

Welcome to YASS!

Two presentations, two videos

Very structured today

Our speakers aren't here yet, so I'll have to wing it

Caregivers split off at 1:30

Please make use of the YASS library!

There are books and movies. Ask Duane if you're interested

Please don't talk while people are speaking. It's distracting

Please turn off your cell phones.

Newcomers!!

Steve. Stroke first week of August. Heard about the group from his doctor at Northwest Hospital

Let Gerrit know if you want the group roster.

Today we have a big box of freebies!

Baseball caps!

Take one now or get one at the Christmas party

Come up after the meeting to get one

Cross out “survivor” on the hat if you give it to a non-stroke survivor

Our regular freebies include grippy paper. Take a piece if you want and pass it around.

Helen brought a bunch of puzzles, take one if you want!

Jane has a birthday this month!

Happy birthday November babies!

Any big accomplishments?

Bill: 15,900-step day and 90 degrees of wrist extension! Used Fitbit to count.

Let me know if I'm talking too fast!

Please help us keep the space clean to show Provail that we appreciate their hospitality.

Best tips for overcoming difficulty?

Mike does exercises with his cane to keep his right hand active

Christmas Party

“Cutthroat” gift exchange (white elephant)

Gifts are worth \$5, so cheap

You can exchange gifts or steal them up to two times

Mike Purdy shared a video from Stanford with stroke survivors

The treatment looks amazing, but we have to be cautious: it's only 11 people

A lot of questions about safety, length of effects, side effects, are still open

Gerrit did a little research about the study and thinks it looks legitimate

Last month Jenny from Medtronic came and told us about the Baclofen implant to help spasticity (tightness)

This month, Dr. Gage is here to follow up and give us more information.

Neurophysiatrist at Virginia Mason

Physiatry is rehab and physical medicine

Physiatrists focus on function and quality of life

Dr. Gage focuses on neurological disorders, so she sees a lot of stroke patients

She talks a lot with her patients about physical functions, bodily functions like spasticity, bowel and bladder function, pain, sleeping issues

Dr. Gage has started a wheelchair clinic to help patients with mobility

Physiatrists use a “holistic” approach – they treat the “whole person”

The doctor works with paralysis/weakness

Using braces, exercises

What about electro-stimulation?

E-Stim is used a lot for foot drop

What are other treatments for spasticity and clonus?

Baclofen

Tizanodene

Valium

Dantrolene

Oral medications have side effects: sleepiness or drowsiness

Dantrolene doesn't make people as sleepy, but it can harm your liver

Botox can be used for specific muscles

Botox doesn't affect the entire body, just the place where it's injected

Botox lasts about 3-4 months and then patients have to go back to the hospital for another injection

There are a few types of injection, so sometimes one type will work better than another

There is also the baclofen pump. It's implanted and gives patients tiny doses over a long time

The pump is implanted in the stomach area

A catheter goes around to your spine

The doctor can adjust the dose you get depending on your needs

The pump has to be refilled every few years

Andrew highly recommends that everyone have a physiatrist

Andrew's physiatrist said that baclofen pumps are better for legs more than arms

Dr. Gage: anecdotal evidence suggests that changing the program on the pump, or changing its location can improve outcomes for arms and legs

A recent study found that pumps helped with arms and legs

It's possible to inject a little bit of baclofen in the spine so you can see how it works before you get it implanted

How long does baclofen stay in the system?

It wears off after about 4-6 hours and then spasticity will come back

When you do a trial, the doctors will monitor you for several hours to see how you respond

About 97% of trials are positive and help people but sometimes the patient just needs a higher dose

Is it normal to take baclofen three times a day?

Yes, baclofen usually only lasts for 8 hours, so people usually take it 3x to manage their spasticity all day

John is taking a combination of baclofen and trazanadene, would he take both in a trial?

No, the trial is only for baclofen

Your doctor may still recommend a combination of drugs, depending on your needs

Baclofen is only for spasticity (muscle tightness, cramps, high tone, spasms)

Sometimes treating spasticity can help you be more functional

Can you tell me more about the recent treatment study?

We'll come back to that.

Does spasticity include single spasms?

Yes. But everyone experiences it differently. Some people have a lot of spasticity when they're resting, but some people have more spasticity when they're busy.

What else do you recommend besides physical therapy?

Seeing someone who specializes in neurophysical therapy is great and I highly recommend it.

Massage can be really great to release tightness.

Acupuncture can be helpful for some people with muscle tension. There's no evidence that acupuncture can help aphasia.

What should people avoid?

People should be cautious with chiropractic doctors. Neck manipulations can be dangerous.

Cranio-sacral specialists may or may not be helpful, but some patients say they help with pain.

What about supplements?

You should always check with your doctor because some herbal medicines may interact with other prescribed drugs.

I do recommend magnesium because it can help with bowels and things.

But I don't have any other specific recommendations.

Do other stroke survivors ever experience numbness or a weird, itchy feeling on their affected side?

It is very common. When the connections between your nerves and your body are impaired, people experience very strange and/or painful sensations.

Gabapentin and other drugs can help with nerve pain sometimes, but we don't know how to treat numbness really.

There are desensitizing agents that might make the numbness feel different, but it won't make the numbness go away.

After seeing an acupuncturist for a few years, John was able to experience some sensation when it was numb before.

There are experimental treatments to electrically stimulate muscles and bring back sensation

For the recent study, it has not been published yet. Dr. Gage heard about it at a conference.

The controls in the study were normal, healthy

Don't know if there were side effects

We have to wait for the paper to come out to know more

We watched a video before you came. They used stem cells to restore function. Do you know anything about that?

Most of the studies have not been that successful.

We don't know enough about stem cells to make this treatment more effective yet

There are a lot of regulations on what types of trials we can perform on people in the US

Hopefully there will be more information soon

What about swallowing problems? How can we help that?

You have to exercise your swallowing muscles to get them stronger

If exercises and swallowing strategies aren't working, there's adaptive equipment to help

Wade had transient paralysis that passed by the time the medics got to him. Is that normal?

Strokes are very complicated

They happen for different reasons

They have different sizes, locations

The effects that people experience can be very different

Sometimes the effects can change very quickly, too

Some people have transient ischemic attacks (TIAs) or “mini-strokes” where the effects are very temporary

It’s important for doctors to get an image of the brain so they can see what’s going on even if your symptoms change

In the baclofen study, did the patients have brief spasticity?

In the study, the people had spastic hemiparesis that was long-standing

To clarify, the study was not to see if baclofen works

The study was to see if people experienced benefits in the arms AND legs

What's the difference between a physiatrist and a neurosurgeon?

Physiatrists don't do surgery. They focus on rehabilitation.

They focus on function and quality of life.

Physiatrists also coordinate care. They work with all of your doctors to make sure you're being treated holistically.

You can see a physiatrist from the day of your stroke until you decide you don't want to anymore.

Do physiatrists just work with brain injuries?

No, they work with a wide range of injuries and disorders.

Dr. Gage specialized in neurological cases.

Is anesthesia required for the trial or pump implantation?

Not for the trial. That's just an injection.

For the trial, the doctors want to see how you're responding so you have to be awake.

For the implantation, that is a surgery, so you have to be anesthetized.

Can you tell us more about stem cell treatments?

We are still trying to develop those. Those are still in the trial phase.

Where do the stem cells come from?

Sometimes they take them from your bone marrow.

Sometimes they take them from placentas or amniotic sacs from babies.

Sometimes they come from animals.

If you have questions, get a business card from Dr. Gage.

Thank you for having us!! We can pass out information for Dr. Gage and about spasticity.