

Year 2021

- Female FSH Patient suffering from extreme Lordosis
- with pronounced neck pain
- Patient does mention “it could be another form of neuromuscular issue”
- Age mid 30’s
- Struggles with walking, neck pain subsides when laying down but lower back hurts

Case 2

Year 2022

- Daughter asks for exercise suggestions for her mother with FSHD diagnosis of 12+ years
- Age, unknown. Probably 60’s.
- Frail for her age
- Upper body started getting too weak to support using assistive device
- Still mobile however, were planning to get her a wheelchair

Case 3

Year 2023/4?

- Mother reaches out for her 16y/o son after both were diagnosed w/FSHD
- Son is very tall; ~ 6’4” (Basketball player)
- RH winged scapula, loss of strength in protraction and abdominal area (push-up and crunch)
- “No lower extremity weakness whatsoever”
- Considering scapula fusion surgery to increase quality of life

Case 4

Year 2024

- Female, Age 63, living w/FSH for 15yrs
- Weakness in shoulder girdle, hips core and drop-foot
- “RH much weaker than left side.”
- Trouble with overhead movements, double winged scapula
- Also considering scapulothoracic fusion surgery.

SOP

I will start off the session by reading the introduction piece to highlight my motivation for this agenda.

Then go into the first case study and share my suggestions I gave to the case subject.

I will then proceed to open up the floor so members can share their own suggestions for somebody in a similar circumstance.

And we continue in this manner...

*Interesting point I would like to know: **Is there a paper or research material pointing to the high prevalence of initial Right Handed winging and weakness opposed to the Left Hand side of the body in FSH cases?**

