

In Touch Newsletter

February 2023

Chinatown Bilingual Support Group celebrates Lunar New Year

Chinatown Bilingual Parkinson Support Group held its first meeting for the year on 7 February. This was also a celebration of Lunar New Year.

The meeting venue was the Australian Chinese Community Association Hall and more than 40 participants including carers and volunteers attended.

Founding president, Julia Fry (who has recently moved into a nursing home) and former President Robert Yeoh also attended. A lot of old friends also attended the party accompanied with their carers

Group Coordinator Rosanna Ng wished everyone good luck and good health in the coming New Year. This was followed by a 45-minute group exercise session.

Rosanna encouraged everyone to exercise diligently to maintain physical and mental health. She then invited the guest of the day, Joanne Lau, to lead everyone in singing and movement with music.

Joanne's wonderful singing encouraged all present to joyfully join in the New Year's celebration. Former president Robert also performed on his harmonica to celebrate.

After the music there was home-made New Year's lunch – delicious pastries cooked by support group participants. There were many thanks to the cooks and volunteers for their hard work which made the event such a success.

Dancing With Music Can Halt Most Debilitating Symptoms of Parkinson's Disease

A new study published in *Brain Sciences* shows patients with mild-to-moderate Parkinson's can slow the progress of the disease by participating in dance training with music for one-and-a-quarter hours per week.

Over the course of three years, this activity was found to reduce daily motor issues such as those related to balance and speech, which often lead to social isolation.

Joseph DeSouza, senior author, principal investigator and associate professor in the Department of Psychology at York University and PhD candidate Karolina Bearss, found people with Parkinson's who participated in weekly dance training, had less



motor impairment, and showed significant improvement in areas related to speech, tremors, balance, and rigidity compared to those who did not do any dance exercise.

Their data showed significant improvements in experiences of daily living, which include cognitive impairment, hallucinations, depression, and anxious mood such as sadness.

The study showed overall that non-motor aspects of daily living, motor experiences of daily living, motor examination symptoms and motor complications did not show any impairment across time among the dance-trained people with Parkinson's group compared to those who do not dance.

Study first of its kind

The study is the first of its kind to follow people with Parkinson's over a three-year period during weekly dance participation with music, providing additional information regarding the nature of progression of motor and non-motor Parkinson's symptoms.

"The experience of performing and being in a studio environment with dance instructors appears to provide benefits for these individuals," said DeSouza.

"Generally, what we know is that dance activates brain areas in those without Parkinson's. For those with Parkinson's disease even when its mild, motor impairment can impact their daily functioning — how they feel about themselves.

"Many of these motor symptoms lead to isolation because once they get extreme, these people don't want to go out. These motor symptoms lead to further psychological issues, depression, social isolation and eventually the symptoms do get worse over time.

"Our study shows that training with dance and music can slow this down and improve their daily living and daily function."

The goal of the research was to create a long-term neurorehabilitation strategy to combat the symptoms of Parkinson's.

Multi-sensory activity

In the study, researchers looked at how a multi-sensory activity, (like dance with music learning) which incorporated the use and stimulation of several sensory modalities in the dance environment – including vision, audition, tactile perception, proprioception, kinaesthesia, social organisation, and expression, olfactory, vestibular and balance control – may influence many of the mood, cognitive, motor, and neural challenges faced by people living with Parkinson's.

Researchers followed collected data from people with Parkinson's over three-and-ahalf years while they learned choreography over the first year and performed it, that is designed to be adaptable to the disease stage and current symptoms for people living with Parkinson's.



In the study, 16 participants with mild-to-moderate Parkinson's (11 males, five females) with an average age of 69, were tested. They were matched for age and severity of disease. Each participant took part in a 1.25-hour dance class at Canada's National Ballet School (NBS) and Trinity St. Paul's church locations.

Dancers participated in dance exercises which provided both aerobic and anaerobic movements. This group was then compared to 16 non-dance people with Parkinson's participants (the reference group) chosen from a larger cohort from the Parkinson's Progression Marker Initiative (PPMI) – a longitudinal research project funded by the Michael J. Fox Foundation for Parkinson's Research (MJFF) and related funding partners.

Learned choreography for a performance

Classes began with live music accompaniment during the seated warm-up, followed by barre work, and ended with moving across the floor. All participants learned choreography for an upcoming performance. Researchers recorded videos, conducted paper and pen questionnaires of all participants, and performed statistical analyses.

"Dance is so complex; it's a multi-sensory type of environment," said Bearss. "It incorporates and stimulates your auditory, tactile, visual, and kinaesthetic senses and adds an interactive social aspect. Regular exercise does not offer these aspects. There's so much more to dance."

Researchers will next examine what occurs in the brain immediately before and after a dance class to determine what neurological changes take place.

"Currently there is no precise intervention with Parkinson's and usual remedies are pharmacological interventions, but not many options are given for alternate exercises or additional interventions to push their brains," said DeSouza.

"Hopefully this data will shed light on additional therapies for this group and be used in the treatment process. There may be changes in the brain that occur with dance with music, but more research is necessary."

Source York University, Canada

The World Parkinson Congress is coming soon!

It's here at last. It is 2023, year of the next World Parkinson Congress (WPC) which will be held from July 4 to 7 in Barcelona, Spain.

This unique event usually takes place every three years in a different country. Anyone with a connection to Parkinson's is welcome to attend.



It is an international forum enabling scientists, clinical researchers, health care professionals, people living with Parkinson's, caregivers, and others to come together under one roof. They discuss, learn, and debate the latest scientific discoveries, medical and comprehensive care practices related to Parkinson's disease.

The WPC is an inclusive event, founded on the belief that getting world leaders out of their professional silos and encouraging cross pollination of the scientific, clinical, rehabilitation, and advocacy communities would expedite the discovery of a cure and cultivate best treatment practices for this disease.

Read about the impact of this cross pollination format in these quirky and touching stories on the <u>Working Parkinson Connections</u> blog page, written by UK-based neuroscientist Dr. Jon Stamford who is also living with Parkinson's.

If you are interested in attending WPC 2023, email <u>pnsw@parkinsonsnsw.org.au</u> or call 1800 644 189.

Voluntary Assisted Dying Act passed by NSW Parliament

Community interest in Voluntary Assisted Dying finally came to fruition with the passing of the Voluntary Assisted Dying Act 2022 by NSW Parliament on 19 May 2022.

NSW Health is now going through an implementation process aiming to bring the legislation into effect from 28 November 2023. This process will oversee and guide the establishment of the specific governance arrangements and processes as required by the law.

See a full overview of the Act and its requirements here.

Certain criteria need to be met by people wanting to access voluntary assisted dying (VAD):

- 1. They must be an adult who is an Australian citizen, a permanent resident of Australia or have been resident in Australia for at least three continuous years.
- 2. They must have been living in NSW for at least 12 months.
- 3. They must have at least one disease, illness or medical condition that is advanced, progressive and will on the balance of probabilities, cause their death within six months (or within 12 months for neurodegenerative diseases like motor neurone disease), and is causing the person suffering that cannot be relieved in a way the person considers tolerable.



- 4. They must have decision-making capacity in relation to voluntary assisted dying and be acting voluntarily.
- 5. They must have the ability to make and communicate requests and decisions about voluntary assisted dying throughout the formal request process.

Medical Specialists providing Voluntary Assisted Dying have to hold specialist registration, general registration of 10 years of practice, approved mandatory training and cannot provide VAD to a family member.

There will be a NSW VAD Care navigator established to act as a primary point for contact of patients, families and clinicians.

In addition there will be VAD Board independent oversight and decision-making body.

Different Activities, Different Benefits

Our bodies are the physical containers through which we live. When we move and feel better, and we live better. We tend to think of health and fitness as only physical. However, fitness is actually multi-faceted including:

- Mental (overall mindset, discipline despite feelings, will power, and quality of input and output)
- Emotional (motivation, inspiration, our feelings, and perception of others' feelings)
- Spiritual (prayer and meditation)
- Social (quality of our interactions with others and our support network)
- Environmental (what you surround yourself with people, sights, sounds, and ideas that you allow to affect the other facets)
- Physical (nutrition, physical activity, biometrics, and annual check-ups). There are even more facets in the physical area, such as:
 - Cardiovascular (heart, lungs and breathing)
 - Strength (ability to lift and move without fatigue)
 - Flexibility (range of muscles without damage)
 - Endurance (length of time you can continue doing an activity)
 - Balance (ability to stand and move without falling)
 - o Agility (ability to alter direction quickly and without falling)
 - Power & Speed (the amount of force you can apply to a movement)

Virtually all activities and sports will deliver benefits for those living with Parkinson's. Skydiving or bungee jumping excluded! Below is a list of some popular sports and activities and the specific benefits they offer.

Walking

• Improves cardiovascular performance, endurance, gait, leg strength and coordination, mobility, and balance.

HIIT (High Intensity Interval Training)



• Cardiovascular benefits, improvements in flexibility, gait, leg strength and coordination, mobility, and balance.

Non-combat Boxing

• Improves cardiovascular, strength, balance, endurance, power, speed, hand-eye and other coordination and improves all Parkinson's symptoms including non-motor ones.

Dancing (all styles are great)

• Targets flexibility, coordination, posture, balance, confidence, mood, agility,

Nordic Walking (a form of cross-country skiing on land)

• Enhancing cardiovascular performance, stride length, whole body strength, balance, coordination, posture and improves gait.

Yoga

- Improves breathing techniques aiding strength, flexibility, and relaxation.
- Reduces stiffness and slowness of movement, improves balance, and lessens stress improving sleep.

Cycling

• Improves heart and lungs, cholesterol, blood pressure, immune system, and mood. Along with decreasing tremors and stiffness while increasing endurance, strength, and coordination.

Tennis/Table Tennis

• Enhances mental alertness, improves reaction times, strength and agility while decreasing rigidity and tremors. There are also benefits for posture, facial expression, speech, and handwriting as well.

Tai Chi

• Improves flexibility, reduces stress, improves muscle strength, and beneficial for a variety of illnesses such as heart disease, as well as balance and coordination.

Every facet of fitness affects the body for better or for worse and most activities and sports offer benefits for those with Parkinson's.

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