Occupational Therapy Management of Hypermobility in Ehlers Danlos Syndrome

Michelle O’Sullivan (OTR/L) & Michele Pavlis (OT)
About Us

EDNF Conference 2010

We re-unite EDNF 2011 & the idea of this presentation is born!
What is Occupational Therapy?

**Occupation:** the roles you play in your life and the performance of tasks and activities than enable you to fulfill those roles

**Therapy:** enabling you to fulfill your roles and find meaning in your activities
Who do we work with?

Team Approach – We work WITH:

- Physical Therapists
- Speech Therapists
- Psychologists
- Doctors & Physicians
- Social Workers & Counselors
What is the aim of OT?

• to promote and maintain your independence in as many aspects of your life as possible
How do I get seen by an OT?

- Referral / Script from your Doctor
- You will need to request this from your Doctor as not all medical professionals understand OT roles and services which are helpful for people with EDS
- You need to specify to your Doctor that you require a full assessment of your activities of daily living
What might the OT do for me?

- Initial Assessment / Evaluation
- Make splints
- Order assistive devices / equipment through your insurance
- If necessary, they may do a home assessment
- Make recommendations for modifications or other equipment that you may benefit from
- Help with problem solving and cognitive strategies
- Recommendations for exercises and activity modification
An OT can help you

• access programs and services in your community

• build and maintain your support systems
What can an OT do for someone with hypermobility?
People usually present with PHYSICAL difficulties:

- after joint dislocations/subluxations with pain
- fatigue
- gastrointestinal problems
- mobility issues
Initial Assessment

Cognitive
Physical
Social
Emotional
Spiritual
“We need to learn to move efficiently so that we can save our limited energy for the important things”
Energy Conservation continued…

- keep frequently used items in a special place which is always the same place!
- write checklists
- keep everyday items such as cutlery, plate & bowl and glass at waist level
Continued…

• make use of online shopping for groceries, or do multiple small shopping trips per week OR – take a friend with you to help & save a trip!

• use a small bag to put frequently used items in

USE YOUR BRAIN to SAVE YOUR BODY
Just because our thoughts impact our pain...
It doesn't mean the pain is ‘all in our heads’

(as we think we hear people tell us)
It doesn't mean that we are somehow willing the pain and making it happen.
It doesn't mean that if we have complete control of our thoughts and always think positively, that pain won't occur.
HOWEVER.... Some ideas:

• Keeping a thought diary
• Working out our instinctual response to pain
  – Do I fear pain?  - Do I gain something from it?
  – Do I dwell on it?  - Do I get fixated on it?
  – Do I catastrophize? - Will people believe me?

• Thought management
  – Is my thought helpful? - Is it a hindrance?
  – How true is what I’m saying to myself?

• Other strategies
Other strategies for pain management

- Relaxation / meditation
- Diversional therapy
- Goal setting & rewards
Relaxation & meditation

• Takes practice
• Particularly helpful strategy for falling asleep
• Commercially available vs. pain management specific
• The Gratefulness Alphabet
Diversional therapy

• Watching TV/ DVDs
• Listening to or playing music
• Reading
• Meeting up with friends or family and doing something/chatting
• Painting
• Craft
• Going to the movies
• Baking/cooking

• Painting your nails (girls)
• Playing games, digital or board games
• Chatting over the phone or Skype with a friend
• Watching sport
• Enjoying nature
• DIY jobs, home projects
Other therapies & modalities

- Heat or ice packs
- Aquatic Therapy
- Physical Therapy
- Cranio-Sacral Therapy
- Reiki and Healing Therapies
- Massage therapy
- Acupuncture
- Pilates
- Tai Chi
- Dry Needling
- Trigger Point Injections
Goal Setting (an OT’s favorite thing)

Create S.M.A.R.T. Goals

- SPECIFIC
- MEASURABLE
- ACHIEVABLE
- REALISTIC
- TIMELY
Rewards

• Intrinsic = internal reward “I did a great job & I’m proud”

• Extrinsic = external reward “I’m going to buy myself a new dress because I did that so well”

• Motivating

• Appropriate
Joint Protection Techniques
before you start, or as soon as you remember thereafter
Should I be doing this at all?
If yes, how should I do this to minimize risk of injury?
Can I do this another way?
What joints am I using, which ones do I need to protect, or which stabilizing muscles do I need to switch on to do this safely?
Am I going to go into my hypermobile range/hyperextension to do this?
Can I cope with any consequences?

Be particularly careful if you are doing anything involving
• Weight
• Repetition
• High impact
• Prolonged static positions
Only if you have worked out the best way to do the task…

if you should be doing it at all!!
• Kitchen
• Bathroom
• Bedroom
• Living Room
• Car
• Work place / work station
Kitchen

- Check countertop height
- Easily accessible utensils and frequently used items
- Minimise the weight of appliances and other items like pots & pans
- Be careful of how heavy food/drink items are that you purchase at the shops
Bathroom

- Is it SAFE?
- Can you reach things?
- Do you need some assistive devices to help you bathe independently?
Bedroom

- Easy access to items used most often
- A good mattress & pillow
- Decrease the amount of electrical equipment & technology in your room
- Make your room as dark as possible to promote sleep
Living room

- Check the height of your sofa or couch
- Are there any trip hazards?
• Check steering wheel and pedal height
• Seat position
• Handicap placard
Work place / work station

- Check desk height
- Check workstation set up
- Take breaks
- Check lighting and airflow
Assistive Devices

- Meal Preparation
- Eating
- Cleaning
- Bathing
- Laundry
- Work / school
- Other
Meal Preparation

JarKey

CanKey

Zyliss 5 in 1 opener

Dycem jar opener

Dycem Grip Mat

Cordless Kettle Tipper
Eating

Cylindrical foam

Rocker Knife

Built-up cutlery

Trolley/Cart

SHARP knives
Cleaning

Long handled cleaning brush

Long handled dustpan & broom

Long handled reacher
Cleaning...

- Long handled brush
- Robot Vacuum
- Long handled toilet brush
- Long handled duster
Bathing

- Long handled toe washer/dryer
- Long handled back sponge
- Toothbrush grip
- Shower Stool
- Toothpaste dispenser
Laundry

Machine Raiser

Easy clothes pins

Drying line

Laundry Trolley
Work / School

- Slope Board
- Footrest
- Copy holder
- Laptop dock
- Gel wrist support
- Ergonomic Mouse
Other

Key Turner

Swivel Seat

1. Locate U-shaped striker on door frame.
2. Insert Handybar firmly into striker.
3. Use as support.

Car Handy-bar
Other...

- Tap Turners
- Blister pack opener
- Meds organizer
- Meds reminder
Opportunity for change
Redefine your purpose
Acceptance
Spiritual/Emotional Impacts

- YOU are not your ability or your dis-ability
- Your EDS does NOT define YOU
- You are a person WITH EDS, not an EDS patient
Continued…

• There will be setbacks along the road; life might change direction completely… but WHO YOU ARE does not change

• When setbacks occur, we need to redefine our expectations and goals, and reassign our energy, skills and talents to new things
An occupational therapist may be just the resource you need to achieve all of this and lead a life that is meaningful to you.

Visit the following for more information about OT in your country:

www.aota.org (USA)
www.cot.co.uk (UK)
www.ausot.com.au (Australia)
www.caot.ca (Canada)
Children’s Book

My Bendy Body
by Michelle O’Sullivan

RRP: US$20

Visit www.hypermobilot.com.au for more info on ordering