



THE WARREN ALPERT
Medical School
BROWN UNIVERSITY

Rhode Island STROKE SYMPOSIUM

**The Experience of Stroke for Individuals and Families:
How the Provider Can Help**

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DISCLOSURE

I have no relevant financial relationship to disclose
My talk will not include any off-label discussion

The Experience of Stroke for Individuals and Family: How the Provider can Help

Presentation Outline

The experience of stroke for the individual and the family: over several time points:

The Acute Injury/The ED

The acute rehabilitation: physical, Cognitive/emotional/behavioral

The transition home

Long term

What you can do – which is best summed up in : Education, Assessment, Communication, Collaboration

Clinical Example

Tony Smith, age 55, sustained left-side stroke (location intentionally left unclear). Runs his own small electrical company, that he has been building for 30 years.

Eliza Jones Smith, age 56, married to Mr. Smith for 28 years. She is an environmental consultant, involved in sustainability.

Three children: Noah age 20 (in college), Ally age 14, Joe age 11: both reside in the home, are active outside of the home

Mr. Smith sustains a left sided CVA, and is sent to the ED

Acute Injury and the Emergency Dept

1. The Onset and Injury:
2. The setting of the ED
3. The experience for the family
4. The immediate decisions that need to be made
5. The impact of feelings and experiences on decision making; long term impact

Physical, cognitive/emotional/behavioral sequelae

Acute Rehabilitation

Right sided hemiparesis

Expressive aphasia with dysarthria

Cognition: comprehension, attention, recall.

Motivation: very focused upon regaining physical strength and speech production

Post Discharge

Mobility: walking with a walker

Communication: Some improvement in speech production: both in aphasia and dysarthria, but continues to need adaptive strategies

Cognition: difficulties in attention and recall, sensitive to distraction

Behavior/Emotion: periods of irritability, changes in initiation and motivation, anosognosia

The greatest difficulties for families are the behavioral and cognitive changes after injury.



Changes in Family Roles and Impact

Structural Considerations

1. Vocational impact on patient and spouse
2. Impact on children
3. Functional changes in domestic roles

Emotional Considerations

1. Loss of purpose
2. Balancing relationships v. caregiving
3. “Contradiction of the Face”
4. Fear & hypervigilance
5. Spiritual questioning
6. Depression and anxiety



How can the Provider Help?

Communication, Assessment, Education, Collaboration

Communication, part 1

1. Know the Setting
2. Know yourself
3. Gain an understanding of how the patient and family feel

How can the Provider Help?

Communication, Assessment, Education, Collaboration

Communication, part 2

1. Establish appointment time structure
2. Deliver information in chunks
3. Speak truth
4. Encourage notetaking and review
5. Discuss and review HIPAA

How can the Provider Help?

Assessment

1. Ask how they're feeling
2. Consider measurements to assess depression and anxiety: the PHQ-2 and the GAD-2
3. Try to get the impressions of both patient and family.

Watch for one speaking for the other.

How can the Provider Help?

Education

1. Explain and educate: cognitive/behavioral consequences
2. Teach how to assess signs:
 - What is "reasonable and expected"
 - When to monitor
 - When to "call in the cavalry."
3. Explain that recovery is long and not linear.
4. Encourage activities that have NOTHING to do with medical.
5. Provide Resources

How can the Provider Help?

Collaboration

1. Be clear about what you know; it's acceptable to say "I am unsure of this"
2. Consult with a colleague when unsure
3. Refer to your colleagues
4. Talk to your multidisciplinary team



Finally:

What's In it For You? (otherwise known as “why bother?”)

1. Increased comfort
2. Shared responsibility through collaboration
3. Trust and communication facilitates knowledge
4. The research indicates: Communication and education decreases malpractice claims

Local and Community Resources

Rhode Island Stroke Support:

Stroke Support Group, Rhode Island Hospital

The Comprehensive Stroke Center at Rhode Island Hospital offers a **stroke support group for stroke survivors and concerned caregivers**, open to the public every second Wednesday of the month from 6 - 7:30 p.m.

Register and Learn More

For more information, please contact Nakeesha Brown at [401-444-8237](tel:401-444-8237) or by email at Nbrown1@lifespan.org.

The Stroke Caregiver Support Group

The Rhode Island Hospital Comprehensive Stroke Center and Just A.S.K. will be hosting a virtual support group for **caregivers of stroke survivors** every third Wednesday of the month from 6 - 7 p.m. via ZOOM.

The support group will provide caregivers with a safe, confidential environment to discuss the stresses, challenges, and rewards of providing care **Register and Learn More**

For more information, please contact Nakeesha Brown at [401-444-8237](tel:401-444-8237) or by email at Nbrown1@lifespan.org.

East Bay RSVP Stroke Club

401-435-7876

Meets 1st Tuesday every month at 1:30 p.m.

Hispanic Stroke Club

Offered in English and Spanish

Contact Esther at 401-274-6783

Meets 2nd Wednesday of every month at 1 p.m.

Please visit <https://www.lifespan.org/centers-services/comprehensive-stroke-center-rhode-island-hospital/stroke-and-cerebrovascular#collapse-accordion-224061-1> for other community resources for southern New England

Recommended Reading

Haddad, M; Uswatte, G; Mark,V; Bechtold, K. 2019. Cerebrovascular Accidents. In L.A. Brenner, S.A. Reid-Arndt, T.R. Elliot, R.G. Frank, B. Caplan (Eds.) Handbook of Rehabilitation Psychology 3 ed (371-398).

Levinson, W. (1994). Physician-Patient Communication: A Key to Malpractice Prevention. *JAMA : The Journal of the American Medical Association*, 272(20), 1619–1620.
<https://doi.org/10.1001/jama.1994.03520200075039>

Patel, B; Rane, A. Part III Scenarios and Frameworks: Teamwork and Teaching. (2022). In *Communication Skills for Surgeons*. Springer International Publishing AG.

National Resources

American Stroke Association:

www.stroke.org

Please review their website for resources to assist patients and their families.

Particularly:

<https://www.stroke.org/en/help-and-support>

For Medical Self-Advocacy

Questions to Ask your Doctor Before Any Test or Treatment

https://www.choosingwisely.org/files/5-Questions_ENG.pdf