



## Quick recap

The meeting focused on sharing experiences and challenges faced by young stroke survivors and their families. Participants, including Susan (the facilitator), Crystal, Jamie, Donna, and others, discussed their personal stories, the impact of strokes on daily life, and the emotional and physical recovery processes. Crystal shared her daughter McKayla's experience with a stroke during a parade, leading to a diagnosis of Moyamoya disease and subsequent surgery. Jamie described her daughter Myla's recovery journey after a hemorrhagic stroke, highlighting ongoing challenges and the importance of regular medical monitoring. The group also discussed the role of caregivers, with Tom Gallup introducing a nationwide brain injury caregiver support group and sharing resources. Susan outlined plans for future meetings, including potential additional teen stroke groups and discussions on topics like prevention, driving adaptations, and bilateral exercises. The conversation ended with participants expressing support for one another and sharing practical tips for managing stroke-related challenges.

## Summary

### Exercise Benefits for Learning and Brain Function

The group discussed the importance of exercise, particularly before learning activities, based on Nate's presentation about a study from the Naperville 203 school district. Nate shared that students who exercised before school showed improved test scores and better attention spans, leading to a recommendation for morning exercise. Several participants, including Gabe and Myla, mentioned their limited morning exercise routines, while Dinithi noted her afternoon workouts and expressed interest in incorporating morning exercise. The discussion highlighted the potential benefits of exercise on brain function and recovery, with Nate emphasizing its importance for both young people and stroke survivors.



## **Personal Stroke Experiences Shared**

The group discussed personal experiences with strokes, with Isabella sharing her story of having a stroke during a heart transplant operation that affected her right hand and speech. Myla described her experience with an AVM rupture two years ago, which required skull removal surgery and initially left her unable to walk or speak. Gabe recounted his experience of waking up with a severe headache that led to hospitalization, while Dinithi shared her story of having a brain cyst removed during her master's program in neuroimaging informatics, which affected her short-term memory. The discussion aimed to learn about different stroke experiences to help participants understand the condition better.

## **Survivor Stories and Caregiver Support**

The meeting began with young stroke survivors sharing their experiences, including Nate, who described a severe headache incident in gym class that led to a stroke, and Layli, who had a stroke at 24 and is still recovering. Michelle shared her recent stroke experiences, including three strokes, and discussed her recovery process. Tom Gallup, a stroke survivor and caregiver support group leader, joined to discuss his ongoing involvement in brain injury advocacy and to invite the group to join his nationwide caregiver support group. The conversation ended with Gabe discussing his son's October stroke and the challenges of navigating medical care and emotional recovery, with Tom offering support and information about his caregiver group.

## **Surviving Strokes: Personal Stories**

Crystal shared her daughter McKayla's experience with a stroke caused by Moyamoya disease, which occurred during a parade performance. Despite initial symptoms like vision problems, McKayla's stroke was not immediately



recognized, leading to emotional challenges for both McKayla and Crystal. Jamie discussed her daughter Myla's recovery from a hemorrhagic stroke, highlighting the ongoing physical and emotional challenges, as well as the uncertainty of future strokes due to an undetermined cause. The group also discussed the importance of monitoring and support for stroke survivors, with Layli offering resources for theater programs for individuals with brain injuries.

### **Teen Stroke Support Meeting Planning**

The group discussed goals and topics for upcoming young stroke survivor meetings, including presentations on prevention versus repair, hearing loss, and driving adaptations. Crystal shared her expertise in EMDR therapy and bilateral activities for trauma recovery, which she will present in March. Susan expressed interest in expanding teen stroke groups and exploring brain injury topics, while also considering caregiver involvement. The conversation ended with Layli offering support to parents dealing with their children's stroke experiences, and Dinithi offering her email for further communication.

### **Caregiver Challenges in Therapy Acceptance**

The group discussed challenges faced by caregivers of children with disabilities, particularly regarding therapy acceptance and balancing support. Crystal shared her daughter's resistance to therapy while feeling the pressure to provide more help, while Myla described similar struggles with her daughter McKayla, who has reached a point of acceptance despite ongoing specialist recommendations. The discussion concluded with Susan announcing an upcoming presentation about "walking with music" technology, scheduled for next Tuesday at 7:30 Eastern Time, and noting that the company has shifted from county funding to seeking partnerships with device providers.