Movement Matters: A Personalized Approach to Exercise and Fatigue Management in ALS

Dr. Katherine M. Burke and Claire MacAdam, PT

ALS ASSOCIATION

Education@ALS.org
800-782-4747

Agenda

- Introductions
- Then and Now
- Exercise Guidelines
- Fatigue management
- Frequently asked questions
- Take Home Messages
- Q&A

Who are we?

Katey Burke PT, DPT, NCS

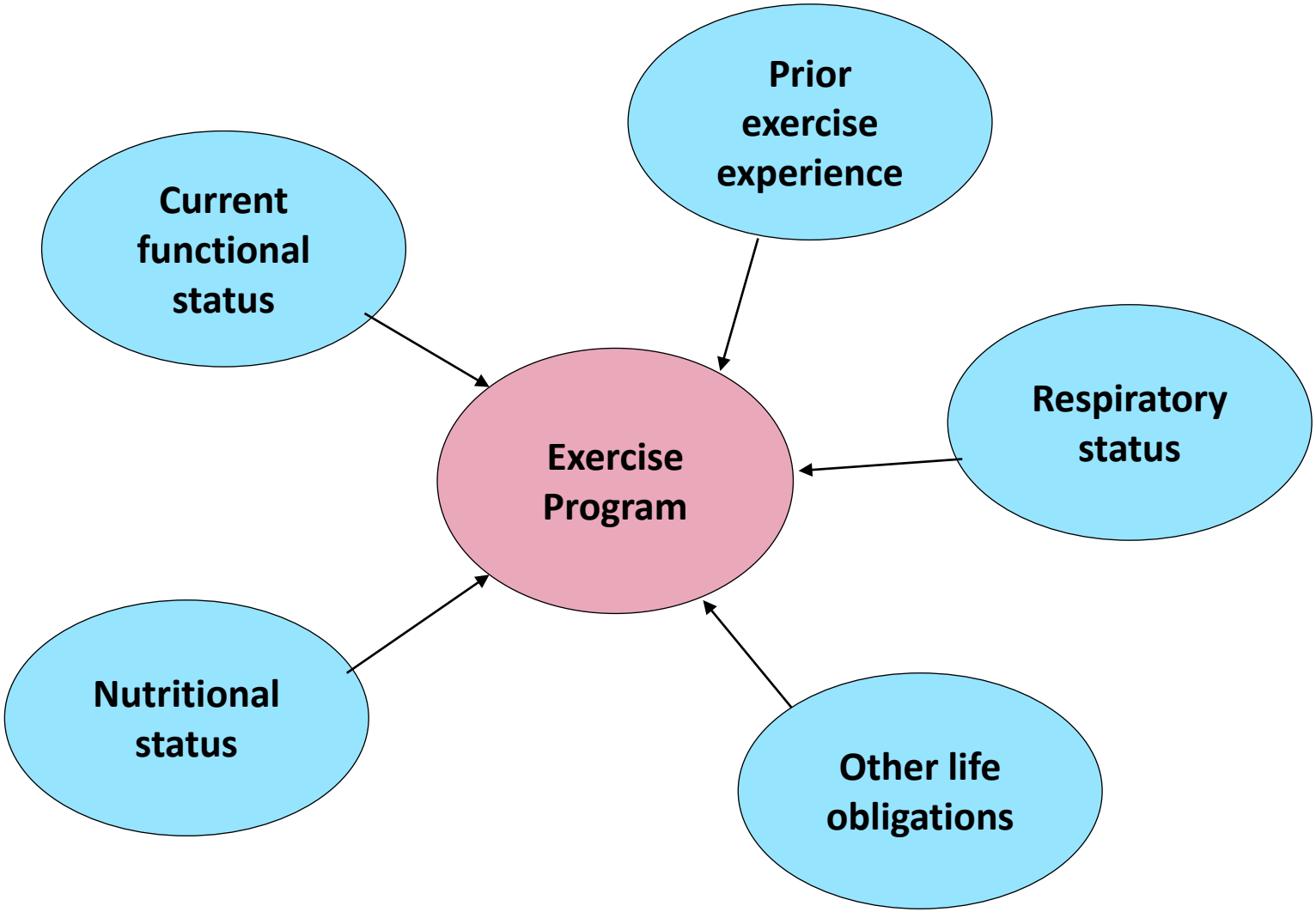
Claire MacAdam PT, NCS

A bit of History
Then and Now

- Then:
  - Don't exercise
  - Not sure if it will make things worse
  - May be best to be sedentary

- Now:
  - There are a lot of benefits to exercise
  - Being sedentary can create its own problems
  - There are guidelines to follow when exercising but we know so much more now about the benefits of exercise and activity

It's an *individualized* approach



General thoughts and guidelines

Our bodies crave and benefit from movement

With ALS, muscles are struggling and going through changes

Can we offer them gentle activity without over stressing them?

- Avoid muscle soreness
- Avoid a sense of overexertion
- Avoid a sense of excessive fatigue
- Feel like you have *recovered* from an exercise routine within 30-60 min.

What do we mean by “exercise”?

- Stretching
- Cardio/aerobic activities
- Resistance training
- Balance training
- Functional activities

Stretching

Benefits

- Maintain joint integrity
- Maintain range of motion
- Prevent contractures
- Muscle relaxation
- Pain management
- Make ADLs (dressing) easier

Stretching

Relevant Research
Fox and Keane 2022; Kalron 2021; Rahmati 2021; Clawson 2018

Guidelines

- Daily stretching (ideal)
- Usually holding for 30-60 sec
- You should be able to breathe throughout
- Should not be painful
- Stretch within your available range of motion; don't force it
- Move slowly in and out of positions
- Can be done independently or with assistance

Cardio/Aerobic Training

Benefits

- Maintains cardiovascular health
- Enhances muscle endurance
- Can help regulate blood sugar levels
- Increase blood flow to brain and extremities
- Can help promote emotional well-being
- Weight-bearing activities can help bone density

Cardio/Aerobic Training

1 - 10 Borg Rating of Perceived Exertion Scale	
0	Rest
1	Really Easy
2	Easy
3	Moderate
4	Sort of Hard
5	Hard
6	
7	Really Hard
8	
9	Really, Really, Hard
10	Maximal: Just like my hardest race

Guidelines

- Choose a safe mode - walking, stationary bike, aquatic/water therapy
- Monitor your breathing throughout
- Start easy and for short duration
- Shouldn't be harder than moderate intensity (50-70% effort)
  - Can use HR monitor or a rating scale to help you figure out appropriate level
- American Heart Association recommends at least 150 minutes of moderate intensity exercise per week for adults.

Relevant Research
Fox and Keane 2022; Kalron 2021; Rahmati 2021; van Groenestijn 2019, Clawson 2018

Resistance Training

Benefits

- Keep stronger muscles gently exercised
- Avoid disuse weakness
- Has the potential to make daily activities easier

Resistance Training

Guidelines

- Avoid muscle soreness
- Avoid a sense of muscle fatigue and overexertion
- Start with low weight, low number of repetitions
  - e.g. 2x5 reps, or 1x10 reps
- Focus on correct form throughout all repetitions
- Focus on stronger muscles

Relevant Research
Fox and Keane 2022; Kalron 2021; Rahmati 2021; Clawson 2018; Bello-Haas 2007; Drory 2001

Balance Training

Benefits

- Train muscles to assist with balance
- Potentially reduce fall risk

Balance Training

Guidelines

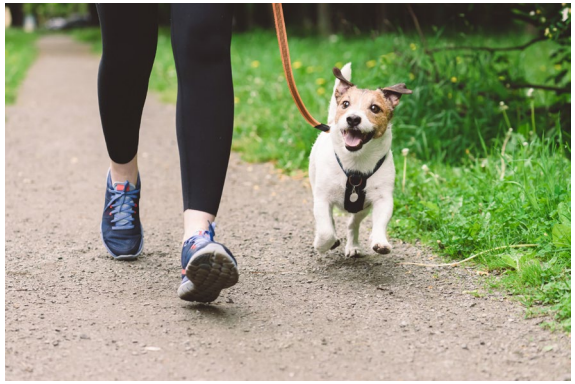
- Stand next to a counter or sturdy surface for all standing activities

Relevant Research
Fox and Keane, 2022;

Functional Activities

Benefits

- Gentle exercise while doing daily tasks
- Avoids fatigue by *blending* your exercise routine with your daily activities
- What activities bring you joy?
- Can friends and family members be part of this plan?



Functional Activities

Guidelines

- Avoid a sense of overexertion
- Avoid excessive fatigue
- Pace yourself throughout the day

Relevant Research
Drory 2011

Fatigue

- Up to 90% of PALS report fatigue as a symptom (Nicholson 2018)
- Varying presentations and contributing factors
  - Activity level
  - Nutritional status
  - Respiratory status
  - Emotional wellbeing
  - Sleep

Fatigue management

- Medical equipment
  - Will it make my task easier, safer?
  - Will it help me conserve my energy?
- Pacing strategies
  - Can I spread tasks out over time?
  - Can I take rest breaks when needed?
- Activity modification
  - Can I sit down to do this task?
- Sleep, nutrition, and breathing support play very *important* roles

Frequently Asked Questions

- Can I exercise?
- What exercises should I do?
- How/where do I start?
- How much should I do?
- Can I work with a PT and/or OT on establishing a program?
- My friend told me “no pain, no gain” – does this apply here?
- If I just work the muscles, will I help keep them strong?
- Has my daily activity routine (ADLs) become my “exercise”?
- I have a program, but I am getting more fatigued with it now, or I just can’t do it all, should I modify it?
- Is there ever a time to stop exercising?

Take Home Thoughts

- It is okay to exercise
- Emphasis on safety and activity tolerance
- Requires continuous modifications
- Exercise program should be *individualized*
  - Team approach
- Talk with your clinical team about what types and amounts are appropriate for you

Questions?

Thank you!

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