

**“Knuckling Up for Aneurysm, AVM, and Stroke Research and Awareness”**

**JOE NIEKRO**  
foundation



**THE JOE NIEKRO FOUNDATION**  
**ROAD TO RECOVERY**

**A patient's guide through the  
recovery process.**

**“Committed to supporting patients and aiding in the research, treatment and awareness of brain aneurysms, AVMs and hemorrhagic strokes.”**



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Welcome to the JNF Family. We are thrilled to welcome you to our group and applaud your courage and strength to be here.

**The Joe Niekro Foundation (JNF) was established to support patients and families and fund research, treatment and awareness of brain aneurysms, AVMs and hemorrhagic strokes.**

**Through strength, passion, and determination, we have built a one-of-a-kind patient advocacy program that educates communities about the risk factors, causes and treatments of these conditions, while providing a safe haven for patients and caregivers to seek support and comfort. And through our persistent fundraising efforts, we have helped fund critical research that is paving the way for neurological advancements in the future.**

**In life there are no guarantees, but what we do have is the power to make the life we have one of significance.**

**Welcome to our Family,**

The Joe Niekro Staff

# THE JOE NIEKRO FOUNDATION

The Joe Niekro Foundation (JNF) was established in 2008 in honor of Joe Niekro, who lost his life from a sudden cerebral brain aneurysm on October 27, 2006. The foundation is committed to supporting patients and families, research, treatment and awareness of Brain Aneurysms, AVM's (Arteriovenous Malformations) and Hemorrhagic Strokes. We provide education on the risk factors, causes and treatments of these conditions, while funding the advancement of neurological research. The following staggering statistics validate the critical need for support, awareness and research funding:

- There are currently 6 million people in the US who have an unruptured brain aneurysm
- As many as 1 in 15 people will develop a brain aneurysm or AVM
- Hemorrhagic Strokes account for 15% of all strokes (approximately 120,000 annually)
- Hemorrhagic Strokes are responsible for more than 30% of all stroke deaths
- Every 18 minutes an aneurysm ruptures
- The average age for an AVM rupture is 17 years old
- Brain aneurysms are most prevalent in people ages 35-60, but 3 out of 10 brain aneurysm patients are children
- Women, more than men, suffer from brain aneurysms at a ratio of 3:2

Although the JNF is a national organization, we strive to give the vitally needed support through locally led support groups. A strong support network is an important part of adjusting to living as a Brain Aneurysm/AVM/Hemorrhagic Stroke survivor. Social support is essential to the recovery process because social isolation can greatly reduce patient recovery and outcomes after suffering any one of these conditions. Many hospitals just are not equipped to offer patients and families ongoing support and rehabilitation post discharge. It is our goal to help bridge the gap and encourage collaboration to provide a comprehensive support program for survivors and their families. JNF Support Groups provide a welcoming and safe haven for patients, families, friends and caregivers to be among others in similar situations where they can share their fears, challenges, successes and failures in an atmosphere where they are loved and accepted by all.

The Joe Niekro Foundation will continue the fight but we need supporters such as you to win. We invite you to become a part of our team, a team fighting each and every day to make a difference in the lives of thousands affected by these fatal conditions. We hope you will ride this journey with us as we continue to take JNF global.



## **SOCIAL SUPPORT IS EXCEPTIONALLY IMPORTANT IN THE RECOVERY PROCESS.**

When you meet others who have endured the same struggle, you're encouraged and realize that you are not alone. In addition to the JNF in-person support groups, we provide several online support communities to help guide you through your recovery journey.

# WE ARE HERE FOR YOU! JOIN OUR FACEBOOK SUPPORT GROUPS

Sponsored by The Joe Niekro Foundation

## **SURVIVOR SUPPORT GROUP**

This group is filled with discussions to engage with other survivors from around the world.

<http://www.facebook.com/groups/aneurysmavm>

## **CAREGIVER SUPPORT GROUP**

Created for caregivers to turn to others with similar issues in attempt to deal with their isolation, powerlessness and alienation. This chat room is a safe haven to be among other caregivers; express fears, challenges, successes and failures in an atmosphere where everyone is loved and accepted by all.

[www.facebook.com/groups/caregiversbrainaneurysm](http://www.facebook.com/groups/caregiversbrainaneurysm)

## **PARENT'S SUPPORT GROUP**

Created to provide a safe haven for parents to feel comfortable, connect with others who "get it" and to understand their thoughts and feelings.

[www.facebook.com/groups/ParentsBAAVM](http://www.facebook.com/groups/ParentsBAAVM)

## **TEEN/YOUNG ADULT SUPPORT GROUP**

Created for Brain Aneurysm, AVM and Hemorrhagic Stroke patients ages 13-24. This group provides a safe place of refuge and comfort for its members to come together, share their stories and lend encouragement to one another.

[www.facebook.com/groups/youngadultaneurysmsurvivors](http://www.facebook.com/groups/youngadultaneurysmsurvivors)

## **HONORING THE TAKEN SUPPORT GROUP**

Created for those who have lost a loved one from an Aneurysm, AVM or Hemorrhagic Stroke. It is a place to connect with other families who have experienced this devastating and life changing loss.

[www.facebook.com/groups/HonoringTheTaken](http://www.facebook.com/groups/HonoringTheTaken)

# WHY BECOME PART OF A JOE NIEKRO FOUNDATION SUPPORT GROUP?



Support is a vital part of recovery and many of America's hospitals do not offer ongoing support and education after a patient is discharged. This means that thousands of individuals are left with unanswered questions, no support, guidance or continued care outside of the basics allowed through their insurance. It is our goal to bridge

this gap and encourage collaboration across the country, resulting in more comprehensive support programs for survivors and their families. Survivors need to turn to others with similar issues in order to deal with their feelings, and our groups allow for this to happen.

The JNF Support Groups provide a variety of benefits, including mutual support, understanding and acceptance, non-judgmental listening, information, validation of feelings, role models and much more. Our groups offer a safe haven for patients, families, friends and caregivers to share their fears, challenges, successes and failures in an atmosphere where they are loved and accepted by all. A few highlights of our support group program include:

- Monthly meetings with a featured guest speaker
- Attendance by physicians and other healthcare professionals, discussing Brain Aneurysm/AVM/Stroke topics
- Open question/answer sessions
- Participant/family-caregiver breakout groups to discuss stories and challenges
- 24-hour one-on-one patient advocacy

Our meetings address issues such as depression, social reintegration, coping with disabilities, nutritional brainpower, exercising your brain and much more. The Joe Niekro Foundation Support Groups play a vital role for survivors and family members by providing emotional and moral support. Members of support groups receive help by learning new coping strategies, relating personal experiences, obtaining information from health professionals and establishing social networks. The JNF Support Groups create a forum of mutual acceptance, understanding and self-discovery to help members realize that recovery is possible.

For more information about our support groups, contact [info@joeniekrofoundation.org](mailto:info@joeniekrofoundation.org).

# DENTED HALO

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We have a dented halo  
Special angels all are we  
Bumped heads on Heavens gates  
Not time to go, you see.

This special dented halo  
Reminds us every day  
To thank our lucky stars  
We were not taken away.

We could have been angels  
In the heavens up above  
But were left with special Halo's  
On Earth to spread our Love.

Our halos are not golden  
For wings we all may lust  
But instead a dented halo  
Was God's choice of gift for us.

So be proud to wear your halo  
Our work here is not through  
We have more love and joy to spread  
And, I'm spreading mine to you.

~Sandi Frunzi~

©2002



# GREETINGS FROM THE GROUP

Why we love JNF

"There are moments that mark your life, moments when you realize nothing will ever be the same. Time is divided into two parts: before this and after this."

– *Tricia Jaquis*

RUPTURED BRAIN ANEURYSM SURVIVOR, 2014, AGE, 41, APEX, NC, USA

"Since I found the Joe Niekro Foundation groups, I no longer feel alone on this journey. We are family!!!!"

– *Darnelia Calmes*

RUPTURED BRAIN ANEURYSM SURVIVOR, 2011, AGE, 40, STARKVILLE, MS, USA

"The Joe Niekro Foundation supplied me with answers and support that even the medical professionals were able to learn from."

– *Cindy Mann*

BRAIN ANEURYSM SURVIVOR, 2014, AGE, 47, DUNCAN, OK, USA

"Recovery is a long road, have patience. I'm a survivor I have the strength for anything!"

– *Jennifer Pociask*

RUPTURED BRAIN ANEURYSM SURVIVOR, 2008, AGE, 45, NEW HAVEN, CT, USA

"I was not able to deal with all of the issues of the aneurysm rupture; this foundation gave me hope!"

– *Crystal Bittner*

BRAIN ANEURYSM SURVIVOR, 2013, AGE, 45, IRON RIVER, MI, USA

"The support from the JNF means the world to me because it makes me realize there are so many others who share the same experiences and can offer answers to my questions."

– *Mary King Bratt*

AVM SURVIVOR, 2009, AGE, 66 NOW, MARION, OH, USA

"Faith, hope, and love will take you giant steps on your recovery journey, and if you run short of any of the three, come find us in the Brain Aneurysm/ AVM Support Group sponsored by the Joe Niekro Foundation."

– *Donna Poole*

BRAIN ANEURYSM SURVIVOR, 2013, AGE 66, PITTSFORD, MI, USA

My favorite saying: "I want to inspire people. I want someone to look at me and say because of you, I didn't give up." (unknown)

– *Brittany La Fontaine*

AVM & RUPTURED BRAIN ANEURYSM SURVIVOR, 2015, AGE, 22, PORT ORCHARD, WA, USA

"When I initially found the JNF Support Group I was completely lost and scared; but with the guidance from so many in the group I was able to learn more about BAs and face my fears. I am blessed to have found JNF and all the members!"

– *Kathy (Tallman) Schleis*

BRAIN ANEURYSM SURVIVOR, 2014, AGE, 45, UNIONTOWN, OH, USA

"Learn to laugh at your own barriers, imperfections, scars, and invite others to laugh with you. I have learned by doing so you are not just educating others of your limitations but also helping understand you are still a human being with a great happy heart!"

– *Maria Kuhn-Bratton*

RUPTURED 18MM BRAIN ANEURYSM SURVIVOR, 2007, AGE 55, SAINT PETERSBURG, FL, USA

"I embrace life and have a deeper appreciation for everyone and everything around me since my ordeal because I am aware of just how quickly your entire situation can change."

– *Dawn York Kindley*

AVM SURVIVOR, 2005, AGE 48, GREENVILLE, OH, USA

"Remember to always take one step at a time."

– *Lindsay Duncan*

RUPTURED BRAIN ANEURYSM SURVIVOR

"Being a caregiver means becoming selfless but don't lose yourself in the process. You cannot expect to be there for your survivor if you can't take care of yourself."

– *Eve Ann D. Jones, Caregiver*

RUPTURED BRAIN ANEURYSM SURVIVOR, 2013, AGE, 29, FRANKFORT, KY, USA

# GREETINGS FROM THE MEDICAL COMMUNITY

Why we love JNF

"A support group can be life saving for a patient and family during their critical recovery period. I have been amazed by the commitment, the diligence and camaraderie of their members. I have been deeply impressed by the benefit my patients and their families have received by interacting with others who have survived the same ordeal. I salute the organizers of The Joe Niekro Foundation for all the good that they do, and am deeply grateful for the benefit my patients have received because of their efforts."

**Dr. Robert F. Spetzler**

DIRECTOR EMERITUS, BARROW NEUROLOGICAL INSTITUTE  
CHAIRMAN EMERITUS, BARROW NEUROSURGICAL ASSOCIATES  
PROFESSOR OF SURGERY, SECTION OF NEUROSURGERY, UNIVERSITY OF ARIZONA COLLEGE OF MEDICINE,  
TUCSON, AZ

"I have long understood that even for those with the best of outcomes, there are often profound and long-lasting stresses that challenge our subarachnoid hemorrhage patients and their families. What I didn't appreciate until I attended one of our local Joe Niekro Foundation Support Group meetings was just how powerful a resource the support group could be. I would encourage anyone involved in the care of patients with aneurysms to attend a support group meeting and see for themselves the truly inspiring work that the Foundation is doing."

**Dr. Cameron G. McDougall**

ENDOVASCULAR NEUROSURGEON, SWEDISH HOSPITAL, SEATTLE, WA

# A LETTER TO OUR SURGEONS

By Donna Poole— JNF Patient Advocate



Hello surgeons! It's us...your success stories, your Brain Aneurysm/AVM/Hemorrhagic Stroke survivors. When we first meet you we arrive with baggage. A few have spent enough time on Google to convince ourselves we're dying. Some are confused, apprehensive or afraid. What's commonplace to you

—repairing the human brain—is terrifying to us. Those of us who have the wizards, the surgeons extraordinaire, count our blessings! When I met my wizard, Dr. B. Gregory Thompson at University of Michigan Hospital, all I could think was, "My, what big hands you have." I wondered if brain surgeons should have such big hands!

I learned to thank God for Dr. Thompson. I tell everyone my wizard, Dr. Thompson, has the most skilled (and perhaps the largest) hands in the business, and for sure the biggest heart! Other surgeons, if you want to know what your patients think of you, join our Facebook support group! Your heads will probably swell so much you may suspect hydrocephalus and seek a brain surgeon for yourself.

Some surgeons may wonder why survivors need a support group. You save our lives, and we love you for it, but we have a long way to go when you release us. We help each other find the way.

Some have wonderful support at home. Others have none. Some survivors are blindsided by unexpected deficits—not that you didn't warn us. You probably did. My husband's cardiologist learned at a recent conference the average patient remembers only 17% of what the doctor tells him.

When we exit your hospitals into unfamiliar territory, some find it only mildly difficult to adjust. Others drown in despair. We need people who understand, and we find them in the JNF Online Support Group. Survivors in our two groups range from newborns to the 70's and include every decade in-between. Currently, we have nearly **8,000** members between these two groups and continue growing everyday!!!!

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I asked survivors, caregivers and parents what the JNF Online Support Groups mean to them. Here are a few of their responses:

"I have made such wonderful friends here. It's comforting to know I don't walk this journey by myself. It doesn't matter if I'm mad, sad, depressed, angry, scared, fearful, happy or shocked by the aneurysm condition—there is always someone who can relate."

"Wonderful friends—valuable information! What an excellent combination!"

"I don't feel alone here as compared to everywhere else."

"It's a comfort zone . . . by far one of the best parts of my journey to wellness!"

"It means hope; it means camaraderie; it means strength."

"Saved my marriage."

"This room has become like family and friends. It has brightened me on dark days, given me hope through pain."

"This room is the place I go to find those parents who 'get it' because they have walked the path. It helps me keep perspective and gives encouragement. I know I am not alone."

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## PLEASE SEND YOUR PATIENTS OUR WAY. THEY NEED US!

Together we discover our combined tears make a rainbow that stretches across the world.



We find hope. We give hope. We grow survivor strong!

For online support:

### Brain Aneurysm/AVM Support Group

sponsored by The Joe Niekro Foundation

<https://www.facebook.com/aneurysmavm>

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### Honoring The Taken Support Group

sponsored by The Joe Niekro Foundation

[www.facebook.com/groups/HonoringTheTaken](http://www.facebook.com/groups/HonoringTheTaken)

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### Caregiver Support Group

sponsored by The Joe Niekro Foundation

[www.facebook.com/groups/caregiversbrainaneurysm](http://www.facebook.com/groups/caregiversbrainaneurysm)

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### Parents of Brain Aneurysm/AVM Children Support Group

sponsored by The Joe Niekro Foundation

[www.facebook.com/groups/ParentsBAAVM](http://www.facebook.com/groups/ParentsBAAVM)

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### Teen and Young Adult Brain Aneurysm/AVM Support Group

sponsored by The Joe Niekro Foundation

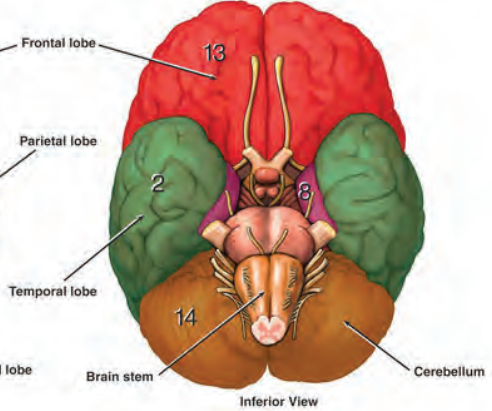
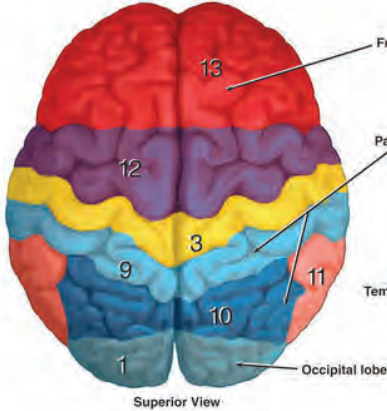
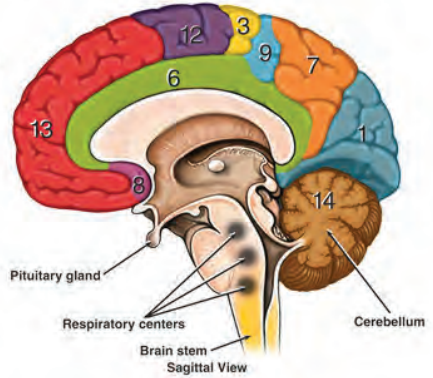
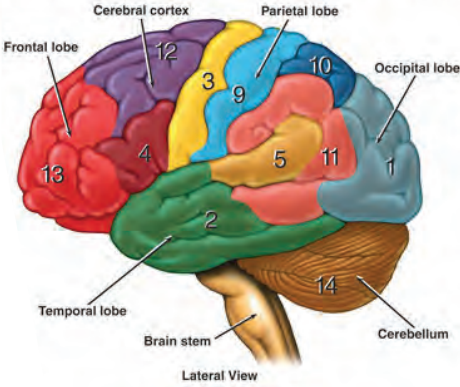
[www.facebook.com/groups/youngadultaneurysmsurvivors/](http://www.facebook.com/groups/youngadultaneurysmsurvivors/)

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Interested in a support group in your facility? Email Us!

[SupportGroups@joeniekrofoundation.org](mailto:SupportGroups@joeniekrofoundation.org)

# ANATOMY AND FUNCTIONAL AREAS OF THE BRAIN



## Functional Areas of the Cerebral Cortex

- 1 Visual Area:**  
Sight  
Image recognition  
Image perception
- 2 Association Area**  
Short-term memory  
Equilibrium  
Emotion
- 3 Motor Function Area**  
Initiation of voluntary muscles
- 4 Broca's Area**  
Muscles of speech
- 5 Auditory Area**  
Hearing
- 6 Emotional Area**  
Pain  
Hunger  
"Fight or flight" response
- 7 Sensory Association Area**
- 8 Olfactory Area**  
Smelling
- 9 Sensory Area**  
Sensation from muscles and skin
- 10 Somatosensory Association Area**  
Evaluation of weight, texture, temperature, etc. for object recognition
- 11 Wernicke's Area**  
Written and spoken language comprehension
- 12 Motor Function Area**  
Eye movement and orientation
- 13 Higher Mental Functions**  
Concentration  
Planning  
Judgment  
Emotional expression  
Creativity  
Inhibition

## Functional Areas of the Cerebellum

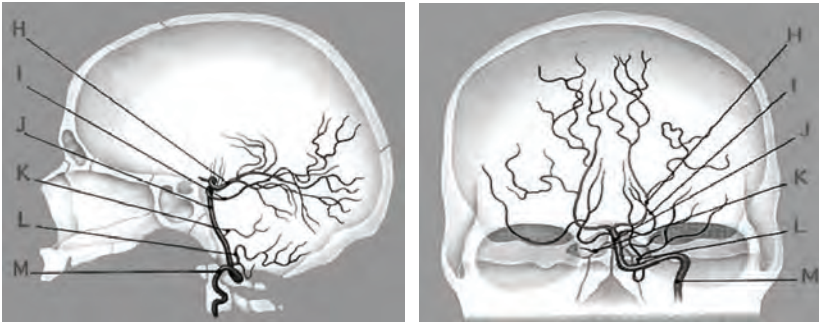
- 14 Motor Functions**  
Coordination of movement  
Balance and equilibrium  
Posture

# INTERNAL CAROTID ARTERY SYSTEM



- A. Pericallosal Artery (PA) Anterior
- B. Cerebral Artery (ACA) Middle
- C. Cerebral Artery (MCA) Anterior
- D. Choroidal Artery (AChA)
- E. Ophthalmic Artery (OA) Internal
- F. Carotid Artery (ICA)
- G. Posterior Cerebral Artery (PCA)

# VERTEBRAL ARTERY SYSTEM



- H. Posterior Cerebral Artery (PCA)
- I. Superior Cerebellar Artery (SCA)
- J. Basilar Artery (BA)
- K. Anterior Inferior Cerebellar Artery (AICA)
- L. Posterior Inferior Cerebellar Artery
- M. (PICA) Vertebral Artery (VA)

# THE JOURNEY OF RECOVERY

## Understanding The Grieving Process



There are a number of very common emotional stages that people with a Brain Aneurysm/AVM/Hemorrhagic Stroke go through. It is important to remember that every survivor reacts differently to the grief over the loss of the person they once were and knew before the brain injury.

There is often a process a survivor will go through and there are a number of very common emotional phases attached to the recovery process. This process is often experienced in defined stages:

- Denial
- Anger and Frustration
- Depression/ Withdrawal
- Bargaining
- Acceptance

Where you are in the recovery process will influence how you react or respond to situations. For example, if you are currently in the state of denial, you are not going to easily accept the doctor not permitting you to drive. The person in denial says there's nothing wrong, even when directly confronted by family members or trained medical staff. Through your denial, you inadvertently hinder progress.

If you are angry or frustrated, it is very difficult for you to deal with the littlest of things and find yourself easily aggravated or blowing up often.

It is difficult to reach the level of **Acceptance**. Acceptance only comes when you are ready and open for it. It cannot be forced and will come in your own time. Being able to accept puts you on a better road to recovery.

# THE JOURNEY OF RECOVERY

## Anger & Frustration



After a Brain Aneurysm/AVM/Hemorrhagic Stroke survivors and family members say one of the most difficult emotions to manage is anger and frustration. Anger will weaken your ability to solve problems effectively, handle changes, make good decisions and get along with others.

There are several reasons why survivors may have difficulty managing anger effectively. Some develop impulsive anger as a direct effect of the damage to the frontal lobe of the brain. In other words, the parts of the brain that normally inhibit feelings of anger and monitor behavior have been damaged and do not function as well. Rage, fear and sexual feelings all come from the middle section of our brain, considered to be the primitive emotional area. The frontal lobes of the brain help plan and control behavior and are involved in saying NO. So the frontal lobes and the primitive parts of the brain act as a balance scale to one another. If the NO part of the system isn't working well, the primitive functions tend to be more prominent. This means the anger threshold is much lower and becomes easily or intensely aroused. It is important to understand that the survivor has lost some degree of control over emotional responses.

Another reason a survivor might have a difficult time handling anger is due to the many issues that arise after the injury. Frustrations start to develop when realization sets in about capabilities/disabilities, financial problems, loss of friendships, the inability to participate in activities and the loss of overall control of their life. After having a Brain Aneurysm/AVM/Hemorrhagic Stroke, many survivors encounter a number of problems they do not know how to resolve, leaving them with feelings of hopelessness. Survivors often say their family members and friends don't understand them or the circumstances they are experiencing. As a result, they tend to demonstrate their anger in the following ways:

- Irritability
- Cursing
- Threatening or aggressive behavior towards others
- Hostility
- Yelling
- Physical harm to themselves or others

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"You will not be punished for your anger, you will be punished by your anger." – Buddha

"Speak when you are angry and you will make the best speech you will ever regret."  
– Ambrose Bierce

"Anger, if not restrained, is frequently more hurtful to us than the injury that provokes it."  
– Lucius Annaeus Seneca



Have you ever noticed that the word **anger** sits inside the word **danger**? Anger can be dangerous if not released in a healthy way. In fact, anger can:

- Cause you to harm yourself or others physically and/or emotionally
- Increase the risk for heart disease, high blood pressure and stroke
- Generate relationship problems and make people afraid of you
- Contribute to feelings of depression, loneliness and/or isolation
- Create stress headaches, stomach issues and/or back pain
- Reduce your ability to make good decisions
- Add to your list of problems

Your best bets are to begin to recognize when and why you are getting angry. Learning to manage anger and frustration can enhance emotional well-being and lead to a healthier, happier life. By recognizing when anger is beginning or what is causing the anger, you can find constructive ways to channel the anger. At JNF, we've developed a SIMPLE technique as a way to express that anger in a healthy manner.

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## **SIMPLE TECHNIQUE FOR EXPRESSING ANGER CONSTRUCTIVELY:**

- S.** Stick to the issue
  - I.** Identify the cause of anger
- M.** Make concessions
- P.** Plan on avoiding situations where there is high risk of aggravation
- L.** Leave the situation, if possible
- E.** Explain to another person how they can be of help to solve the problem

After trying the SIMPLE technique, ask yourself these questions:

- Did I accurately perceive the problem?
- Did I choose the right time and place?
- Did I avoid exaggeration?
- Did I stick to the issue?
- Did I focus on the incident itself, rather than a personal attack?

Recognize that you have the power to control your emotions. Speak calmly and take a time out if needed. Doing these **SIMPLE** things will make the biggest difference in your internal anger and how that is represented on the outside.

It is part of human nature to grieve when we lose something. One part of a grief reaction is anger and finding a target to blame for our losses. Survivors can work through this stage and cope with anger more effectively by talking about their feelings. Anger is a common issue following a Brain Aneurysm/AVM/Hemorrhagic Stroke. Unfortunately, frustrations are a reality of life, but how you decide to handle them can make all the difference.

# THE JOURNEY OF RECOVERY

## Denial



The previous topic of discussion introduced The Journey of Recovery, which all Brain Aneurysm, AVM and Hemorrhagic Stroke survivors will experience. It is important to remember that each survivor grieves differently. Survivors won't necessarily experience all of the emotions (Denial, Anger and Frustration, Depression/Withdrawal, Bargaining and Acceptance); nor will they experience the emotions in exact order listed. However, all survivors whether you had a rupture or not will experience at least one or two of these emotional stages.

"It's not in denial. I'm just selective about the reality I accept."

– Bill Watterson

"It takes a lot of courage to face up to things you can't do because we feed ourselves so much denial."

– Zoe Saldana

"I protect myself by refusing to know myself."

– Floriano Martins

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Denial is often a survival technique used by Brain Aneurysm/AVM/Hemorrhagic Stroke survivors when the reality of their situation cannot be accepted; they have not come to terms with what has been lost. Change in one's life can stir up fear, anxiety or uncertainty and people often respond to such changes with the denial defense. Denial is a protective barrier – a wall a person builds to create an alternate reality. That alternate reality only exists for one person – the person who built the wall.

There are two types of denial a survivor could experience. The first type of denial is an emotional one in which something so horrible or frightening has occurred and a person is not willing to deal with it. Often you will hear, "I'm fine" or "There's nothing wrong with me." It is much easier for a survivor to minimize or deny the severity of having a Brain Aneurysm/AVM/Hemorrhagic Stroke rather than learn compensatory strategies or to work towards a new normal. It is not unusual for survivors to remain in denial their entire lives.

The second type of denial comes from the physical changes to the brain due to an injury (bleeding, bruising or swelling). The brain refuses to, or cannot process denial or may not be cognitively aware of this type of emotion. Often the medical system will unknowingly support denial. Far too often doctors will say, "Just go home and live your life, you'll be fine." For many survivors, they don't get better and start to question why they're not back to their normal selves.

They have these odd events and keep rationalizing them away, such as forgetting their best friend's name or putting the ice cream in the refrigerator instead of the freezer. It is not uncommon for a driver's license to be revoked by medical staff due to a brain injury and the survivor argues, "I'm fine to drive."

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## **DEFENSES SURVIVORS WILL USE FOR DENIAL:**

- Changing the subject
  - Projecting
  - Arguing
  - Smiling & Laughing
  - Blaming
  - Comparing
  - Justifying
  - Withdrawing
  - Rationalizing
  - Joking
  - Intellectualizing
  - Silence
  - Minimizing
  - Bargaining
  - Analyzing
  - Explaining
- 

## **GENERALIZING**

The difficulty with denial is that most are unaware that they are in denial. Getting past denial requires more than admitting the problem; survivors have to accept their new life fully. Accepting changes in oneself after a Brain Aneurysm/AVM/Hemorrhagic Stroke can be incredibly difficult because most people are afraid others will view them as being unintelligent or stupid because of their deficits. Working through denial is not about admitting to a problem; instead it is about deciding to confront the problem.

It isn't easy to tell if denial is holding you back, but if you feel stuck or if someone you trust has suggested that you are in denial, you might try:

- Ask yourself what you fear
- Think about the potential negative consequences of not taking action
- Allow yourself to express your fears and emotions
- Try to identify irrational beliefs about your situation
- Journal about your experience
- Open up to a trusted friend or loved one
- Participate in a support group
- Speak to a mental health provider

By fully accepting your life as a Brain Aneurysm/AVM/Hemorrhagic Stroke survivor and your deficits/disabilities, you can make your life work. Know that life is so much better once you confront a situation rather than to pretend it doesn't exist. Denial can sabotage any progress towards the start of your new life as a Brain Aneurysm/AVM/Hemorrhagic Stroke survivor. Running from your grief only delays the pain and sorrow you need to experience to be able to move on and towards healing. Movement through denial takes lots of time and willingness but, when you succeed, it represents a beautiful achievement and a chance to begin living your life anew.

# THE JOURNEY OF RECOVERY

## Depression



In the general population, it is expected that 6 out of 100 people experience a significant depression over the course of their lives. However, researchers state patients who've experienced a traumatic brain injury are 10 times more likely to suffer bouts of severe depression. Depression following a brain

injury is the most prevalent psychiatric disorder with some reports stating that 52% of patients will experience depression the first year and an increase of 61% of patients within 7 years. Researchers do not know when depression is most likely to occur after a brain injury, but most agree that patients will see the beginning stages of depression within the first year. More than half of the people with a brain injury who are depressed also experience significant and high levels of anxiety.

Depression is more than feeling sad. It is normal for someone who has had a Brain Aneurysm/AVM/Hemorrhagic Stroke to feel saddened by the problems caused by these conditions. For some survivors, feelings of sadness can extend beyond the normal.

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"Depression is the inability to construct a future."

– Rollo May

"There are wounds that never show on the body that are deeper and more hurtful than anything that bleeds."

– Laurell K. Hamilton

"Depression is a prison where you are both the suffering prisoner and the cruel jailer."

– Dorothy Rowe

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## SIGNS OF DEPRESSION

- Feeling down, depressed or sad most of the day
- Changes in your sleeping habits, such as sleeping poorly or sleeping more than usual
- Loss of interest in usual activities such as favorite hobbies, time with family members activities with friends
- Increased use of alcohol, drugs, or tobacco
- Decrease or increase of appetite, whether or not you are hungry
- Strong feelings of sadness, despair or hopelessness
- Thoughts of suicide
- Lack of concentration or motivation

Having depression after a Brain Aneurysm/AVM/Hemorrhagic Stroke is a painful and emotional experience, and it compounds many of the challenges patients already face. Depression is an important problem due to its effects on health, productivity and quality of life. Depression can interfere with an individual's ability to achieve rehabilitation goals and reach long-term independence.

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## **EFFECTS DEPRESSION CAN CAUSE IN BRAIN ANEURYSM/AVM/HEMORRHAGIC STROKE PATIENTS:**

- Results in poorer rehabilitation outcomes
- Reduced activities of daily living
- Increased experience of failure
- Increased stress
- Reduced employment
- Increased chance of divorce
- Reduced social interactions
- Increased sexual problems
- Reduced life satisfaction
- Results in poorer health-related quality of life

Many different factors contribute to depression after having a Brain Aneurysm/AVM/Hemorrhagic Stroke, and these vary a great deal from person to person. In fact, even the level of depression will vary depending on the significance of the injury. Some survivors can have problems adjusting to their new changed lives as they become more aware of the issues or deficits they are living with. As their insight into their condition grows, they are more likely to become irritable, anxious or easily frustrated. Emotional and behavioral changes make it difficult for survivors to get along with others and put strains on personal relationships.

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## **FACTORS FOR DEPRESSION**

Physical changes occur in the brain after an injury - Depression may result from injury to the areas of the brain that control emotions. Changes in the levels of certain natural chemicals in the brain, called neurotransmitters, can cause depression.

Emotional response to injury - Depression can arise as a survivor adjusts to living with a disability or starts to grieve for the life they once lived before the Brain Aneurysm/AVM/Hemorrhagic Stroke. Patients will have emotional reactions to their physical issues, loss of friends, reduced activities or poorer health. A patient may be grappling with questions such as, "why is this happening to me?" or "how can I cope with a downward spiral in my ability to function?" and "what will happen to my family if I can no longer take care of them anymore?"

Factors unrelated to injury - Some people have a higher risk for depression due to inherited genes, personal or family history and other influences that were present before the brain injury. It is important to realize that there are different kinds of depression and that no symptom of depression should be taken lightly. Of particular concern is a type called major depression and is characterized with symptoms more intense or severe. Individuals with major depression may think about suicide, have a plan for suicide or successfully complete a suicide.

Individuals who have seizures as a medical consequence of a traumatic brain injury are at risk for developing depression. A seizure occurs when there is a temporary electrical imbalance in the brain. A person having a seizure can experience uncontrollable body movements, heightened or decreased sensations and varying levels of awareness. Survivors with seizures will report that they feel fearful about the uncertainty of having a seizure.

Depression after having a Brain Aneurysm/AVM/Hemorrhagic Stroke is not just a difficult and painful emotional experience, but it compounds many of the challenges survivors already face. Not all brain-injured patients are alike. Depression symptoms and symptoms of a brain injury (deficits) can appear separately and at different times. The symptoms of depression and a brain injury can appear to mirror one another. They can overlap and be complex, making it difficult for some doctors to distinguish between the two. Not all patients may link their symptoms to a brain injury or recognize what they are experiencing. Questions such as, "is it common for brain injured survivors to feel fatigued easily and have a much more difficult time concentrating?" are frequently asked and could be due to the brain injury or depression. Depression compounds these issues and problems. Patients with both a brain injury and depression have greater difficulties with cognitive skills. This can lead to problems in the rehabilitation process because the ability to think and concentrate is essential to learn new skills, make decisions and solve problems.

Having a Brain Aneurysm/AVM/Hemorrhagic Stroke is devastating to a person's life. A brain injury is an invisible injury, and depression is one of the many invisible disorders that can threaten recovery. It is important that survivors and caregivers remain vigilant about the possibility of depression, as well as be committed to taking steps to treat it. If you have symptoms of depression, it is imperative to seek professional help as soon as possible, preferably with a health care provider who is familiar with brain injuries. Family members, friends and caregivers of Brain Aneurysm/AVM/Hemorrhagic Stroke survivors should monitor their loved ones for signs of depression. Depression symptoms should be discussed with a physician or healthcare provider and you should ask for a referral to a neuro-psychologist who specializes in treating depression in brain injury patients. Other properly trained professionals include psychiatrists, psychologists or social workers. Depression is a medical problem and it is best to get treatment early to prevent needless suffering and worsening symptoms. By accepting depression as just another obstacle to overcome in the road to rehabilitation, much of the fear and stigma surrounding this condition will be removed.

# THE JOURNEY OF RECOVERY

## Bargaining

### WHAT IS BARGAINING?

In an attempt to suppress the pain unleashed during the anger and frustration stage, Brain Aneurysm/AVM/Hemorrhagic Stroke patients will try to exert some control by bargaining their way out of a situation. Patients will make desperate attempts to bring their former life back by offering deals or making agreements to a higher power or themselves. People confess that they do not participate in particular activities anymore in order to pretend that their life is unchanged. Bargaining is the phase of the grieving process in which people try to go back in time and change what has occurred. In some cases, bargaining also becomes a tool of preventing change of circumstances when the alternative is too painful to tolerate. Bargaining becomes a method to make a truce with a higher power.

Brain Aneurysm/AVM/Hemorrhagic Stroke survivors become lost in a labyrinth of "If only..." or "What if..." statements. We want life restored to what it was, the only life that we've ever known. If only we could go back in time: get to the doctor sooner, recognize the condition quicker, go to a better hospital, and the list goes on.

Remorse and guilt are the companions to bargaining. Survivors tend to find fault in themselves and believe they could have done things differently. It is not uncommon to bargain with the pain that is felt; we will do anything not to feel the pain of our loss. In the bargaining stage, survivors may find themselves intensely focused on what they or others could have done differently. They may also think about all the things that could have been and how wonderful life would have been if not for this unpleasant situation.

Bargaining essentially brings optimism, or the illusion of hope, to a despairing situation. By offering something in exchange for the happy resolution of a sad situation, the sufferer perceives an option of a positive outcome. This can be a comforting notion before acceptance has settled in. Unfortunately, trying to negotiate a way out of the hurt, survivors remain in the past and put off the healing process.

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### HOW TO STOP BARGAINING

The first step in overcoming the bargaining stage of grief is to learn about bargains. Bargaining can literally go on for years after a difficult reality has occurred. It's an alternative method of thinking that keeps us from really having to accept something we just don't want to accept. Begin by taking a look at the numerous times you attempted to make your bargain work. You've offered up the right things in exchange for your old life back and you've used all the correct words to plead, but nothing has changed. Once you've looked at the fact that your difficult reality is not going to change, you can make a decision to stop trying to get it to change. Essentially, if you

desire to move on with your life and get to the acceptance stage, you have to stop bargaining. The truth is that the difficult reality is not going to change. Make the decision to stop trying to get it to change.

*MYTH: The pain will go away faster if you ignore it.*

*Fact: Trying to ignore the pain you are feeling or keep it from surfacing will only make it worse in the long run. For healing to begin, it is necessary to face your grief and actively deal with it.*

*MYTH: It's important to appear to be strong when in fact I don't feel this way.*

*Fact: Feeling sad, lonely, or frightened is a normal reaction to all the losses you are experiencing now. The single most important factor in healing from bargaining is having the support of other people. Even if you aren't comfortable talking about your feelings under normal circumstances, it's important to express them when you're grieving. Sharing the loss of your former life makes the burden of grief easier to carry.*

Turning to friends and family members is a great way to stop bargaining. This is the time to lean on the people who care about you the most, even if you take pride in being self-sufficient and strong. Accept the assistance that is being offered. Often, people desire to help but don't know how to. Make sure to tell them what you need.

Join a support group. The stages of mourning our prior lives can be very lonely even when you have loved ones around you. Sharing your sorrow, anger, anxiety, fear and sadness with others who have experienced living with a Brain Aneurysm/AVM/Hemorrhagic Stroke can help you understand the methods to living a life that is happy and fulfilling. Wherever the support comes from, accept it and do not grieve alone. Connecting with others will help you heal.

If your bargaining stage continues, talk to a therapist or a counselor who is experienced in brain injuries. An experienced therapist can help you work through intense emotions and overcome the obstacles to your grieving process. Contact a clinical board certified neuropsychologist if you feel any of the following:

- Life isn't worth living
- Wishing you had died
- Blaming yourself for your current condition
- Feeling numb and disconnected from others for more than a few weeks
- Are having difficulty trusting others
- Are unable to perform your normal daily activities



Suffering a significant change in your life can be painful and may conjure unpleasant emotions. The pain of grieving of our prior lives can be seen both emotionally and physically, and unfortunately there is no way to avoid it. Denying or resisting the pain of grieving can lead to physical symptoms and can also prolong the grieving process. You will find new ways to learn to accept and deal with the reality of your current situation. Acceptance does not necessarily mean instant happiness. Given the pain and turmoil you have experienced, you can never return to the prior you that existed before this tragedy. But, you can become a stronger you! You will start to look forward and actually plan things for the future. Eventually, you will be able to think about your prior life (pre-Brain Aneurysm/AVM/Hemorrhagic Stroke) without pain and sadness. You will once again start to anticipate the good times to come and find joy and pleasure in living. Moving onto the final stage of acceptance is a better reality, rather than trying to strike deals to go back in time. When you finally arrive at acceptance you come to realize you are in a place of understanding, that you are going to be fine with the new reality and life you are living. You may even find that you have changed at your core level by getting past your grief. You can become someone who learns to live their life again, rather than merely surviving.

# SURVIVOR ACCEPTANCE

## Lessons Learned



With each Brain Aneurysm/AVM/Hemorrhagic Stroke survivor that comes into our life, we have the chance to redefine what a survivor means as we watch them find their inner strength and forge through significant challenges. They exhibit qualities such as determination and grace that are unparalleled in any other group of people we meet.

Understanding is the first step to acceptance, and only with acceptance can there be recovery." – J.K. Rowling

"The most terrifying thing is to accept oneself completely." – C.G. Jung

Brain injury survivors are people who bravely choose to tolerate pain and hardship for the simple sake of life.

We have put together 10 most important lessons survivors learn after becoming a brain aneurysm survivor.

1. Understand that life doesn't need to stop the day you are diagnosed, but that is the day you start fighting.
2. The most valuable people in life will be the friends who loved you when you weren't so loveable.
3. No one ever got in trouble by doing things right.
4. Be around the people you want to be like, because you will be like the people you are around.
5. It's not being a survivor that will hold you back, but it's who you think you are not.
6. The time will pass anyway. You can either spend it creating the life you want or spend it living the life you don't want. The choice is yours.
7. Never compare your life to others. You have no idea what their journey is all about. Sometimes
8. the worst things that happen in our lives put us directly on the path to the greatest things that will ever happen to us.
9. Pick your battles, because you don't have to show up to every battle you're invited to.
10. One can either be a victim or survivor; there isn't room for both titles in your life.

Coping with your injury is ultimately a deeply personal and singular experience — nobody can help you go through it more easily or understand all the emotions that you're going through. But others can be there for you and help comfort you through this process. The best thing you can do is to allow yourself to feel the grief as it comes over you, embrace every emotion and learn from it. Resisting will only prolong the natural process of healing. There will be times when you think that this stage will never come. But we assure you that it will!

Please be patient and let your process guide you, and you will find your way.

# MARRIED TO A BRAIN ANEURYSM/ AVM/ HEMORRHAGIC STROKE SURVIVOR



Rarely do couples imagine a Brain Aneurysm, AVM or Hemorrhagic Stroke in their future when they commit to "for better or worse, in sickness and in health, til death do us part". Yet, it is estimated that 1 in 15 people will develop a Brain Aneurysm or AVM and nearly 120,000 Hemorrhagic Strokes occur every year in the US.

Nothing can be more physically and emotionally demanding than the trials a spouse faces once their partner is diagnosed with an Aneurysm, AVM or Hemorrhagic Stroke. Spouses, more than any other member of the family, are often confronted with the most difficult issues. When a partner becomes brain injured, roles and duties within the family structure are often permanently changed. Non-injured spouses are often perplexed and challenged to figure out methods and resolve ways to maintain income, family issues, their own needs, household management, and conflicts over medical care and treatments. Typically spouses who have become caregivers feel like their marriage has altered drastically since their partner incurred a Brain Aneurysm/AVM/Hemorrhagic Stroke. Traumatic or severe brain injuries can cause a great deal of stress and disruption to a marriage. When a partner becomes a caregiver, they often feel like they are now in an unequal marriage with resentment arising from both sides.

The cognitive and behavioral changes associated with a Brain Aneurysm/AVM/Hemorrhagic Stroke alter the survivor, as a person and a partner. It's not unusual for the survivor to have new personality traits, anxieties, limitations, mood variations, frustration tolerances, and lack of self-control; which only further complicates the situation. Spouses become surprised by how these changes in the survivor will alter the status of the marriage. Often the non-injured spouse is left trying to figure out how to incorporate their partner into the already well-established family structure. Sometimes consequences of the brain injury require the survivor need supervision, and too often the spouse is forced to take on a parental role causing discomfort and tension for both partners. Some spouses accept the role of caregiver and are willing to surrender the previous role of equal partner within the marriage. But, the task of coping with the role of caregiver is lonely and challenging.

When a Brain Aneurysm/AVM/Hemorrhagic Stroke survivor returns from the hospital, the spouse often doesn't fully understand how much time and energy is required to play the role of caregiver, nor are they equipped with enough information about the long-term effects of brain damage. This amount of dependency will often go unnoticed by extended family members. They rarely see the sacrifices made by the spouse to help their loved one make a better recovery or enjoy a better quality of life. It is not uncommon for very little support and assistance to be offered by outside family members, resulting in a strained relationship between the caregiving spouse and family.

Survivor spouses will avoid get-togethers and couples they once socialized with before the injury. Reluctance to place the injured spouse in social gatherings could be due to the survivor's irregular or embarrassing behavior. They may also be due to the caregiving spouse's attempts to protect their spouse for embarrassment or frustrating situations. Over time, those once considered to be close friends might begin to migrate away. Isolation and loneliness become an issue for both spouses.

In any marriage, when a person takes on new responsibilities, there will be higher levels of stress. Partners of Brain Aneurysm/AVM/Hemorrhagic Stroke patients have significantly more responsibilities and find they have less and less time for their personal interests. Neglect of self is a primary issue with caregivers and will lead to unhealthy physical and mental conditions. Eventually, emotional exhaustion can occur which is known to develop into compassion fatigue. To stay healthy and happy, every spouse needs to seek a respite from caregiving responsibilities. Understand that reaching out and asking for help is not a sign of weakness, nor does it mean that you don't care or love your spouse.

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## **WHERE SHOULD A CAREGIVER SEEK HELP?**

Helpful services such as in-home health aides or personal care assistants can provide the spouse with respite from the caregiver role. Spouses who receive this support will find that they have more time to enjoy personal interests and will see stress levels and tension decrease, lowering their chance for burnout and increasing their level of patience.

Never underestimate the power of a support group. Social workers will often suggest joining a Brain Aneurysm/AVM/Hemorrhagic Stroke support group. This is a fantastic way for both spouse and survivor to have a social outlet to share their stories, experiences and thoughts with others going through similar situations. Not only do they provide peer-to-peer support, but they are full of resources for finding additional information about brain injuries. These meetings are a great way to voice concerns or seek new methods of coping.

Support and assistance can be found by building relationships with the survivor's family. Members of the family can contribute breaks from caregiving for the spouse. This also can be a way for the family to build the relationship with the survivor and remain active in their life.

Programs provided by the National Disability Rights Network can help with health care, transportation, personal decision-making and Social Security disability benefits. Referral services within this organization can help people with brain injuries find solutions to problems involving education, discrimination, and employment. To find out more, visit [www.napas.org](http://www.napas.org) or call (202) 408-9514.

Brain Injury Association of America (BIAA) or the Brain Injury Alliance (BIA) are national programs with state affiliates. These organizations can help in providing information, education and support to individuals, families and professionals affected by a Brain Aneurysm/AVM/Hemorrhagic Stroke. To locate your local chapter for assistance, visit [www.biausa.org](http://www.biausa.org).

# QUESTIONS TO ASK YOUR DOCTOR

## Preparing for Surgery/Treatment



1. What possible problems should I look for after brain surgery?
2. What happens after I am discharged from the hospital after brain surgery?
3. What type of operation do I need?
4. What do you expect the surgery to achieve?
5. Will the operation cure my brain aneurysm/AMV/Hemorrhagic Stroke?
6. Will I need any other procedure after surgery?
7. How likely is it that the aneurysm/AVM/Hemorrhagic Stroke will come back at some time in the future?
8. What are the risks and benefits of this operation/procedure?
9. What are the likely long-term effects of this operation?
10. How can I best prepare myself for this operation?
11. When I wake up, will I be in intensive care?
12. How long do you expect me to be unconscious after surgery?
13. What are the possible complications of this type of operation/procedure?
14. What will happen if I don't have surgery?
15. Is there any other type of treatment I could have?
16. How long will it take me to get over this operation?
17. How can I help myself recover?
18. Who will speak to my family after the surgery?
19. What kind of timeframe am I looking after for total recovery?
20. Is complete recovery possible?

Please note: This list is not meant to be all-inclusive, rather a guideline to get you to think about the things that you might want to discuss with your doctor. All cases are unique, so some of these questions may not apply to your case, and you may want to add some additional questions as well. You may want to talk with your doctor about what you need to do to designate a health care proxy - someone to make decisions for you when you are unable. Also, be sure your file has emergency names and contact phone numbers.

# QUESTIONS TO ASK YOUR DOCTOR

## After Surgery/Treatment



1. What possible side effects should I look for after treatment?
2. What are the signs of infection?
3. What do I do about constipation?
4. What is the time frame for my recovery?
5. Is it possible to completely recover from treatment of a brain aneurysm/AVM/stroke?
6. What activities am I allowed to do?
7. What medications am I allowed to take?
8. Am I permitted to drive?
9. Can I drink alcohol?
10. Can I have sex and when?
11. Can I dye my hair?
12. Am I permitted to travel by airplane?
13. What other types of doctors should I see? Should I schedule an appointment with a Neurologist, Neurophysiologist, and/or a Neuropsychiatrist?
14. How can I help myself recover?
15. Who do I call if I have questions about how I am feeling?
16. Will there be any follow-up after treatment?
17. I am nervous about the hardware that will be used to treat my brain aneurysm. If I bump my head, will the coils/clips come undone?
18. What is a DVT (deep vein thrombosis)? What are the symptoms?
19. Am I allowed to leave the country?
20. Can I fly in an airplane?
21. Are there support groups available?

Please note: This list is not meant to be all-inclusive, rather a guideline to get you to think about the things that you might want to discuss with your doctor. All cases are unique, so some of these questions may not apply to your case, and you may want to add some additional questions as well. You may want to talk with your doctor about what you need to do to designate a health care proxy - someone to make decisions for you when you are unable. Also, be sure your file has emergency names and contact phone numbers.

# SURVIVOR NETWORK UNITED FOR CHANGE PATIENT ADVOCACY PUBLIC AWARENESS OUTREACH & EDUCATION RESEARCH FUNDING TEAMWORK

The Joe Niekro Foundation is committed to supporting patients and aiding in the research, treatment and awareness of brain aneurysms, AVMs and hemorrhagic strokes. Our goal is to raise awareness about the risk factors, causes and treatments of these conditions, while helping support the advancement of neurological research. We provide public education and advocacy, support for patients and families, and develop awareness programs and educational materials for hospitals, clinics and other institutions nationwide.