BRAIN ANEURYSMS

RECOVERY GUIDE

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Working Towards a World Without Ruptures.

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OUR MISSION

Provide information about and raise awareness of the symptoms and risk factors of brain aneurysms to prevent ruptures and subsequent death and disability.

Work with medical communities to provide support networks for patients and families.

Advance research to improve patients' outcomes and save lives.

Undergoing treatment for a brain aneurysm is a major life event that continues long after discharge from the hospital. Survivors face the potential for physical, emotional, and cognitive changes that can be minor or significant, short-term or long-lasting.

Recovery for patients who suffered a ruptured aneurysm tends to be longer and more difficult than it is for patients whose aneurysm did not rupture. Older people and those with chronic medical problems may also recover more slowly than younger, healthier individuals. Some patients may require rehabilitation. Others are able to care for themselves after a short period of recovery. As these examples demonstrate, each individual and situation is unique and recovery times will vary.

One of the most frequently asked questions by brain aneurysm survivors is, “How long until I get better?” Unfortunately, there is no way to predict how long it will take to improve, or even how much improvement will occur.

There will be a better chance for recovery if the survivor and the family maintain hope, even when facing a long recovery process. Rehabilitation pioneer George Prigatano, PhD, points out, “If the brain is alive, it can learn.” Remind yourself often of this: the brain can learn new skills for a lifetime.

Patients recovering from aneurysm treatment experience many changes and challenges. We prepared this booklet to provide you and your caregivers with information about many of the most common changes, with suggestions for how to deal with them. You will also find additional information on many of the topics in this booklet on our website: bafound.org.

AFTER YOUR TREATMENT

You can expect some changes in the first few days and weeks following your treatment. Which of these you experience and how long they last depends on a number of factors, including whether your aneurysm had ruptured prior to treatment and the type of treatment (open or endovascular) you had.

OPEN SURGERY

Issues after open surgery (clipping) may include:

Incision Pain/Numbness

The pain usually occurs at the incision site. It may take several weeks for the incision to heal. After this time, you may experience brief episodes of sharp pain in the incision area as the nerves grow back. This is not cause for concern. The pain will go away with time. The incision area can also feel numb; this may or may not get better with time. It may be uncomfortable to sleep on the side with the incision, but it is safe to do so.

Hearing Loss

You may notice muffled hearing in the ear on the same side as the incision. This is due to fluid accumulation and will get better with time. However, it may take several weeks to notice improvement.

Jaw Pain

Jaw pain may occur when you open your mouth to eat or brush your teeth. This is due to manipulation of the muscles during surgery. The pain will improve over time. You may be able to speed up your recovery by opening and closing your mouth (about 10 times) at least four to five times a day, gradually increasing how wide you open it. Let your surgeon know if the pain persists after six weeks; in this case, physical therapy may be advised.

Clicking Noise in Head

This commonly occurs when you position your head in different ways. While alarming, there is no need to be concerned. This is the bone healing and a normal part of the recovery process. The clicking goes away after several weeks.

Seizures

Seizures may occur at the time of aneurysm rupture or sometimes as a result of surgery on certain parts of the brain. Your neurosurgeon may put you on an anti-seizure medication in the hospital. In certain cases your doctor will have you continue this medicine after you go home. If there are no further seizures, the medicine is usually continued for only a short time. If you are on anti-seizure medicine, it is important that you take the medicine as prescribed.

ENDOVASCULAR TREATMENT

Issues after endovascular treatment (also called embolization) may include:

Groin Pain

There may be bruising and discomfort where the catheter was inserted in the groin. You should avoid strenuous activity and hot baths for one week after treatment. A hematoma (hard large blood clot) can develop at the site. Should this happen, or if there is increased pain or swelling in the area, contact the doctor who performed the procedure.

Hair Loss

Radiation or the contrast dye used during the procedure can occasionally result in hair loss. This usually only affects a small area and is temporary — the hair will grow back. Keep in mind that stress and medicines can also cause temporary hair loss.

POTENTIAL DEFICITS

Survivors of brain aneurysms may experience short- and/or long-term physical and/or neurological deficits as a result of a rupture or treatment.

For survivors of a ruptured aneurysm, the deficits are often greater, more noticeable, and require a longer recovery period.

Many of these deficits improve with time, but physical, occupational, and speech therapy can be very helpful and should be considered even when deficits are minor. Therapy can provide specific strategies and discussions with a therapist can help with general coping.

Persistent difficulties with focus, memory, or cognition (such as: language processing, organizational skills, concentration, decision making, and higher-level thinking skills) can be a challenge. Survivors should seek out assessment from a neuropsychologist or a speech-language pathologist to determine their level of cognitive functioning, life skills, and related issues during activities of everyday life.

Sometimes, family members who see you daily will be the first to notice any subtle changes or slight deficits that may not be obvious to you or others. Often, some deficits become apparent only after you return to a more demanding lifestyle. You should talk to your therapist or doctor about how to deal with these challenges.

Some — but not all — survivors may experience the following:

- Physical and mental fatigue
- Chronic headache or head pain (mainly ruptured aneurysms)
- Concentration headaches
- Vision deficits: partial or complete blindness, or peripheral vision deficits
- Cognitive problems (such as short-term memory difficulties, decreased concentration, perception problems)
- Articulation and speech-delivery problems
- Behavioral changes
- Loss of balance and coordination
- Arm or leg weakness

PHYSICAL CHANGES

Fatigue

Fatigue is the most common problem in the recovery process. You may feel tired all the time and have no energy or "get up and go." Normal everyday activities, even simple ones such as taking a shower, may wear you out. You may take more naps, only to find that you have trouble sleeping at night.

This is normal. Keep in mind your body has been through a lot and needs rest before it can function well again. As time goes on, gradually increase your activities and the amount of time you spend doing them. It can take months before your activity level returns to where it was before your treatment. Try not to get discouraged, and take it one day at a time.

If you frequently have trouble sleeping, talk with your healthcare provider. Sometimes the short-term use of a sleeping medication may be helpful.

Also, have your family limit your visitors. Visitors mean well but can wear you out. If they want to help, suggest they prepare a meal or do shopping for you.

Headaches

Many patients experience headaches. Headaches are usually more of a problem for those whose aneurysm ruptured. The headaches can vary in intensity from day to day, and last for several weeks or longer. Please note that some aneurysm patients have a long history of headaches. These headaches will not be cured by treatment of the aneurysm, as they are not related. The headaches may seem to go away for a while but unfortunately usually return.

Headaches can be frightening, particularly if you had an aneurysm rupture. Keep in mind that the likelihood that a treated aneurysm will rupture is almost zero. Headaches due to aneurysm rupture are not only severe, but sudden. Call 911 in the rare case that a severe and sudden headache occurs.

In general, prescription pain medications may be needed for the first couple of weeks after your treatment. You should switch to over-the-counter pain medications, such as Tylenol, as soon as possible. If headaches are not eased by pain medications — or if the headaches continue even after several weeks — notify your doctor.

Vision Problems

Some people have specific problems with vision due to the location of the aneurysm. Others have problems with focusing or blurry vision as a result of subarachnoid hemorrhage. Problems with focus and blurred vision are common and tend to improve over time. If vision problems do not improve, contact your doctor. Consultation with a neuro-ophthalmologist might be helpful.

Diminished Sense of Smell and/or Taste

Survivors often report changes in their ability to taste and/or smell. If the aneurysm ruptured, smell and taste deficits can be caused by blood that irritates the nerves that control these senses. If the aneurysm did not rupture, smell and taste deficits can occur if the aneurysm compresses the surrounding nerves. Unfortunately, these deficits may not get better with time.

Low Back Pain

Some people experience low back pain and/or shooting pain down the back of the leg. If the aneurysm ruptured, your back pain may be caused by blood in your spinal fluid that is irritating the nerves. This will get better with time. Low back pain can also be due to lying in bed for many days and lack of activity. This type of back pain usually gets better as you increase your activity level, but may require physical therapy. Gentle stretching or a heating pad may help relieve the pain. Notify your healthcare provider if low back pain persists.

Constipation

Constipation is common and may be due to inactivity and/or a diet low in fiber or fluids. The major cause of constipation after aneurysm treatment is the use of narcotic medications. Constipation usually improves with increased activity and decreased use of pain medications. Stool softeners like Colace can be helpful, as are mild laxatives such as Metamucil. Avoid straining when having a bowel movement.

Slowed Reaction Times

In most people, reaction time is slower during recovery for at least some period of time. It is not safe to drive under these circumstances. Follow your doctor's advice as to when you can resume driving. If you have memory/cognition, visual, or certain other physical problems, you should not attempt to drive. The Department of Motor Vehicles provides testing to determine whether/when you can return to driving.

ATTENTION AND EXECUTIVE FUNCTION

Attention/Focus

Most survivors have problems focusing. Their attention span is short. They start something but do not finish it and find their attention drifting from one thing to another. They get easily flustered when they try to shop, for example.

Some of this may be due to fatigue, another reason why rest is so important. However, the main reason is that the brain is still trying to heal itself and is not yet functioning normally. In this situation, the brain cannot do too much at one time.

Executive Function

Living the most fulfilling life possible requires juggling multiple goals, making complex decisions, and solving problems that life invariably creates. Most survivors find it challenging to return to optimal functioning, which requires carrying out this juggling act flawlessly while achieving goals and removing obstacles.

Many find themselves struggling to know what to do first, how to organize their day or goals, or find ways to get themselves unstuck. Some experience a sense of being overwhelmed, in addition to poor motivation and general lethargy, making it difficult to get through the day. Finally, some may notice a general impulsivity when doing work that requires careful evaluation and comparison of options.

Here are some tips to help you focus and improve your executive function:

- Break up projects into short mini-projects.
- Make a daily schedule of activities and stick to it as much as possible.
- Have a family member assist with projects and help you remember to focus.
- Seek out a quiet room if necessary.
- Avoid noise and lots of people as this can be overwhelming. Instead participate in quiet, enjoyable one-on-one activities such as going for a walk with a friend or out to dinner at a quiet restaurant with a family member. Avoid busy places like malls.
- Do not try to do too much at one time. For instance, do not try to simultaneously watch TV, do a crossword puzzle, and talk on the phone.

MEMORY

Memory involves many parts of the brain, and if a brain aneurysm rupture or treatment damages any of those areas, your memory will be affected.

Survivors of ruptured aneurysms usually do not remember the event or much of what happened in the hospital, and never will. This can be disconcerting but is normal.

Many survivors regain their ability to remember as they continue to heal, while some continue to have difficulty with short-term or working memory for years. Survivors might remember events from ten years ago but cannot seem to remember who called yesterday or where they put their keys.

Absorbing, storing, and recalling information are some of the challenges survivors face after a rupture or treatment of a brain aneurysm. Learning new material in general may be difficult. Some have difficulty with something called prospective memory, which is the ability to remember future events. Here are several strategies for coping with these issues.

To help absorb information:

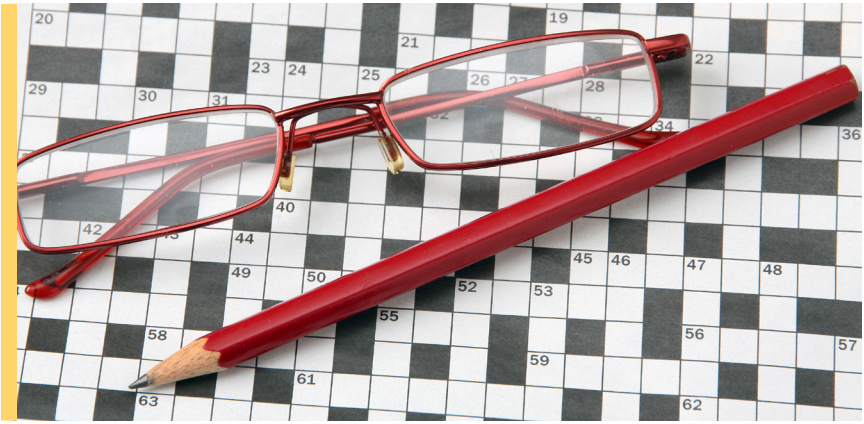
- Link — associate new information with old information.
- Simplify — avoid sensory and language overload. Shorten sentences for easier understanding; break up large pieces of information in order to focus better.
- Use apps that help with memory or record new information on your smartphone. Write down notes or memos to help jog your memory.

To help store information:

- Repeat and rehearse — immediately after someone says something or you learn something new, repeat it to yourself. Then wait a few minutes, and repeat it again to see if you remember.

To help recall information (this is hardest for most survivors):

- Organize — Use a daily planner, calendar, or device such as a smartphone to schedule your day. Never before were “sticky notes” so important. Invest in several packages of these. You can also consider an audio recorder or use your smartphone’s recording function if that will help you remember things.
- Written plan and “notes-to-self” — Write down all important information, such as doctor appointments, social engagements, birthdays and other important events, and medication schedules.
- Create a personal data bank — Create a central database to access addresses, phone numbers, and any other information that you will need to meet with people (including doctors and therapists) and recall what specific discussions you had with them.
- Routine — Recovering from serious illness requires a healthy and well-planned routine. Routines solidify and anchor memories, so they can be recalled much more quickly and with less frustration. Put important items such as keys in the same place each and every time.
- Regular reviews — Each evening, review your day’s events and recall specific details.
- Play — Crossword puzzles, word searches, and other games help with information recall.



SOCIAL-EMOTIONAL CHANGES

Some patients may experience some or all of the following social-emotional changes.

Loss of Emotional Control/Confusion

Most survivors experience temporary loss of control over emotions. This can manifest itself in anger, frustration, and lashing out at yourself and others. You may find that you get tearful for no reason at all. Confusion about what is happening to you is also common, so do not be reluctant to talk about it. These symptoms will get better with time. If it becomes too difficult to deal with, seek counseling.

Self-Esteem/Relationships

You may have changes in your self-esteem and self-confidence as a result of new physical and mental limitations. It is important to talk to your family, doctor, and therapist about how you feel and how to adjust to the "new" you.

You are not any less capable of leading a normal life. It is just going to require adjusting and giving yourself time to heal. You may notice changes in relationships with family and friends, so it is important to discuss your feelings with them. Many times these changes are temporary and as you recover, your relationships often return to normal.

Isolation

You may feel different, or isolated, as a result of the aneurysm treatment. But you are not alone. Attend Brain Aneurysm Support Group meetings or connect with others on the Brain Aneurysm Foundation's online support community (see pages 19 and 20).

Depression and Anxiety

Depression and anxiety are very common among survivors, whether you suffered a ruptured aneurysm or were treated for an unruptured aneurysm. These may be caused by the aneurysm itself and also by the many life changes that may occur as a result of the aneurysm. But there is no need to suffer in silence.

Depression is not simply a passing blue mood or a sudden feeling of sadness that goes away as quickly as it came. It is an illness that affects your body, mood, and thoughts. Depression impacts your appetite and sleep, how you feel about yourself and others, and how you think about life. Treatment, which usually consists of a combination of medication and talk therapy, can help you deal with depression and feel better.

If you experience some of these symptoms below, it is important that you openly share your concerns and feelings with someone close to you, as well as a healthcare professional who understands your condition, such as a neuropsychiatrist or neuropsychologist, licensed psychologist, psychiatric nurse, licensed social worker, or counselor.

- Feelings of sadness on a daily basis; crying more than usual
- Guilt and regret about past events and current problems
- Anger, irritability
- Disturbing, morbid, or suicidal thoughts
- Lethargy/no motivation
- Loss of interest or pleasure in activities, including sex
- Altered appetite: weight loss or gain
- Disturbed sleep (early-morning awakening, disturbing dreams)

RETURNING TO WORK/SCHOOL

For many people, work is an important part of their identity. In many cases, returning to work or school is an achievable goal. But how you defined work before your treatment may be different from how you define it now. Perhaps you will decide to work or return to school part-time instead of full-time, for example.

If you are considering returning to work or school, you will certainly have many questions. When can I return? What types of work can I do? What if I go back to work and realize I am not able to perform the same functions I once could? If I am receiving Social Security Disability Insurance, how will returning to work affect this? Are there services to help me ease into returning to work?

If you decide to return to work or school and your doctor says it is okay to do so, you might face some challenges. Many people are not aware of the "background" deficits associated with brain trauma, so your employer may not understand that expecting you to perform at your previous capacity might be unrealistic.

Before returning to work or school, it is important for you to be assessed by a neuropsychiatrist, neuropsychologist, or other rehabilitation professional to determine what cognitive deficits you may have, as they will impact how you function in the workplace/classroom. These deficits might include memory, organizational skills, language processing, concentration, and higher-level thinking skills. Cognitive therapists can work with you to regain some functioning, as well as offer strategies for compensating for any deficits.

Many survivors rely on Social Security Disability Insurance (SSDI) benefits. SSDI allows you to work on a trial basis for up to nine months before terminating your benefits. SSDI also offers vocational rehabilitation programs to assist you with finding work suited to your special needs. If necessary, physical aids can be provided, as well as job-placement services. Contact your local Social Security office for more information.

AIDS TO RECOVERY

You will have good days and bad days, negative thoughts and positive thoughts, moments of peace and moments of turmoil. Celebrate the good days, enjoy the peaceful moments of solitude and reflection, and write down positive thoughts so you can remember them. Keep in mind that healing and recovery is a marathon, not a sprint.

One key to a positive recovery is to resume your responsibilities and activities gradually, and with confidence. Although these responsibilities and activities might be different than in the past and take on a whole new meaning, they allow you to make progress and contribute to the success of your recovery. So ask yourself, "What have I always wanted to do with my time? Are there interests I want to pursue? How can I turn this situation into a positive one that makes me feel good about myself?"

Journaling

Keeping a journal allows you to express your feelings and develop an inner peace about your condition. Journaling is also a good way to monitor progress of certain cognitive functions, like handwriting, language, and storytelling.

If you are unable to write, use a recorder or ask a friend or family member to be your "scribe." This will be therapeutic for both of you. Other ways to express your feelings are through poetry, song, painting, and meditation.

Support Groups

Being diagnosed with or treated for a brain aneurysm is a life-changing experience. Many survivors and their loved ones benefit from ongoing support through attendance at monthly support groups.

The Brain Aneurysm Foundation started the first support group in Boston in 1992. Since then, the foundation has worked with healthcare providers across the United States and Canada to establish more than 60 support groups.

Support groups, which are typically held monthly and led by healthcare professionals, help by:

- Letting survivors and loved ones know they are not alone and that others understand what they are going through.
- Providing a confidential setting where members can share emotions, experiences, and challenges with others in similar circumstances.
- Providing a forum for solving problems and sharing ideas.
- Providing reliable health information, reasonable expectations for recovery, and resources.
- Enabling healthcare professionals to educate patients — and for patients to educate healthcare professionals — about their experiences.
- Helping patients find appropriate resources.

A list of Brain Aneurysm Foundation-approved support groups is on our website (bafound.org). If you are a healthcare professional interested in organizing a support group in your area, contact the Brain Aneurysm Foundation, which will assist you.

Online Support

The Brain Aneurysm Foundation's growing online brain aneurysm support community (bafsupport.org) provides a forum for survivors and loved ones affected by brain aneurysms to find support and share information, joys, and concerns with others from the comfort and privacy of their homes. The forum section allows members to ask questions or start a discussion about topics of interest to survivors, caretakers, and those who have lost a loved one to a brain aneurysm. The blog section allows members to share their stories, concerns, and photos, and find comfort from others in the community. Some members have formed their own groups: "Living with an Aneurysm" and "Aneurysm and Migraines" are two examples.

Individual Psychotherapy

Brain aneurysm survivors can face a number of challenges: as mentioned previously, difficulties with anxiety, depression, and lack of confidence and self-esteem are not uncommon. While some survivors return to their previous level of functioning, others may be adapting to the "new normal" in their lives. In this situation, individual psychotherapy can be a valuable component of your return to good health. In many states in the United States, mental health services are covered by medical insurance. Your primary care doctor and/or your neurosurgeon can provide a referral. Insurance companies maintain an online list of mental health providers in your area.

A NOTE TO CAREGIVERS

Family and close friends play a key role in a patient's recovery. You can be your loved one's eyes and ears, advocate for good care, and encourage and support their healing. Many survivors make a nearly full recovery, with some residual deficits, but the process is long, taking weeks, months, or even years. Therefore, supporting a survivor requires patience and understanding.

Once your loved one returns home from the hospital or rehabilitation facility, the hard work begins. With some survivors, deficits can alter their personality and temperament so accepting this "new" person is the first step in helping him or her recover and move ahead. Often the deficits might not be obvious at first, but nonetheless impact your loved one's functioning and the ability to interact with others at home, the workplace, or other social settings.

These will help with the recovery process:

- Set small, achievable goals for you and the survivor.
- Be aware of your loved one's strengths and weaknesses, physically and cognitively, so you can prevent them from adding stress to your lives.
- Seek therapy, whether individual and/or group therapy, to work through your own emotions.
- Join a brain aneurysm support group (find locations at bafound.org) or connect with others on the Brain Aneurysm Foundation's online support community (bafsupport.org).
- Develop a plan, reward yourself, and always talk to one another.
- Find time to have fun together.

NOTES

The content of this booklet was reviewed by members of the Brain Aneurysm Foundation Medical Advisory Board.

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