

‘Smart’ Exercises for Men with Kennedy’s Disease



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Background

When I was in my 30's and early 40's, I thought that any muscle weakness could be overcome by just exercising more. I ran longer and harder, lifted more weights, and pushed myself harder on the treadmill. As I became older, however, I found that I could no longer perform most of these exercises. The trouble was that I still enjoyed exercising and believe it is good for me.

Through the years I have had to modify and evolve my exercise program to better fit my capabilities. Today, I perform isometric and light aerobic exercises (arms, legs, hands, throat, and face). It appears to help keep me fit and I still enjoy the workout.

This exercise guide draws upon my experiences and the experiences of others to outline potential 'smart exercise' programs for men with Kennedy's Disease when weight training and treadmills are no longer a viable option. Three neurologists familiar with Kennedy's Disease have reviewed this guide and support the use of a 'smart' exercise program.

If you have any questions, please contact me at kennedysdiseaseinfo@gmail.com.



Bruce Gaughran

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Disclaimer

The information and recommendations contained in this ‘guide’ are the opinions of the author and are based upon his experiences. Anyone reading this ‘guide’ agrees to the following conditions.

The information provided in this ‘guide’ should not to be considered medical advice. The ‘guide’ should also not be considered a substitute for the advice of a trained medical professional or physical therapist. It is recommended that you consult with your family physician and neurologist prior to beginning any exercise program.

The author has made a reasonable effort to ensure that all information provided is accurate, but as with any living document, errors might occur. It is entirely the responsibility of the reader to determine the validity of any information provided. Any decisions made based upon the information received from this ‘guide’ are entirely the reader’s responsibility.

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The Concept – Exercise and Kennedy's Disease

Several neurologists confirm that light and (I will use the term) 'smart' **exercising is good for your muscles and motor neurons** because it stimulates them and keeps them functioning longer. Another benefit of exercise and stretching is that **it can cause 'cell inhibition'** (*see page 9, #2*).

However, any type of activity that overly taxes your muscles could be detrimental to your condition. The key is to just do what the body feels comfortable doing. Never exceed your capabilities. **The goal is to stimulate the healthy muscles and motor neurons without doing any harm to them.**

Instructions

1. These exercises should be performed slowly. Performing an **exercise slowly** actually helps prevent muscle damage and requires fewer repetitions to gain the same benefit.
2. Use the **70% Rule** with every exercise. This rule is meant to prevent any damage to the muscles. **The Rule:** Only perform about 2/3 of the number of repetitions that you can comfortable perform. Do not attempt to perform 'just one more' repetition because that is the one that might cause some damage. As your muscles gain strength and flexibility, add more repetitions without breaking the 70% rule.
3. Especially in the beginning, do not attempt to perform all of these exercises every day. Break them up into two or three day cycles where you perform certain exercises one day and others on another day.
4. The exercises discussed below are meant to be examples. Use these or create your own exercise program to fit your particular needs.

Do No Harm

1. Always consult your physician before beginning any new exercise program.
2. Your first concern should be for your safety.
3. Your second concern should be to 'do no harm' to your muscles. Use the 70% Rule described above.
4. If you feel pain during an exercise or a stretch, discontinue that exercise for the day.

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Exercise Examples

A. LEG EXERCISES

Note: The exercises below are meant to flex and stimulate the muscles. If performed properly, they will also strengthen or maintain strength in the muscles. **Important:** After each exercise flex the muscle groups a few times to help release the tension.

1. **Stand on One Leg:** Use a grab bar in front of you for balance. Stand on one leg for two to three minutes. Then switch to the other leg. When first starting out, one or two minutes could be more than enough time. As your strength grows, three minutes or more is possible. This exercise will strengthen the quads and will improve your balance.
2. **Back Twists:** While holding the grab bar, twist to the left as far as comfortable and then hold the position for five seconds. Then twist to the right and hold the position again. As you twist, place additional pressure on the outside of the foot and ankle in the direction of the twist. Perform ten-to-twenty twists to each side. This exercise will improve your foot and ankle strength as well as improve your balance.
3. **Walk in Place:** While holding the grab bar, walk-in-place. Actually perform the walking motion including the slight lifting of the knee and foot. Increase the number of steps-in-place as your strength improves. Work up to 200-to-300 steps. This is a good aerobic exercise. It will also help improve your overall leg strength.
4. **Knee Lifts:** While still holding the grab bar, lift the left knee so that the thigh is almost parallel to the floor. Point the toes downward. Using the knee as the pivot point, slowly rotate the foot in a clockwise circle for ten-to-fifteen revolutions. Point the toes upwards. Rotate the foot in a counter-clockwise direction for another ten-to-fifteen revolutions. Repeat the process with the right leg. This exercise will help improve your quad and ankle strength.

B. UPPER BODY EXERCISES

Most of these are isometric exercises. **Important:** After each exercise slowly flex the muscle groups a few times to help release the tension.

1. **Grasp and Hold:** Directly in front of your chest, place a ruler (or similar type object) between your thumbs and index fingers. Grasp and hold the ruler by compressing the thumbs against the forefingers. While tightly grasping the ruler, attempt to pull the hands apart. Hold the posture for a count of 30.
2. **Press the Fingers Together:** With your elbows straight out to the sides and parallel to the floor, spread your four fingers and thumbs and touch them together – with the fingers

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facing straight up. Arch your palms so that only the fingers touch and the palms are 2-3 inches apart. Now apply pressure to your fingers – using your triceps – pushing as hard as comfortably possible on the fingers. Hold this posture for a count of 10.

3. **Biceps Pull Apart:** Grasp your hands together in front of chest with the elbows facing out to the sides and parallel to the floor. Attempt to pull your hands apart for a count of 20. Increase the count as your strength improves. Repeat the same process behind the neck.
4. **Triceps – Push Hands Together:** Place your palms together in front of you with your elbows facing out to the sides. Attempt to push the two palms together for a count of five. Increase the count as your strength improves.
5. **Side Lifts:** Extend your arms straight out to the side. Make a fist with your palms facing down. While inhaling and keeping the arms straight, slowly lift the arms straight above your head. Once fully extended, begin to exhale as you allow the arms to slowly fall back to the parallel position. Perform 10 repetitions. When through, allow the arms to rest comfortably at your sides. Repeat the exercise with your palms facing up. Note: If this is too easy, grasp a 12 ounce soda can in each hand.
6. **Front Lifts:** Extend both arms straight out in front of you. Make a fist with your palms facing up. While inhaling and keeping the arms straight, slowly lift the arms straight above your head. Once fully extended, begin to exhale as you allow the arms to slowly fall back to the parallel position. Perform 10 repetitions. When through, allow the arms to rest comfortably at your sides. Note: If this is too easy, grasp a 12 ounce soda can in each hand or use light dumbbells.
7. **Front Curls:** Use a 12 ounce soda can or light dumbbells for this exercise. Grasp the right knee with your left hand. Lean forward and place your right elbow on the inside of your right knee and on the outside of your left arm. With your palm facing out, straighten your arm until it is almost touching the floor. Now slowly curl the arm up until your hand is touching your right shoulder. Slowly return the arm to the starting position. Perform 10 repetitions and then switch to the left hand.
8. **Front Press:** Using your cane (or a broom), bring the cane up to your chest with the palms facing out (a press position). While exhaling, slowly push the cane/pole above your head until the arms are fully extended. Hold the posture for a count of 3. While exhaling, allow the arms to slowly return to the front of the chest. Perform 10 repetitions.
9. **Back Press:** Using your cane (or a broom), raise the cane up above your head and lower it to the back of your neck with the palms facing up. While exhaling, slowly push the cane/pole above your head until the arms are fully extended. Hold the posture for a count of 3. While exhaling, allow the arms to slowly return to the back of your neck. Perform 10 repetitions.
10. **Back Curl:** Grasping your cane (or a broom) with your palms facing down, raise it over your head and let it rest on the back of your neck (your palms should now be facing up). Slowly curl the arms upward until they are straight above your head. Slowly return the arms to the starting position at the back of your neck. Perform ten repetitions.

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C. BACK AND STOMACH EXERCISES

1. **Bend from the Waist:** Sit on the edge of your chair with your feet flat on the floor. Place your hands on your hips. Breathe out as you slowly bend as far to the left side as comfortable. As you inhale, straighten back up to the upright position. Breathe out as you slowly bend to the right. As you inhale, straighten back up. Breathe out as you slowly bend down in front of you. Inhale as you straighten upright. Look up at the ceiling and bend backwards as you exhale. As you inhale, straighten up. Perform 10 repetitions.
2. **Pelvic Twist:** Stand up straight with your feet about should-width apart. Place your hands on your hips. Using your tailbone as the center point, very slowly rotate your hips in a circle to the left. Try to only use your hips and not your knees in the rotation. Perform 10 slow circles. Perform the same exercise in the other direction.
3. **Modified Crunch:** Lie down on a bed or the floor. Bend your knees so your feet are flat on the floor. Cross your arms in front of your chest with your hands touching your shoulders. Attempt to perform a sit up by using your abdominal muscles. When near the top of the position, hold the position for a few seconds and then slowly release the muscles until you are flat on the floor (bed) again. It is important to keep the motion smooth and not jerk upwards. The idea is to stimulate the muscles, but not hurt the back by over-extending your capabilities. Perform 10 repetitions.

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Swallowing Exercises

These exercises are to make it easier to swallow food. This exercise was for patients that had had throat surgery and the muscles became weak after the surgery. It is to strengthen the swallowing muscles for patients that had swallowing problems after throat surgery. I do not know if it will help for KD, but feel it helps me.

1. Stick your tongue out. Bite down lightly on the tongue to hold it in position. Swallow ten times while holding that tongue between the teeth.
2. Make the sound “EEEEEEEEEEEEEEEEEEEEEEEE” on and off and you will feel the neck and throat muscles stretch.

Breathing Exercise

Lie on your bed or on the floor. Alternatively, sit up straight on the front of a chair. Place your palms over your stomach. Using your abdominal muscles (not your chest), slowly breathe in to your abdomen. Hold your breath for a couple of seconds. Slowly exhale using your abdominal muscles to push out all of your air in your lungs.

Note: You should be able to watch your hands move out from stomach and back into your body if you are doing this exercise properly.

Perform 10 of these deep breaths. After you are comfortable that you are breathing correctly, close your eyes. This exercise can be practiced anytime. As this exercise becomes more comfortable, add more deep breaths until you are doing 30 or more.

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Exercise for Sedentary People (*)

-Armchair Fitness-

"When the commercial comes on, you go to work"

In the past, exercise therapy was seen as alternative medicine - "real" medicine was pills or surgery. After all, medical schools don't spend time on exercises - those are taught in gyms and the YMCA. Everybody has always known it's good to work-out, but now we are starting to develop scientific data about the use of exercise in medicine. This program features very frequent, short mini-work-outs of individual muscles and is designed to correct the loss of muscle tone that goes with neuromuscular problems.

1. Identify your weak muscles and learn how to use antigravity positions to improve the power of those specific muscles. Learn the names of the muscles.
2. Find muscles not primarily affected by exercise for improvement in mood and motivation and for pain reduction (think about cell inhibition and endorphin release).
 - **Cell inhibition** is what happens when an activity just started, such as an exercise (or an acupuncture needle or back scratch or massage), temporarily blocks an unpleasant sensation like a chronic pain. The nerve transmits the pain signal to a cell in the spinal cord which is inhibited by the new "traffic" caused by the new stimulus. It's why pinching the cheek blocks the pain from the anesthesia needle in dentistry, and why rubbing a child's wasp bite helps the pain.
 - **Exercise and stretching** (working the muscles and joints) **produces stimuli for the spinal cord and brain** (central nervous system), which is one reason we feel better when we move.
3. Avoid straining and don't hold your breath. Change to a different muscle if you feel any pain.
4. Look up Tai Chi & Qigong methods, and adopt new exercises if there is no risk of falling.
5. Aerobic exercise is also encouraged (20 min 3 x week) emphasizing water programs, elliptical trainers and stationary bikes over treadmills and walking, unless falling is not a risk — but aerobics cannot replace this frequent (every 30 mins) anti-gravity program, which is aimed at building strength in specific muscles.
6. Examples of the 2-minute drill — go in any sequence and don't try to do more than one or two in any 2-minute period:
 - Arm elevation for 1- 2 min
 - Slow biceps movement with hand weights
 - Cock-up wrists and finger spread (widely enough to produce mild discomfort)
 - Grip and hold
 - Push down on chair arms (triceps)
 - One leg raise (hip flexion) for 10-15 seconds, then other side

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- Quadriceps — lock one knee with heel on floor then sit back and raise the leg a few inches off floor, keeping knee locked - hold position for 15-30 sec then switch sides to avoid back strain
- Ankle "cock-up and hold" (tibialis anterior)
- Ankle eversion or feet out (peroneus longus)
- Get up 5 times as slowly as possible, minimize or eliminate the push with hands (quads and gluteals)

“Then sit back and enjoy what you were doing until the next two minute period comes along”

() Provided by Linton C. Hopkins, M.D., Emory University School of Medicine*

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Pool Exercises

Several people with Kennedy's Disease have reported good results with pool therapy. Some use a program developed through a licensed physical therapist. Below are two examples of exercise programs that might work for you if you have access to a pool.

A. POOL THERAPY

The sessions can be up to hour long conducted in a pool with a ramp, which allows you to walk into the pool, or a hoist to lift you out of the water afterwards. It is preferable to have a therapy pool with 95 degree water. The hour session consists of exercises such a leg lifts, jumping jacks, arm movements, bending and stretching, walking, etc.

The buoyancy of the water will permit you to move without having to deal with your body weight. The challenge of exercising on land is losing your balance, which does not happen in the pool. Also when you move, the warm water messages the muscles. Frequency: When you first start, try twice per week. If this is too much and you feel tired or exhausted afterwards, only go once a week.

The exercises discussed below are meant to be examples. Use these or create your own exercise program to fit your particular needs.

- Stretching Exercises
 - Stretch calf muscles. Stand on right leg with knee straight. Lean forward while keeping heel on floor. Hold 10 seconds. Repeat on left.
 - Stretch hamstrings. Put right leg straight out in front with foot resting on edge of pool. Lean forward. Hold 10 seconds. Repeat on left.
 - Stretch quadriceps. Bend right knee and grasp right ankle behind you. Hold 10 seconds. Repeat on left.
 - Stretch gluteals. Stand with back against wall. Bring right knee up to chest. Hold 10 seconds. Repeat on left. Side bends. Hold side of pool with left hand, feet together away from edge. Allow hips to sag toward edge of pool by bending at waist 10 times. Turn and face in opposite direction.
 - Stand with feet wide apart, lean side to side 10 times to stretch inner thighs.
- Hip, Back and Stomach Exercises
 - Hip circles (Hula Hoop exercise) - Stand with your feet shoulder width apart. 10 times clockwise, 10 times counter-clockwise.
 - Hold onto edge of pool. Keep elbows straight. Rock hips forward and back 15 times.
 - With back against wall, hold onto edge of pool. Tighten abdominals and raise knees to chest, then lower feet to floor. Repeat 10 times.
- Leg and Balance Exercises

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- Walk forward and backward across pool as fast as you can 5 times.
- Side-step across pool 5 times.
- Stand on right leg, raise the left knee up to the chest and stomp down on floor 10 times. Repeat exercise on the right side.
- Stand on right leg, kick left leg straight out behind and then bring the left knee forward to chest 10 times. Repeat the same on right side.
- Stand on right leg. Kick left leg in large circle. Movement should be at hip only. Keep left knee straight. 10 times clockwise, 10 times counter-clockwise. Repeat on right side.
- Jumping Jacks - 30 times.
- Run in place - 30 times.
- Stand with left side to pool and hold onto edge. Kick right leg forward and back like pendulum. Movement at hip only. Keep knee straight. Repeat 10 times. Turn and face in opposite direction. Repeat last 4 exercises using left leg this time.
- Kick right leg straight out to side. Alternate, bringing leg down in front, and then behind left leg 10 times. Turn and face in opposite direction. Repeat last 4 exercises using left leg this time.
- Hold right leg out to side with knee bent. Do circles with lower leg, 10 times clockwise, 10 times counter-clockwise. Turn and face in opposite direction. Repeat last 4 exercises using left leg this time.
- Hold onto edge of pool, put both feet on wall. Kick them straight out behind and then bring them back to the wall 10 times.
- Flutter kicks with legs stretched out behind 20 times. /
- Scissor kicks 10 times.
- Face pool wall. Stand on right leg. Do 10 knee bends and then 10 heel raises. Repeat on left leg.
- **Arm Exercises**
 - Rotator cuff exercise: put one arm next to side with elbow bent to 90 degrees. Rotate forearm in and out 10 times. Repeat on other arm.
 - Cup hands and pull water in toward you using forearms 10 times.
 - Push water away from you with backs of hands 10 times.
- **Wrist Exercises**
 - Stretch wrist flexors by holding arm out straight with palm facing up. Bend wrist down using other hand. Hold 10 seconds. Repeat on other side.
 - Stretch wrist extensors by holding arm out straight with palm facing down. Bend wrist down using other hand. Hold 10 seconds. Repeat on other side.
- **Neck Exercises**

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- Stretch side of neck by placing right hand behind back. Tilt head to left. Hold 10 seconds. Repeat on other side.
- Neck half-circles. Avoid tilting head back. Repeat 10 times slowly.
- **Shoulder Exercises**
 - Stretch right up straight up overhead. Hold for 10 seconds. Repeat with the left arm.
 - Shoulder shrugs 10 times.
 - Shoulder blade pinches 10 times.
 - Alternating shoulder rolls 10 times.
 - Extend arms, push chest out, pinch shoulder blades together. Hold 10 seconds. Stretch back of shoulder by pulling arm across body. Hold 10 seconds. Repeat on other side.
 - Push-ups at edge of pool 10 times.
 - Push-ups behind back, holding kickboard 10 times.
- **Foot Exercises**
 - Rock from heels to toes 10 times.
 - Using opposite heels and toes, rock forward and backwards. Alternating 10 times.
 - Toe curls – crunch toes 10 times.

B. AQUA AEROBICS

For all of the exercises shown below, start slowly. Don't do any more than ten reps for each exercise or two laps walking/Aqua Aerobics. You can increase the number of reps in the next session if you felt okay at the end of the previous session. Always use the 70% rule stated at the beginning of this article.

1. Using a kickboard, swim several crosswise laps in about 3-4' of depth. Use the kick board as a "plow" under water to increase resistance or use reverse hand strokes to provide resistance. Use long strides to stretch unused ligaments and muscles. The "plow" provides some upper body work out.
2. At the pool's edge, face the side and place your hands on the edge for balance and leverage. Using the right leg, perform a set of leg circles (leg stiff) clockwise then counter clockwise to each side. Then perform the same exercise with the left leg.
3. At the pool's edge and facing sideways, perform a set of leg swings with the outside leg. Swing back and forth keeping the leg stiff through the forward stroke. Face the other direction and perform the same exercises with the other leg.
4. In waist deep water, perform deep knee bends. If you are not strong enough or have the balance, face the side of the pool and place your hands on the edge of the pool to help support yourself.

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You can also supplement this program with additional laps (walking or easy strokes) between exercises. This program normally can be completed in about 30 minutes. Once the above exercises are completed and if you still feel good afterwards, you can supplement them with Aqua Aerobics as well. Aqua Aerobics is basically a "jog" in deep water wearing a floatation belt designed for the purpose.