

Movement is key to supporting adults with Down syndrome

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UNLV physical therapy professor Thessa Hilgenkamp works with a patient inside the Cardiovascular Research and Exercise Lab, which focuses on how the body responds to exercise. Her work focuses on movement in people with Down syndrome. Credit: Josh Hawkins/UNLV

Over the past few decades, research and greater awareness has helped

adults with Down syndrome—and a well-trained support system—to be more physically active in their daily lives.

At UNLV, Thessa Hilgenkamp is an exercise physiologist and assistant professor in the Department of Physical Therapy within the School of Integrated Health Sciences.

She runs the Cardiovascular Research and Exercise Lab (CARE-Lab) and has combined her passion for movement with her commitment to supporting individuals with Down syndrome to be physically active and live healthier lives.

Down syndrome is the most common chromosomal disorder, affecting 1 in every 700 babies born each year. Defined as having a third copy of the 21st chromosome, it can also affect people very differently.

Most people with Down syndrome have ligamentous laxity, meaning they have a lot of flexibility in their joints.

"This can cause issues with their musculoskeletal system, which can create problems over time with pain and movement," she said. "But with the correct exercises and support, we have the opportunity to help them move better throughout their lives."

She added that there is a broad range of features and characteristics that might not occur in everyone with Down syndrome, and the range of intellectual disability can vary greatly, as well.

Movement is at the heart of Hilgenkamp's life, as well as her life's work over the past 20 years helping adults with Down syndrome.

"Physical activity isn't just a hobby, it is a basic human need," she said. "Sometimes it gets cast aside as an option, but I don't feel that's what

physical activity is."

Growing up in the small Dutch town of Dalfsen, much of Hilgenkamp's youth was spent inside a gym. Her affinity for getting others to move their bodies for the sake of their health led her to her Ph.D. program at the Erasmus Medical Center in Rotterdam in 2008. Her doctorate program was called, "Physical Activity and Fitness in Older Adults with Intellectual Disabilities."

Hilgenkamp is also the clinical director for "FUNFitness" Healthy Athlete Screenings at Special Olympics Nevada, a supporting organizer of the Las Vegas Down Syndrome Connections conference, and serves on the board of GiGi's Playhouse, a national organization offering free therapy-based programming to the Down syndrome population.

She and her physical therapy students also developed a research partnership with Sarah Mann from Mann Method Physical Therapy in Colorado where they build sustainable workout routines for people with Down syndrome.

How does having Down syndrome make movement more difficult?

From a cardiovascular side of things, their heart rate can't go up as much as it would for those who don't have Down syndrome. The maximal heart rate for those with Down syndrome is 25–30 beats per minute less than their peers.

Because of their [heart rate](#), in addition to balance and musculoskeletal issues, some activities cost more energy. The connections through our bones and the power in our muscles help us to move, and if you have loose joints (ligamentous laxity), and more relaxed muscles (hypotonia),

your muscles are forced to work harder.

If you combine these notions, a walk to the mailbox or a coffee shop is a lot higher in intensity for individuals with Down syndrome.

We all pick a walking speed that is based on our idea of energy conservation, and for people with Down syndrome, their speed is often slower because of how much energy it takes.

Can you explain the physical and mental benefits of movement for individuals with Down syndrome?

Exercise helps us all. When I work with people with Down syndrome, helping them learn to move their body better and more easily helps them access the world in a very different way.

Being strong and stable physically gives us all the opportunity to pursue our dreams. I'm very passionate about educating people to provide support so we can all go out into the world and do all of the things we want to do.

What helps people with Down Syndrome increase movement the most?

For people with intellectual disabilities, the support system they have around them is critical. Many activities and opportunities are not easily accessible to individuals with intellectual disabilities.

Educating parents and caregivers on how to support a commitment to a healthy lifestyle is a critical part of supporting movement. And once you are comfortable in your body and movement and have access to the activities you enjoy, you'll be confident in so many other things.

For people with Down syndrome, they've had to work through this their entire life—exerting extra energy, effort, balance and focus to participate in all movement activities. There is often a misconception that people with Down syndrome are lazy, or they don't like to move. People with Down syndrome have a unique anatomy that makes movement more challenging. They truly work harder with every step.

When did you begin studying the health of adults with Down syndrome?

I started my research career in Down syndrome as an unpaid research assistant right after my master's program. My former master's thesis advisor needed help for a study he was doing on circadian rhythm and Alzheimer's disease in Down syndrome. I was asked to organize some fitness testing for research, and I really loved it.

Communication with individuals with Down syndrome is incredibly honest. If they like something, they will let you know. If they don't like something, they will also let you know.

It was an eye-opening experience to see how to best work with individuals with Down syndrome. I started learning about how little was actually known about the [physical activity](#) needs for people with Down syndrome and knew that I needed to learn more.

How have you seen developments in Down syndrome awareness over the years?

I think what has changed over the course of my research has been that people with Down syndrome have become a bigger part of the conversation. I don't think they felt that their voices were being heard before.

Now people are more connected, and with support, they have a lot more to say about their preferences. There are more opportunities where they can be successful and build their skills. That was not the case in the early 2000s.

Do you have any advice for parents who have a child with Down syndrome? What can they do to help their child be as healthy as possible?

I would say keep exploring new activities and find something that you enjoy doing together. Think of incorporating [movement](#) into your daily activities, like walking your dog, and expand on that when you find something that they love.

What I hear from families after our program with Mann Method Physical Therapy is that their son or daughter is initiating more activities or family outings. Their posture is improved, and they have more confidence. That's what I love about what I do. Once you get that feeling of success and confidence through exercise, it can be addictive.

Our physical therapy students are helping to build those continuing education programs so other physical therapists can learn how to provide a solid workout routine for people with Down syndrome. We believe that feeling good in your body helps you feel good in life. As we say at the CARE-Lab, this is how science meets practice!

Provided by University of Nevada, Las Vegas

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