

November 1, 2021



STROKE SPECIAL INTEREST GROUP

Academy of Neurologic Physical Therapy

In this newsletter...

- **Stroke Corner:** Palliative Care After Stroke
- Students: Submit your questions to be answered by Stroke experts!
- **NEW** Elections information now available: Sign up to run for ANPT or SIG Office!

Stroke Corner Article Review: Palliative Care After Stroke

Thanks to Heather Hayes, DPT, NCS, PhD for Submitting This Review

This summary includes the following sections:

- References
- Definition of palliative care
- Example of a bereaved family post-stroke
- Summary of why palliative care was consulted after stroke
- Concerns with end-of-life awareness after stroke
- A tool to assist communication in addressing goals of care (REMAP)
- An example of shared decision making
- Recommendations
- Resources for patients, caregivers, clinicians

REFERENCES

Cowey E, Schichtel M, Cheyne JD, et al. Palliative care after stroke: A review *Int J Stroke*. 2021;16(6):632-639.

Article link. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8366189/>

The American Stroke Association published a policy statement in 2016 on Palliative Care and Cardiovascular Disease and Stroke. Article link:

<https://www.ahajournals.org/doi/epub/10.1161/CIR.0000000000000438>

Braun LT, Grady KL, Kutner JS, et al. Palliative Care and Cardiovascular Disease and Stroke: A Policy Statement From the American Heart Association/American Stroke Association. *Circulation*. 2016;134(11):e198-225.

WHAT IS PALLIATIVE CARE?

Palliative care (defined by the World Health Organization) is “An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

The ASA policy guidelines defines palliative care as “patient- and family-centered care that optimizes health-related quality of life by anticipating, preventing, and treating suffering,

should be integrated into the care of all patients with advanced cardiovascular disease and stroke early in the disease trajectory. Palliative care focuses on communication, shared decision making about treatment options, advance care planning, and attention to physical, emotional, spiritual, and psychological distress with inclusion of the patient's family and care system."

Palliative care is often interpreted as end-of-life or withdrawal of care. It is not hospice.

The ASA policy states "Palliative care is an essential health benefit that is central to high-quality overall care. Integrating palliative care in the management of patients with advanced CVD and stroke may provide the following benefits: 1) Improved patient and caregiver understanding of disease, treatment, and prognosis; 2) Improved treatment of symptoms and relief of suffering; 3) Shared decision making based on patient values, preferences, and goals; 4) Enhanced patient-clinician communication; 5) Individual advance care planning based on benefits, risks, and burdens of care; 6) Improved patient and caregiver outcomes; 7) Improved preparation for end-of-life and associated care; 8) Bereavement support. An integral part of Palliative care is shared decision making.

AN EXAMPLE:

Supplementary Material:

Table 1

Experienced of a bereaved carer

Experience of a lady whose father had a stroke in the UK-and a summary of the key learning points

"A severe stroke on a loved one has a profound impact on the family. My father, an active, independent man, became severely disabled, requiring 24-hour care. Life was never to be the same again.

Our journey involved a turbulence of emotions as we helplessly watched events unfolding, wishful of an improvement that would never come.

My father's care saw him hospitalised for 5 months, dying two months later in a care home following a further stroke. The emphasis was continually on rehabilitation, which we encouraged. Unbeknown to us this was a physical impossibility. As time passed, dad became emotionless, discouraged and would stare with great sadness – almost saying, "Is this what life has become?" Our expectation of a recovery was fading fast.

Families hope for the best but need to be prepared for the worst. In order to avoid family disagreement on the course treatment, open and honest conversations regarding the extent of any recovery or life expectancy are essential. Being shown the brain scan helped us to accept the severity of the stroke.

Simple acts of kindness and compassion mean a lot. In his final weeks, the personal care provided by staff was very comforting."

Key learning

- Stroke has a profound psychological effect on family as well as patient
- Open and honest discussions about stroke severity and likely outcome are essential to avoid false hope and treatments that have no realistic chance of making a difference

The power of kind and compassionate care should not be underestimated

NEEDS FOR A PALLIATIVE CARE CONSULT POST-STROKE INCLUDED THE FOLLOWING.

During the hospital stay: dysphagia primarily, but also death rattles, dyspnea, pain, anxiety, confusion or delirium, and agitation.

After hospital discharge included; constipation, seizures, pain, N/T, sleep disturbance, nausea/vomiting, B/B incontinence; hopelessness or loss of meaning; thoughts about death.

OF CONCERN ABOUT END-OF-LIFE AND STROKE.

Professionals are less likely to know end-of-life symptoms in stroke patients rather than cancer patients. Cognitive impairment, aphasia, dysarthria were barriers to pain and access to services.

ASSIST IN COMMUNICATING WITH PATIENTS WHEN ADDRESSING GOALS OF CARE.

<https://www.uptodate.com/contents/discussing-goals-of-care#H106822025>

The term is called REMAP.

Reframe why the direction has changed

Expect emotion and empathize

Map the future

Align with the patient values

Plan medical treatments that match patient values.

EXAMPLE AFTER SEVERE STROKE AND SHARED DECISION MAKING

Table 2. Strategies for health care professionals during shared decision making after severe stroke

• Acknowledge “shock” and suddenness of stroke and its profound effect on the patient and family
• Identify patient’s wishes early on; e.g. advanced directive, Power of Attorney, any previous conversations about views of living with severe disability, patient’s “values”
• Ask about, and address any guilt, e.g. “If only I’d found him sooner”
• “Truth telling” be as honest as you can be about likely outcomes
• Showing CT brain scan may help to show extent of stroke and align family and health care professionals’ expectations about recovery and goals of care
• Try to avoid allowing the family to feel responsible for decisions about:
• Cardiopulmonary resuscitation
• Artificial feeding or intravenous fluids
• Let family know that dignity/symptom control are paramount whatever the decision
• Offer further meetings
• Document the discussion to ensure consistency of messaging.

(from Chest Heart & Stroke Scotland’s online Stroke Training and Awareness (STARS) training module: “Sensitive and Effective Conversations at the End of Life after Acute Stroke.” with kind permission of CHSS. <http://chsselearning.org.uk/>).

RECOMMENDATIONS:

Clinicians should consider systematically seeking “palliative care problems”.

Shared decision making needs careful consideration of patient’s values and beliefs.

Clinicians need to be honest, yet compassionate, about outcomes.

Palliative care specialists have extensive experience of similar palliative care problems in other patient groups. Stroke units already include multiple aspects of palliative care from the team; however, closer linking with palliative services may facilitate improved care for stroke survivors’ and families.

ADDITIONAL RESOURCES

Here is a resource for families.https://getpalliativecare.org/wp-content/uploads/2021/01/GPC_WhatYouShouldKnowHandout_2019.pdf

There is a palliative care provider directory:<https://getpalliativecare.org/provider-directory/>

The APTA has a palliative care and hospice Special Interest Group under Oncology

The APTA learning center has a course titled Integrating Physical Therapy into home palliative care services. <https://learningcenter.apta.org/Student/MyCourse.aspx?id=c79013b3-3417-4bb4-b060-48d17f62ab5f&ProgramID=dcca7f06-4cd9-4530-b9d3-4ef7d2717b5d>

The APTA has published a Clinical Practice Guideline on Palliative Care for Adults (members only).

Don't Forget About This Q&A Resource!



STROKE SIG STUDENT INFO

Academy of Neurologic Physical Therapy

Don't forget! We're here to answer your questions

The [Stroke SIG Student Corner](#) initiative brings Stroke experts together to answer student questions (but you don't have to be a student to submit your question). Check out our Student Corner website for videos of Stroke experts answering previous questions and for the question submission form.

[SUBMIT QUESTIONS HERE](#)

Run for Office! ANPT and Special Interest Group Elections



Plan ahead and consider running for a position on the Stroke SIG board!

The following Stroke Special Interest Group are open:

- Chair Elect
- Vice Chair
- Nominating Committee

Nominations are due March 21, 2022 and you are encouraged to self-nominate. The nomination link is now live on the [ANPT Elections Webpage](#).

Elections will be held April 4 - May 4, 2022. Three year terms begin July 1, 2022.

All Stroke SIG board positions involve attendance at monthly meetings and leadership of one of our Stroke SIG initiatives, such as our podcast, Student Corner, Social media, or weekly newsletter.

For more information on Stroke SIG initiatives, visit our page [here](#).

Don't hesitate to reach out to our Nominating Committee for more information at strokesig@gmail.com

Nominating Committee Members:

- Rachel Prusynski
- Ginny Little
- Mackenzie Wilson

ELECTIONS WEBSITE

VISIT THE STROKE SIG ONLINE!



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