ProHealth & Fitness PT OT, PLLC

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James Nussbaum, PT, PhD, SCS, EMT

Clinical and Research Director

www.prohealthptot.com

The Critical Need for Skilled Physical and Occupational Therapy Evaluation and Treatment to Improve Function and Quality of Life in Patients with Charcot Marie Tooth Neuropathy

ProHealth & Fitness, James Nussbaum, PhD, MSPT, SCS, CSCS, EMT

The Critical Need for Skilled PT and OT Evaluation and Treatment to Improve Function and QOL in Patients with CMT

"EVERY patient with CMT should be evaluated by a skilled PT and OT"

CMTA
Charcot-Marie-Tooth Association

ProHealth & Fitness, James Nussbaum, PhD, MSPT, SCS, CSCS, EMT

ProHealth & Fitness

Skilled PT and OT to Improve Function and QOL in Patients with CMT

Disclaimer:

- JN's opinion, there are many who disagree
- All exercise and activities should be cleared by an expert
- Consult YOUR doctor PRIOR to engaging in any new activity
- You may ask your doctor to speak with another expert

There is no sponsor, and I have no interest(s) to disclose

"EVERY patient with CMT should be evaluated by a skilled PT and OT"

Skilled Physical Therapy and Exercise to Improve Function and QOL in CMT

-BACKGROUND
-DEFINITION(S)
-IMPAIRMENTS
-LITERATURE
-HOW TO IMPROVE FUNCTION
-SUMMARY, Q & A

Skilled PT and OT to Improve Function and QOL in Patients with CMT

Quality of life (QOL) improvement is the goal of most patients and therefore should be very high on the priority list of goals for healthcare practitioners. Every person has a different hierarchy of factors leading to improved physical function and QOL, however there are a few fundamental items reported by many, including: Independence in activities of daily living (ADL), comfortable mobility, and community access. Physical function in general, mobility, ADL, and control over one's life can all be negatively impacted by weakness, pain, joint restrictions, sensory loss, and imbalance. These symptoms and impairments along with others are often seen in patients with a diagnosis of Charcot Marie Tooth disease (CMT). They all negatively impact physical function and QOL and should be skillfully addressed by healthcare practitioners in an effort to help their patients with CMT.

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PROHEALTH & FITNESS

Skilled PT and OT to Improve Function and QOL in Patients with CMT

The purpose of this abstract is to advocate that every patient with a diagnosis of CMT undergo an evaluation and treatment (if warranted) by PT and OT to help improve physical function and QOL. Patients newly diagnosed or with long standing CMT typically see Neurologists, Orthopedists, Physiatrists and other medical and healthcare professionals. Unfortunately, rehabilitation specialists, physical (PT) and occupational (OT) therapists, who are the experts in physical function and dysfunction, are not common (or common enough) members of the healthcare team providing regular skilled care for patients with CMT. Physical and Occupational therapists use many modalities when treating their patients including therapeutic exercise and activities, neuromuscular re-education and manual therapeutic techniques to improve independence and physical function. Understanding each individual patients' medical history, complexities, personal goals, impairments, and current functional deficits, enable a skilled therapist to identify a plan of care to achieve short and long term goals and improve function and QOL.

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PROHEALTH & FITNESS

BACKGROUND

James Nussbaum, PT, PhD, SCS, EMT

American Red Cross –	Instructor
NYS Department of Health –	Emergency Med Technician
NYS Department of Health -	Fall Prevention Task Force
Johnson & Johnson Health Care Systems -	Health & Fitness Specialist
Touro College of Health Science -	MS PT
National Strength & Conditioning Assoc. -	CSCS , Strength Specialist
NYC Department of Education -	Senior Physical Therapist
Cambridge State University -	PhD Pathokinesiology
American Physical Therapy Assoc. -	Sports Certification Specialist
Andrews University, Touro College, LIU -	Clinical Instructor
Touro College PT Program –	Advisory Board
Charcot Marie Tooth Association –	Advisory Board
TRIARQ – Medical Advisory Board -	Research Co-Dir
International and National Presenter -	PT and Exercise

"The primary goal of healthcare should be to improve quality of life (QOL)"

What impacts QOL?

- Independence
- Mobility
- Comfort
- Control

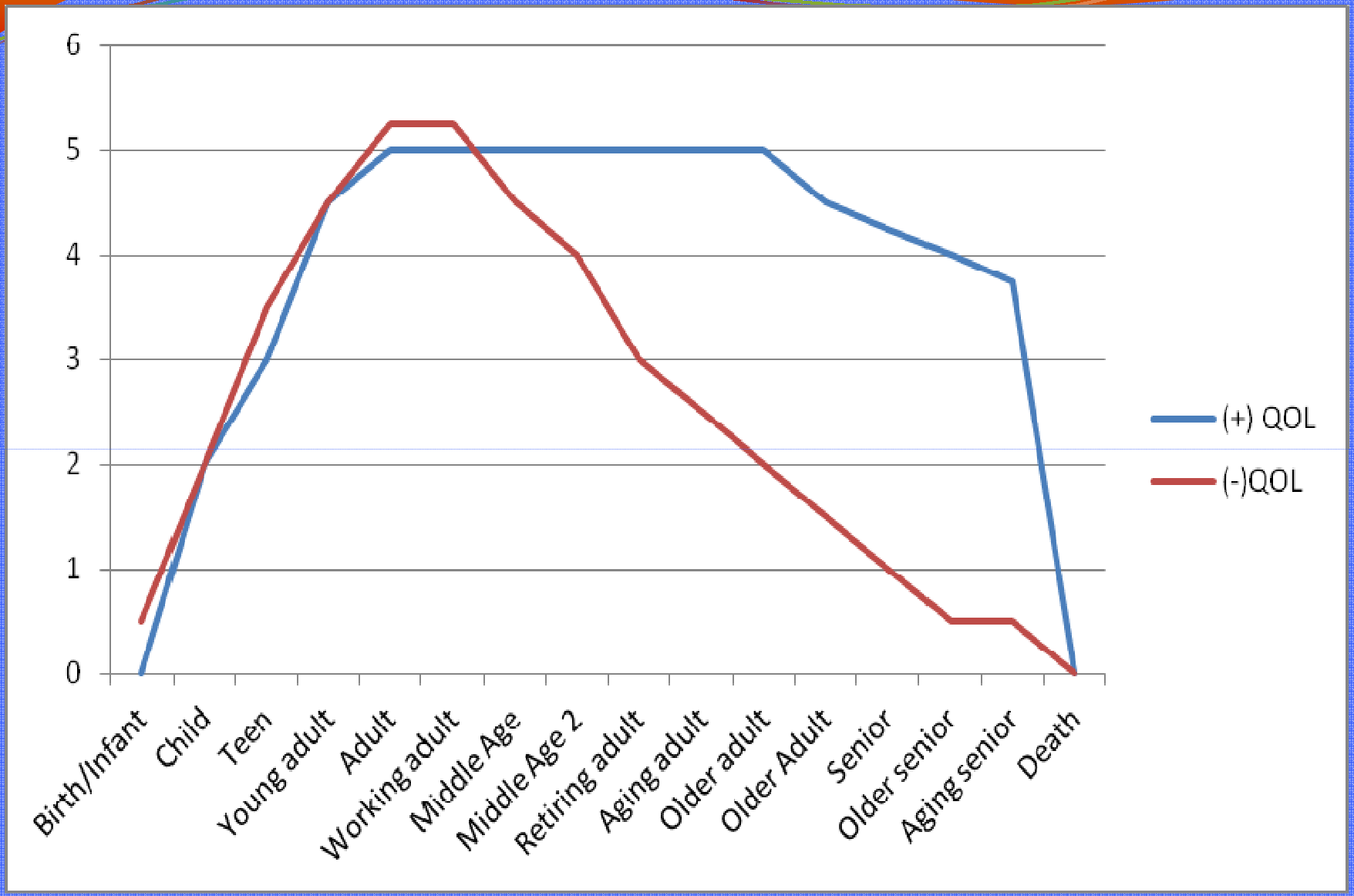
Each specialist plays her/his part in working with their patient to improve QOL

GOAL:

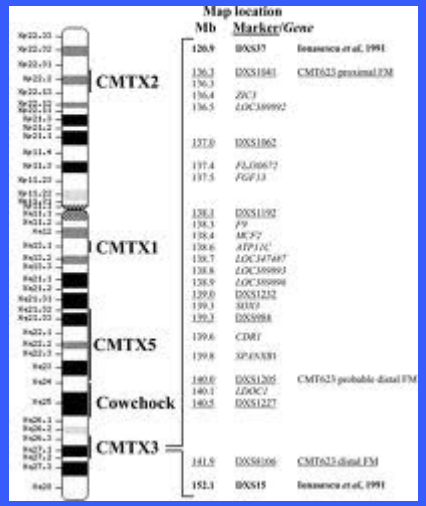
Functional independence
Activity tolerance
Mobility
Activities of daily living
Recreational activities
Enable patients to have choices

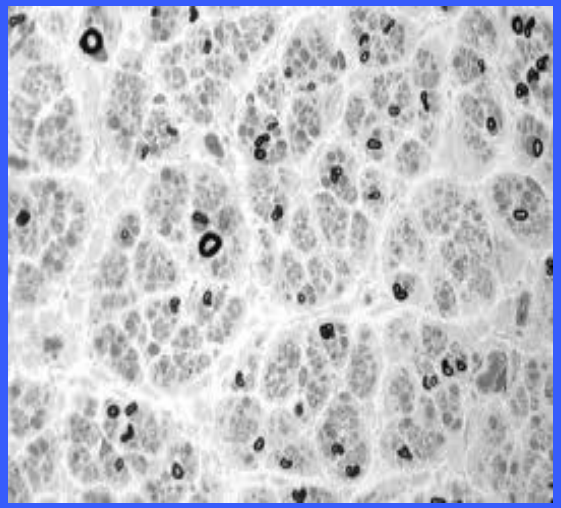
Who are the experts in testing and improving function?

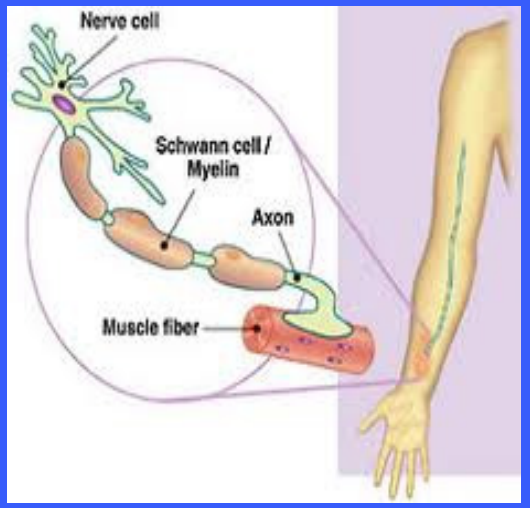
"ACTIVE DAYS" adapted from Patricia Painter, PhD
Y axis (1 through 6) = activity/functional levels X axis (birth through death) = life span



Skilled Physical Therapy and Exercise to Improve Function and QOL in CMT







ProHealth & Fitness, James Nussbaum, PhD, MSPT, SCS, CSCS, EMT

Skilled Physical Therapy and Exercise to Improve Function and QOL in CMT

FUNCTION → QOL

DYSFUNCTION → IMPROVEMENTS →QOL

ProHealth & Fitness, James Nussbaum, PhD, MSPT, SCS, CSCS, EMT

DEFINITIONS

EXERCISE:

Physical exercise is any bodily activity that enhances or maintains physical fitness and overall health and wellness. It is performed for various reasons including strengthening muscles and the cardiovascular system, honing athletic skills, weight loss or maintenance, as well as for the purpose of enjoyment.

PHYSICAL THERAPY:

Physical therapy or physiotherapy is a health care profession primarily concerned with the remediation of impairments and disabilities and the promotion of mobility, functional ability, quality of life and movement potential through examination, evaluation, diagnosis and physical intervention.

*Wikipedia

DEFINITION

FALL

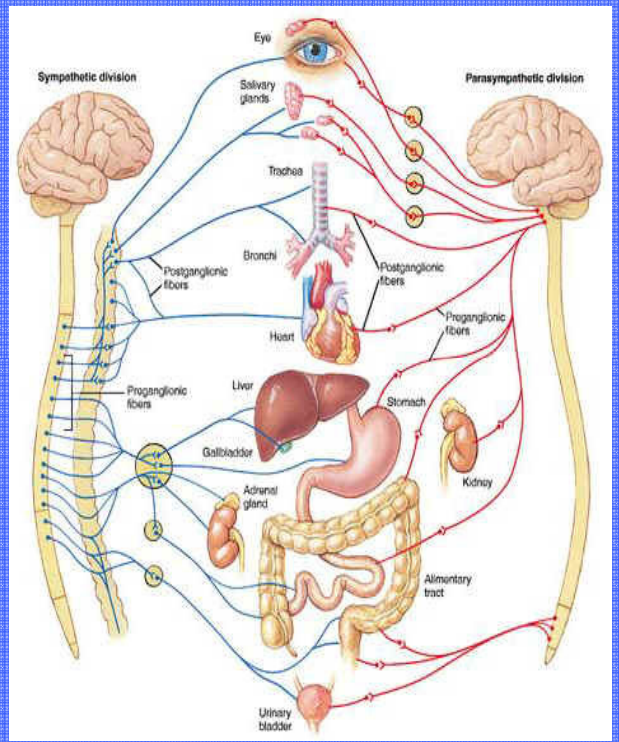
"An event, which results in a person coming to rest inadvertently on the ground or other lower level"

World Health Organization

IMPAIRMENTS

Across the Neurological Spectrum

- CMT
- Other PN
- CVA
- MS
- PD
- ALS
- Alzheimer's
- Dementia
- SNP
- TBI
- Etc.



IMPAIRMENTS





- PAIN
- FATIGUE
- WEAKNESS
- MUSCLE LOSS
- SENSORY LOSS
- IMBALANCE / FALLS
- JOINT DEFORMITIES
- AUTONOMIC DYSFUNCTION

- CO-MORBIDITIES

IMPACT

FUNCTION

INDEPENDENCE

QUALITY OF LIFE



LITERATURE REVIEW





PUBMED "PD and Exercise " = 957 citations

"MS and Exercise" = 853 citations

LITERATURE REVIEW





PUBMED "CMT and Exercise " = 40-53 citations

LITERATURE REVIEW





IS EXERCISE GOOD or IS EXERCISE BAD?

(in patients with a chronic progressive neurological disorder like CMT)

LITERATURE REVIEW





CONSENSUS?

LITERATURE REVIEW

Michael Shy
Steven Scherer
Robert Chetlin
Sharon DeMuth
L. El Mhandi
Fransisco Fernandez
W.M. Fowler
R. Ted Abresch
Gita Ramdharry***
MANY MORE



PUBMED "CMT and Exercise " = 40 citations
"Strength Training and CMT = 10!!!

LITERATURE REVIEW

POSSIBLE PITFALL

"OVERWORK WEAKNESS"

-CHEMICAL
-STRUCTURAL
-ELECTRICAL
??????????????

DOMINANT HAND VERSUS NON DOMINANT

LITERATURE REVIEW – OVERWORK WEAKNESS

Verifying the hypothesis of overwork weakness in Charcot Marie Tooth
Annemieke Videler J Rehab Medicine 2010

Overwork weakness in Charcot-Marie-Tooth disease
Vinci et al. Arch Phys Med and Rehab 2003

Dystrophinopathy in two young boys with exercise-induced cramps and myoglobinuria
C. Minetti et al. European J of Ped 1993

Over-Weakness in Fascioscapulohumeral Muscular Dystrophy
Johnson and Braddom Arch Phys Med and Rehab 1971

LITERATURE REVIEW

OVERWORK WEAKNESS

Overwork weakness in Charcot-Marie-Tooth disease.
Vinci P. et al. Arch Phys Med Rehabil 2003

Importance of overwork weakness.
Fowler WM Jr. Muscle Nerve 1984

Overwork weakness with evidence of muscle damage in a patient with residual paralysis from polio.
Peach FE. Arch Phys Med Rehabil 1990

Effects of excessive use of remaining muscle fibers in prior polio and LV lesion.
Borg K. Et al. Muscle Nerve 1988

LITERATURE REVIEW – OVERWORK WEAKNESS

The hypothesis of overwork weakness in Charcot-Marie-Tooth: a critical evaluation.

Van Pomeren et al. J Rehabil Med 2009

It has been reported that the non-dominant hand of patients with Charcot-Marie-Tooth disease is stronger than the dominant hand as a result of overwork weakness. The objective of this study was to determine if this hypothesis could be verified in our population. Twenty-eight patients with CMT in the Netherlands.

CONCLUSION:

In our population, the dominant hand of patients with Charcot-Marie-Tooth disease type I and II was equally strong as the non-dominant hand, suggesting that there is no presence of overwork weakness in the dominant hand in our group of patients. This implies that patients with Charcot-Marie-Tooth disease do not have to limit the use of their hands in daily life in order to prevent muscle strength loss.

LITERATURE REVIEW

AUTONOMIC DYSFUNCTION

EXERCISE TRAINING IMPROVES AUTONOMIC PROFILES IN PATIENTS WITH CHARCOT–MARIE–TOOTH DISEASE

EL MHANDI et al. MUSCLE & NERVE 2011

8 patients – interval training improves heart rate variability (autonomic function) by increasing parasympathetic activity

LITERATURE REVIEW

STRENGTH AND MUSCLE FIBERS

RESISTANCE TRAINING EXERCISE AND CREATINE IN PATIENTS WITH CHARCOT–MARIE–TOOTH DISEASE
ROBERT D. CHETLIN et al. *Muscle Nerve* 2004

Patients respond to resistance training with muscle fiber adaptations, and improvements in strength and function.

LITERATURE REVIEW

Activities of Daily Living (ADL)

Resistance Training Effectiveness in Patients With Charcot-Marie-Tooth Disease: Recommendations for Exercise Prescription
Robert D. Chetlin et al. Arch Phys Med Rehabil 2004

12 weeks home based resistance training program.
Conclusions: Resistance training improved strength and ADLs equally in men and women.

LITERATURE REVIEW

Activities of Daily Living (ADL)

Resistance Training Effectiveness in Patients With Charcot-Marie-Tooth Disease: Recommendations for Exercise Prescription
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12 weeks home based resistance training program.
Conclusions: Resistance training improved strength and ADLs equally in men and women.

LITERATURE REVIEW

Outcome Measures

Outcome Measures and Rehabilitation Treatment in Patients Affected by Charcot-Marie-Tooth Neuropathy A Pilot Study

Maggi et al. Am J Phys Med Rehabil 2011

Eight (☹) patient participated in twice weekly activities for 8 weeks. "No dropouts or worsening in any of the different outcome measures were observed after TreSPE. The ankle angle and the time to walk 6m were the only measures that significantly improved after treatment."

LITERATURE REVIEW

ROBUST STUDIES?

UNEQUIVOCAL EVIDENCE?

CLEAR PROGRAMATIC PROTOCOLS?

WHITE PAPERS AND RECOMMENDATIONS?

BUT DOES THAT MEAN THAT>>>

PEOPLE WITH CMT SHOULDN'T EXERCISE?



WHAT TO DO IN THE ABSENCE OF CLARITY

FIND A (CMT) CENTER OF EXCELLENCE

CONSULT WITH EXPERTS

BE PROACTIVE

SUPPORT ASSOCIATIONS

"ALWAYS AND NEVER"
shouldn't be used too often

FIND SKILLED PTs and OTS, get evaluated

LITERATURE REVIEW, JN's OPINION

EVERYONE SHOULD EXERCISE

EVERYONE WITH CMT SHOULD EXERCISE

EXERCISE IS GOOD FOR EVERYONE

-AT THE RIGHT TIME
-IN THE RIGHT DOSE
-USING THE RIGHT MODE
-APPROPRIATE INTENSITY
-PROPER REST PERIOD(S)

UNDER SKILLED GUIDANCE/SUPERVISION

HOW TO MAKE FUNCTIONAL CHANGE?

USE THE EXPERTS IN FUNCTION

PHYSICAL THERAPISTS

OCCUPATIONAL THERAPISTS

TEAM WORK

PATIENT, FAMILY, HHA, CSW, NEURO, PM&R, ORTHO, P&O, RHEUM, CARDIO, PULM, PSYCH, etc.

I WANT TO GIVE THIS A TRY, NOW WHAT?

FIND A SKILLED PT and OT and get an EVALUATION

SPEAK TO YOUR DOCTOR

INSURANCE.....$$$$$$$

WHAT IS COVERRED?

- TODAY VERSUS NEXT WEEK, TWO WEEKS...

HOW TO MAKE FUNCTIONAL CHANGE?

EVALUATION: ID DEFICITS

LISTEN TO THE PATIENT
SKILLFULLY LOOK AT FUNCTION
OUTCOME MEASURES
Objective, valid, and reliable

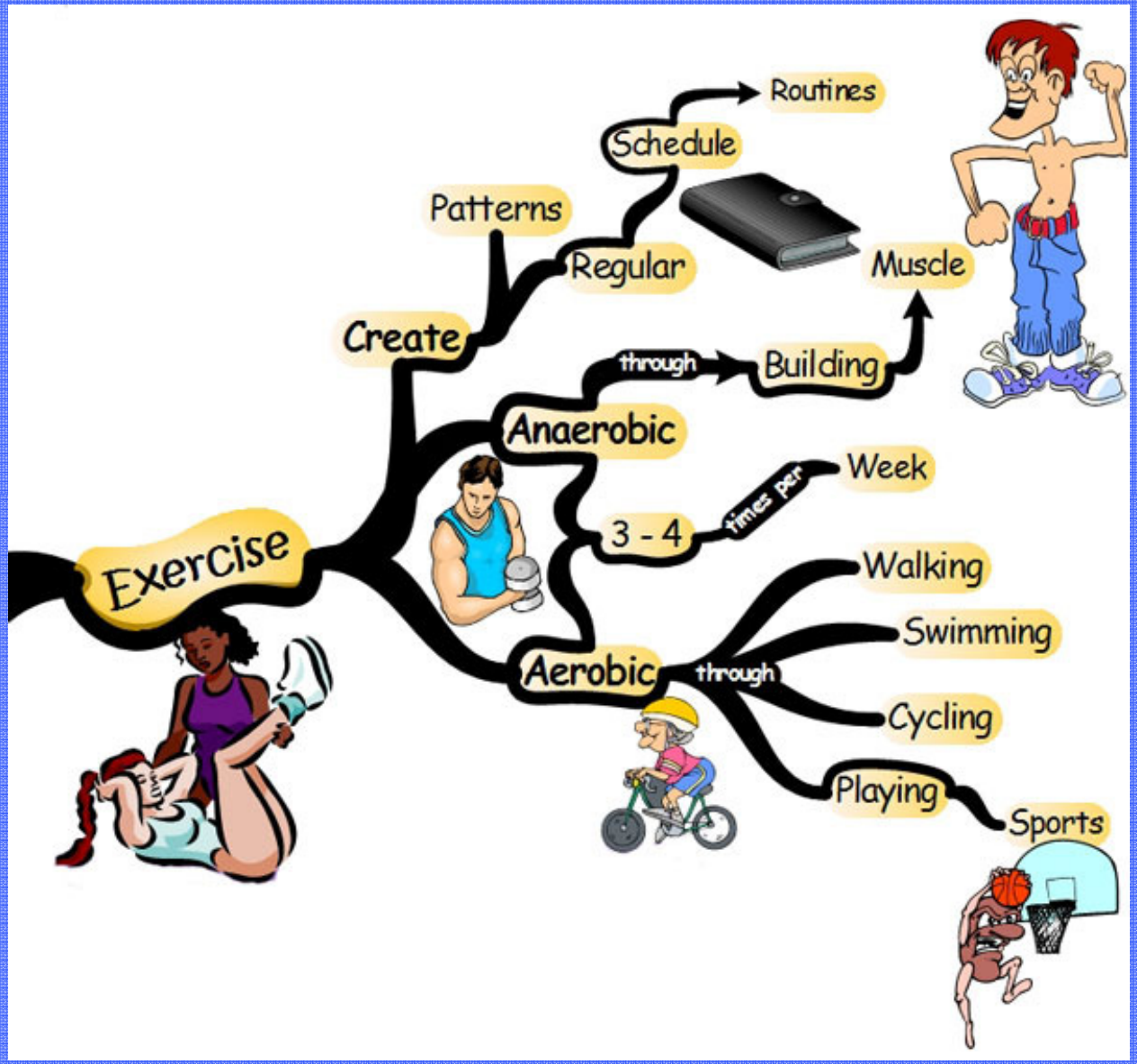
INTERVENTION(S)

LISTEN TO THE PATIENT
SKILLFULLY LOOK AT FUNCTION
OUTCOME MEASURES
Objective, valid, and reliable

Occupational Therapy Intervention

- ADL training – Basic and Instrumental
  - Dressing, Grooming, Feeding, and Writing
- Fine motor control
  - Intrinsic muscle strength, dexterity, coordination
- Trunk, Shoulder, Elbow, and Hand function
  - Improve motion with mobilization and PNF
  - Decrease pain with modalities
  - Strengthen with therapeutic exercise/activities

PROGRAM DESIGN



SKILLED PHYSICAL THERAPY INTERVENTION

EVALUATION

Objective, valid, reliable outcome measures

PLAN OF CARE

Treatment specifics, contraindications

THERAPUETIC ACTIVITIES

Transfer training, AD fitting and utilization

ORTHOTIC MANAGEMENT

Recommendation, fitting, functional usage

NEUROMUSCULAR RE-EDUCATION

Static and dynamic balance activities, posture

MANUAL TECHNIQUES

Soft tissue work, joint mobilization, pain Rx

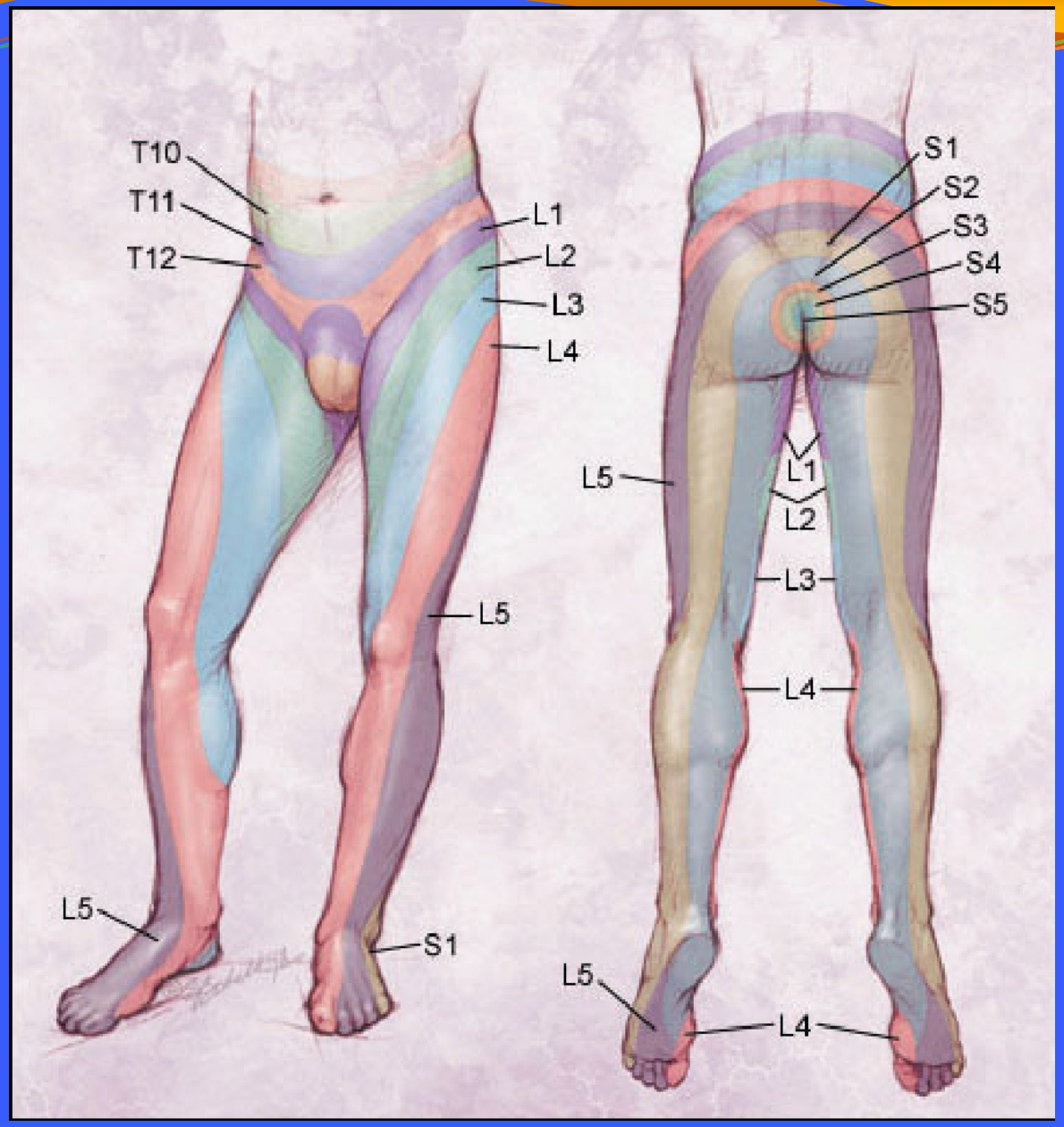
THERAPEUTIC MODALITIES

E-stim, US, cold laser, NIRPT, thermal, more?

THERAPEUTIC EXERCISE

Program design principles, HEP

ANATOMY



EVALUATION

SUBJECTIVE
OBJECTIVE
ASSESSMENT
PLAN



OUTCOME MEASURES

CLINICAL TESTS
FUNCTIONAL TESTS
QUESTIONNAIRES

REPEATABLE!

FALL/BALANCE (RELATED) ASSESSMENTS

- TUG
- Gait Speed
- FAB
- BERG
- DGI
- 4 Square
- mCTSIB
- STS (5,10,30,60)
- ABC
- FES
- SAFE
- STEADI

ProHealth & Fitness PT OT CMT PROGRAM

Effective Exercise for the Prevention of Falls: A Systematic Review and Meta-Analysis

Catherine Sherrington, et al

Journal of the American Geriatric Society 2008

THERAPUETIC EXERCISE

Program Design

Principles:

Mode, Repetitions, Sets, Intensity, Rest, Frequency, Volume

Energy system

-Intensity

HR

%RM

RPE

-Work:Rest

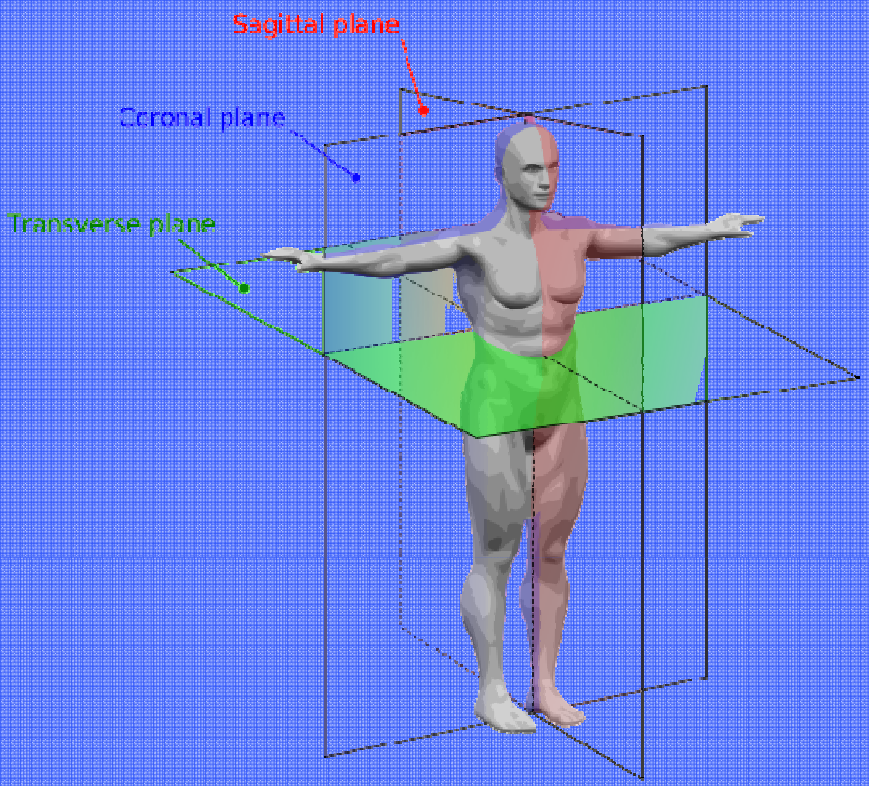
Rest

Duration

Assess ←→Modify



PHYSICAL THERAPY



DIRECT APPROACH

INDIRECT APPROACH

LOWER EXTREMITY

EXERCISE CHOICES:



SIMPLE → COMPLEX?

COMPLEX → SIMPLE?

OKC versus CKC?

MODE, VOLUME, INTENSITY, FREQUENCY, REST, ...?

IN THE PRESENCE OF PATHOLOGY?

EXERCISE CHOICES:

Do’s and Don'ts



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"THE WATER IS THE BEST PLACE TO EXERCISE"?

SAID WHO?



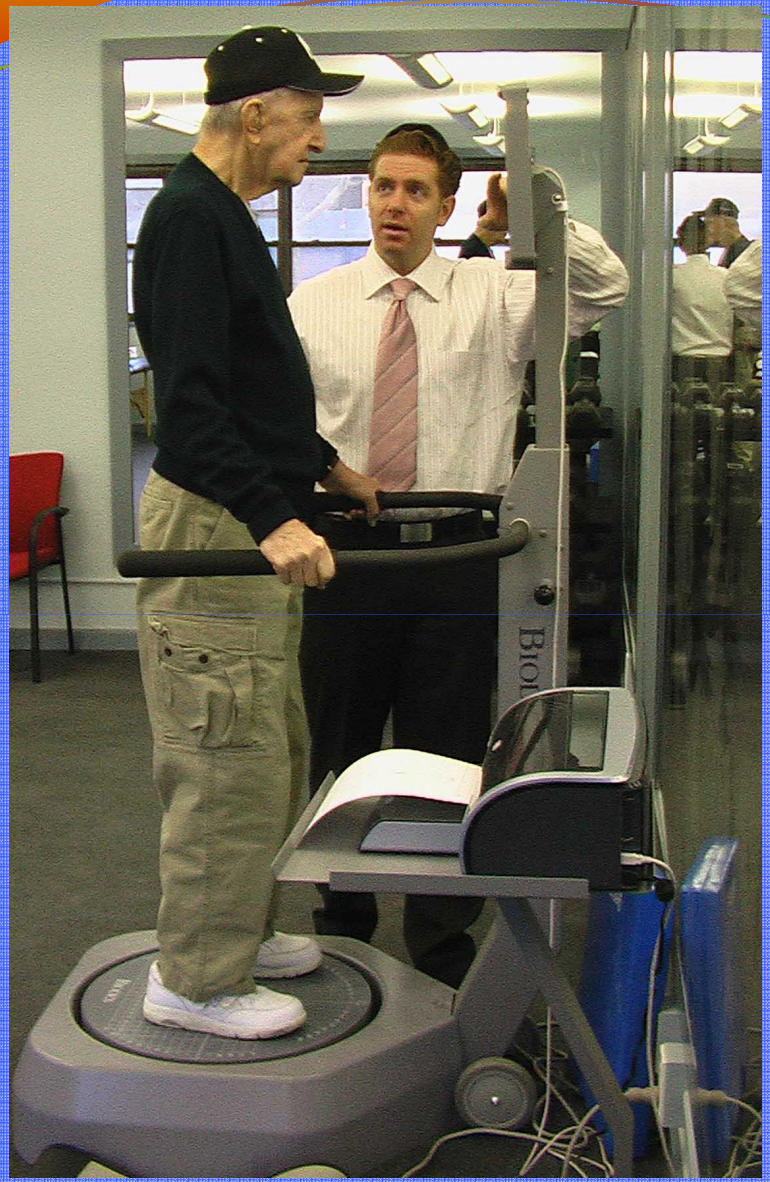
MOVEMENT vs. MUSCLES

SYNERGISTIC MUSCLES
AGONIST vs. ANTAGONIST
OCK vs. CKC
CONCENTRIC or ECCENTRIC
STABILITY vs. MOBILITY
LENGTH TENSION RELATIONSHIPS

LOWER EXTREMITY

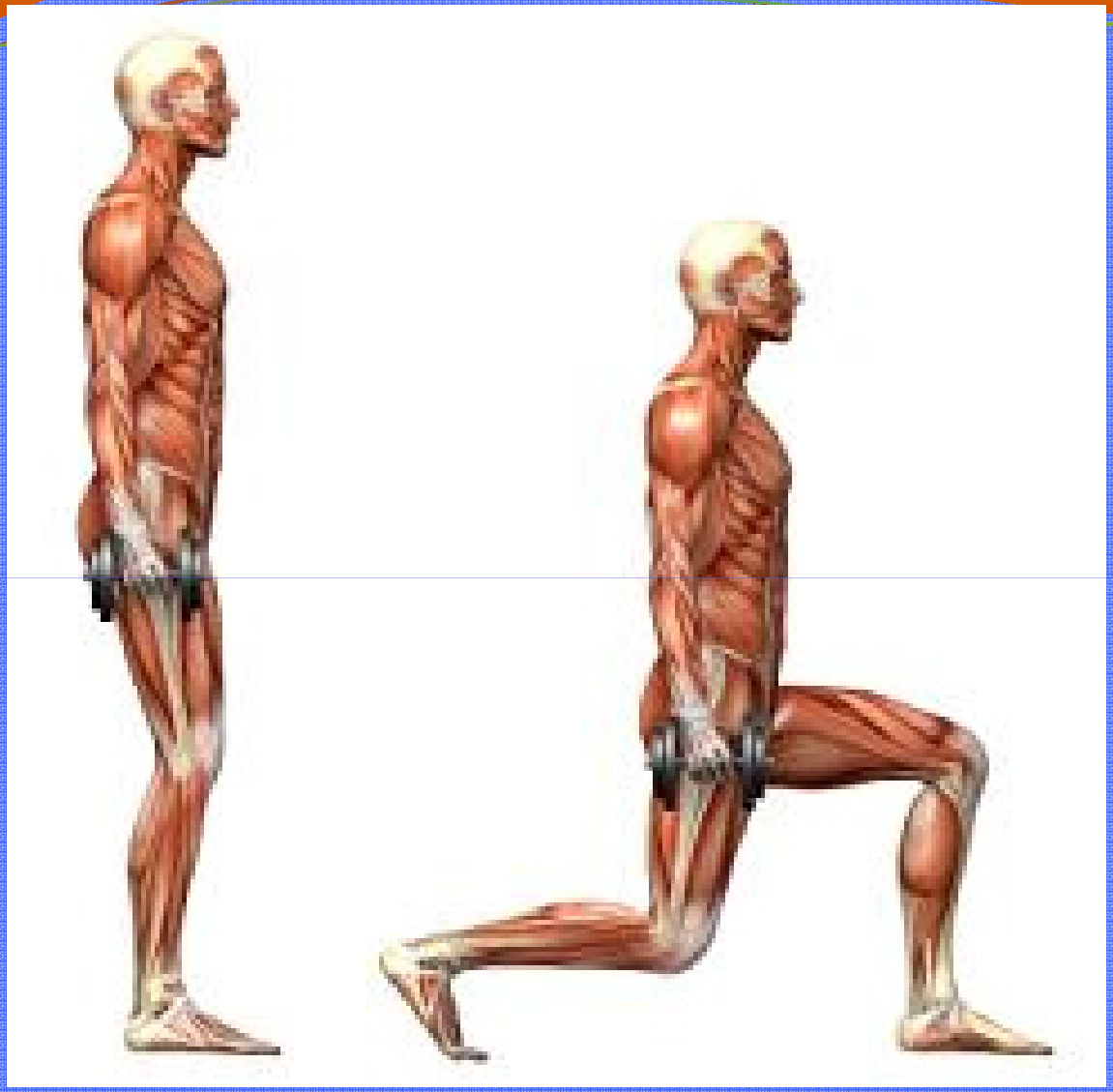
EXERCISE CHOICES:

- SIMPLE → COMPLEX?
- COMPLEX → SIMPLE?
- OKC versus CKC?
- MODE, VOLUME, INTENSITY, FREQUENCY, REST, ...?



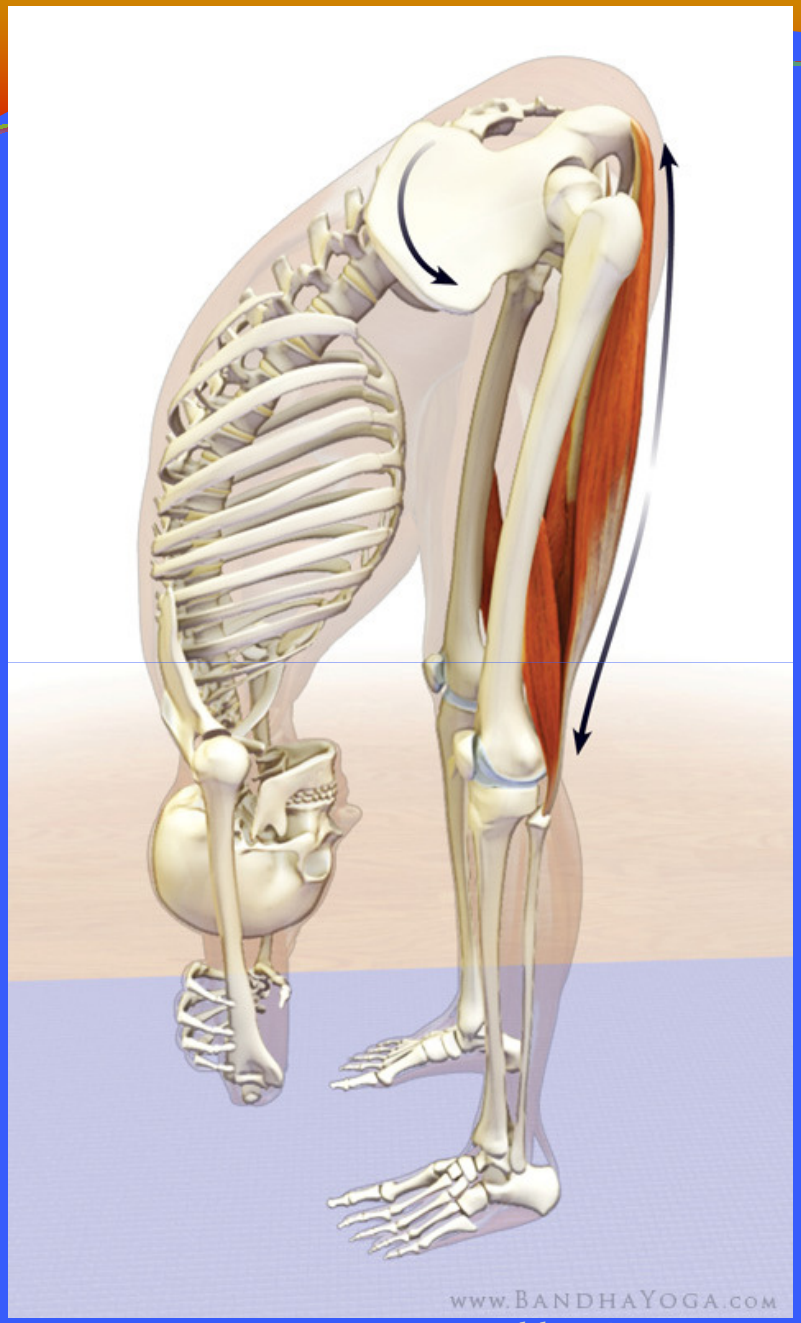
BIODEX BALANCE SYSTEM

LUNGE



SQUAT





Where is the ROM coming from?

What are the passive restraints?

What are the active restraints?

Flexibility vs. ROM

What am shooting for?

Lower Extremity



PROPRIOCEPTION

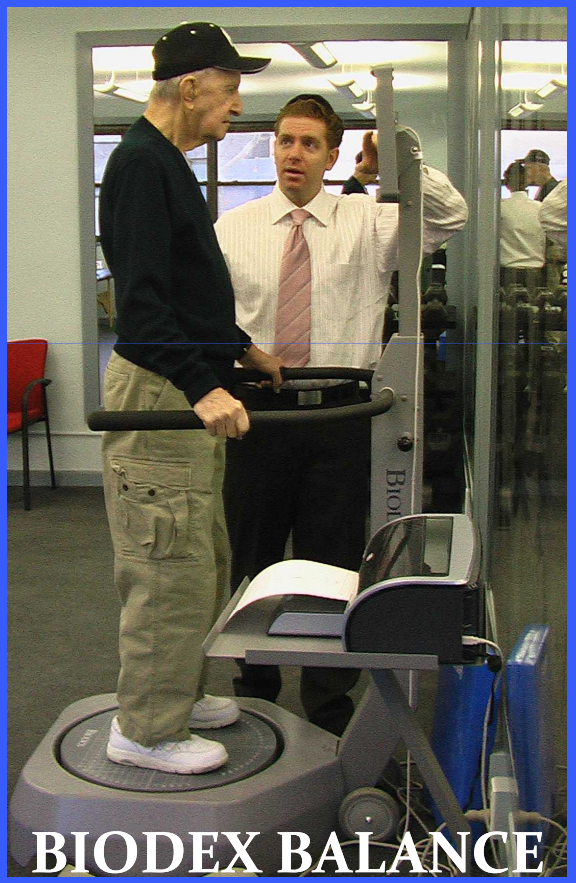


Physical and Occupational Therapy

MACHINES or NO MACHINES?



BIODEX UE & LE



BIODEX BALANCE

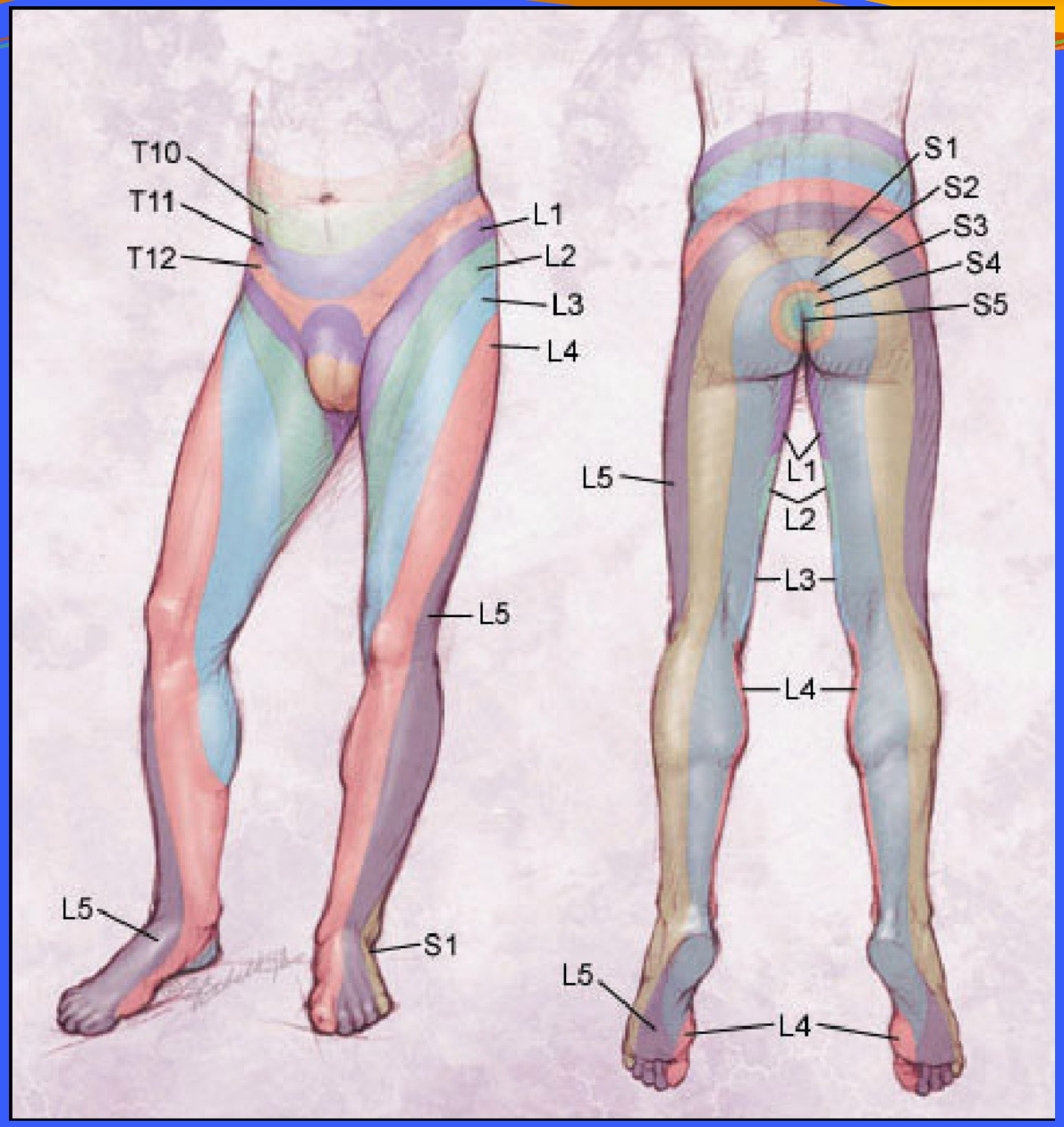


KEISER TRAINER

ProHealth & Fitness PT OT CMT Program

- **Evaluation**
  - Identification of deficits
  - STG and LGT
- **Plan of Care**
  - Summary of evaluation
  - Recommendations
  - Precautions/Contraindications
- **Implementation**
  - Skilled PT and OT Services
- **Progress Report**
  - Functional Progress

ANATOMY

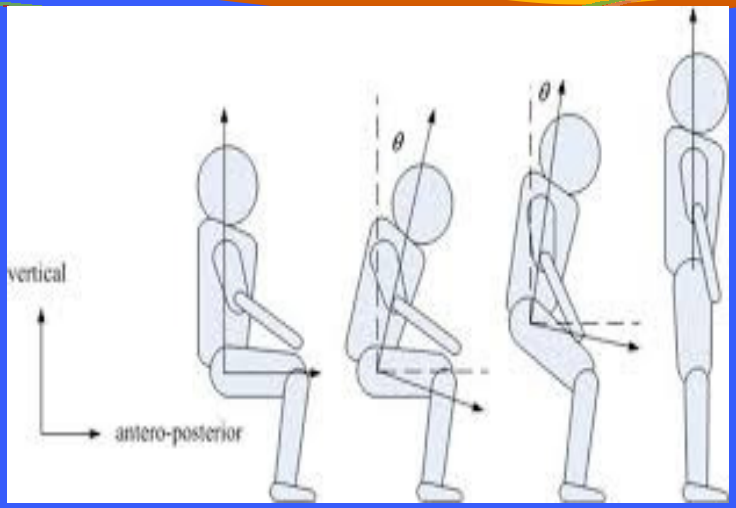


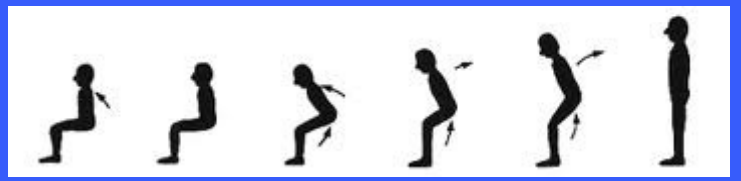
SQUAT



SQUAT → STS

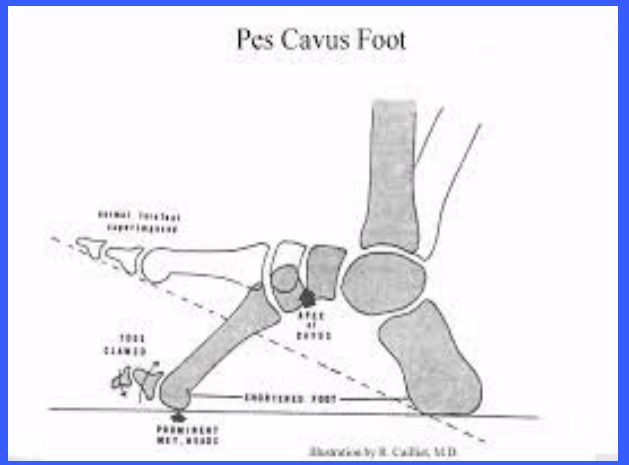


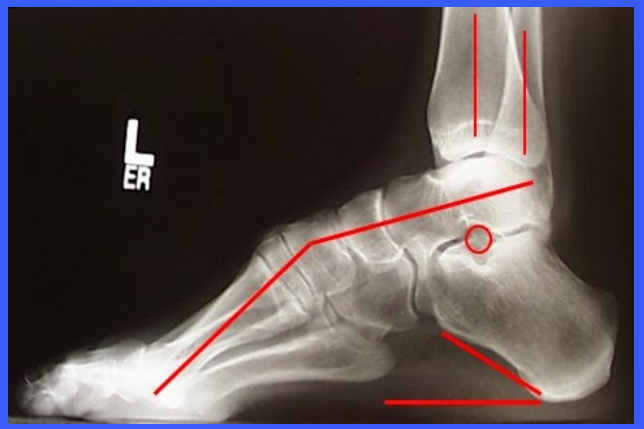




SQUAT







SQUAT







SQUAT







SQUAT





SQUAT







SQUAT – Sit To Stand









Control

Technique

Range of Motion

Strength

Balance

Motor learning

Activity tolerance

Task acquisition

SQUAT ← ← ← STS



ProHealth & Fitness

WE CAN WORK TOGETHER TO MAKE A DIFFERENCE



CALL A LOCAL THERAPIST TODAY

COMMUNICATION IS KEY

ProHealth & Fitness, James Nussbaum, PhD, MSPT, SCS, CSCS, EMT

ProHealth & Fitness PT OT ←→ CMT

Through skilled therapy:

Falls can be prevented

ADLs can be made more independent

Mobility can increase

Community access can be enjoyed, and

Quality of life can be improved

IT STARTS WITH AN EVALUATION

Health Care = Quality of Life

ProHealth & Fitness PT OT

CMT Program



ProHealth & Fitness PT OT



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ProHealth & Fitness PT OT

THANK YOU

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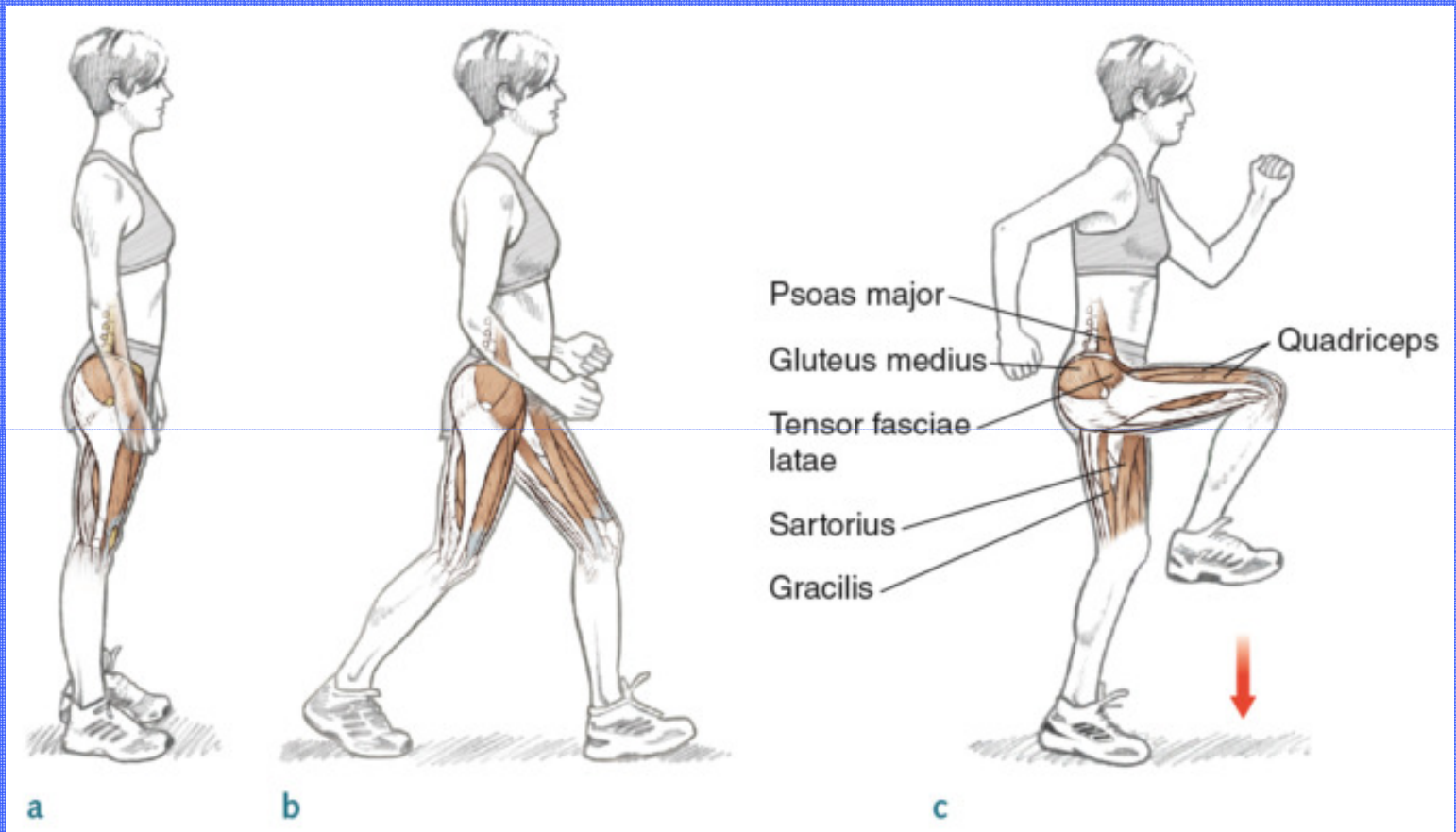


Figure 3.2 *(a)* A motion 1, *(b)* A motion 2, and *(c)* A motion 3.

STATISITCS

FALLS:

U.S. > $30 billion on falls

1 of 3 adults >65 will fall

1 of 2 adults >80 will fall

AAOS: >90% of > 352,000 annual hip Fx in the U.S. are the result of a fall.

Only 25% pts s/p hip Fx - full recovery

>20% mortality < 1 year post hip Fx

~25% institutionalized rest of their lives s/p Fx

Center for Disease Control - US

NEW STATE TASK FORCE ON FALL PREVENTION



Among adults 65 and older who are hospitalized due to a fall:

60% end up in a nursing home or rehab center
11% suffer a traumatic brain injury
27% experience a hip fracture

Can we prevent Falls?

Exercise can reduce fall rates

Balance training

~ 50 hours of intervention over 6 months

Numerous programs work!

Sherrington et al, JAGS 2008

WHO PAYS FOR IT?

FALL PREVENTION PROGRAMS

INDIVIDUALIZED:

SPECIFIC DEFICITS

UNIQUE LIMITATIONS

LTG – IMPORTANT TO PATIENT

GROUP:

LEAST COMMON DENOMINATOR

LIMITED BY SAFETY CONCERNS

HOW DOES SKILLED PHYSICAL THERAPY PREVENT FALLS?

- STRENGTH TRAINING
  - Program Design
    - Mode, Volume, Intensity, Frequency
    - Rest Periods, Fiber Types, ……..
    - 3 X 10?
    - Plan of Care

HOW DOES SKILLED PHYSICAL THERAPY PREVENT FALLS?

- PERTURBATION TRAINING
- MULTI DIRECTIONAL LUNGING
- EXECUTIVE FUNCTION WORK
- REFLEX AND POWER TRAINING
- SENSORY INTEGRATION

HOW DOES SKILLED PHYSICAL THERAPY PREVENT FALLS?

Turn the purposeful, habitual

- **REPETITION**
- **ENVIRONMENT**
- **BUILD UPON SUCCESS**
- **CREATE SKILLS and HABITS**
- **INSTILL APPROPRIATE CONFIDENCE**


positive
help
fit
regiment
things
way
exercise
including
vitamins
happy
weight
dedicated
necessary
side
supplemen
add
easily
settings
lifestyles
much
thin
stores
gym
time
lifestyle
health
easy
tores
offered
taking
take
healthy
offer
work
acquire
presence
idea