

Brain Aneurysm Recovery Guide



Disclaimer

This patient education resource is not medical advice. It shares common health facts, advice and tips. Some of the information provided in this resource may not apply to you. Please talk to your doctor, nurse or other health-care team member to see if this information will work for you. They can also answer any questions or concerns that you might have.

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Introduction

If you are reading this, you or someone you know may have had bleeding in the brain called a "brain aneurysm" or "subarachnoid hemorrhage." This is a type of stroke. Aneurysms have few known risk-factors. They can affect younger and seemingly healthy people. Aneurysm bursts, or ruptures, happen without warning and can greatly change many things in your life. Many people do not know what to expect after they leave the hospital. It is likely you will notice more changes once you're back in your own home.

It can be scary not to know what to expect after an aneurysm. But, making it to the hospital and receiving treatment is already a huge step towards recovery! Many people who have brain aneurysms do not make it to the hospital. If things seem hard or difficult, try to remember that you have already accomplished a big goal: You survived your aneurysm.

It is difficult for anyone to tell you how long recovery will take. Recovering from an aneurysm can take a long time and will be different for each person. This is because the problems caused by the aneurysm depend on where the bleed happened in the brain.

This pamphlet is a short guide to help you understand changes you might notice after you leave the hospital. Here are a few things to remember:

- Everyone's recovery after an aneurysm is different.
- It can take months or years to recover from an aneurysm.
- No one is able to tell you exactly how long it will take to feel better. It is normal for it to take a long time.
- This pamphlet includes common changes that you or your family may notice. You may experience some, all, or none of them depending on how your brain was affected by the aneurysm.
- Recovery may be slow, but in many cases it is possible. Be patient and kind to yourself or your loved one(s).
- People who have an aneurysm are often much younger than people with other types of stroke. As a result, different aspects of your life may be impacted (e.g., return to work or to school, parenting, etc.). You have

already made great steps towards recovery by surviving the initial aneurysm and by receiving care at the hospital.

Potential Changes You May Notice

Physical Changes

Fatigue

- This is one of the most common problems during recovery from an aneurysm.
- Fatigue is a lack of energy or feeling very tired, and it is different from not getting enough sleep. You may experience both physical and mental fatigue. Fatigue may make it difficult to get up and do normal activities. You may get tired more easily.
- You may also have trouble sleeping, which could make fatigue worse. One-third of people who had an aneurysm say they have problems sleeping.

- As many as two-thirds of people who survived a brain aneurysm feel fatigue up to 3 years or even longer after their aneurysm.
- Try to return to doing things slowly to give your body and muscles time to adjust.

Headaches

- A lot of people have headaches after an aneurysm. The headaches may keep coming back for years. Two-thirds of people have regular headaches for more than 2 years.
- How bad your headache is may change every day, but they could last for weeks.
- It can be scary to have a headache after your aneurysm, but they are not always a bad sign.
- Headaches that happen because of an aneurysm rupture are sudden and severe. Call 911 if a severe and sudden headache returns.

Vision Problems

 Depending on where the aneurysm was in the brain, you may have blurry vision or problems seeing. Vision tends to improve over time.

Worse Sense of Smell and/or Taste

- You may not be able to smell or taste as well as you did before. Unfortunately, a loss of smell or taste usually does not get better with time.
- A quarter to one-third of patients have worse sense of smell or taste after an aneurysm.
- Loss of sense of smell/taste may also affect how much you feel like eating (your appetite).

Low Back Pain

- Some people have low back pain or shooting pain down the back of their legs. This may be the aneurysm irritating your nerves. It could also happen when you are lying down for a long time without exercise.
- The back pain usually gets better as you increase your physical activity.

Constipation

 Constipation after an aneurysm may be because of your diet, the type of medications that you're taking, or not getting enough physical activity. Constipation usually gets better as you move around and/or take less pain medication.

Slower Information Processing

- Information processing includes how much and how fast our brains can make sense of the things we see, hear, and feel every day.
- Most people process information more slowly after their aneurysm. This can mean you react slower than you used to, for example when you drive. This can make it dangerous to drive, especially if you also have memory or vision problems.

Seizures/epilepsy

- Some people may have seizures when they first recover but do not have a long-term seizure disorder.
- In rare situations, seizures may keep coming back. Your doctor can order medications that can help manage or completely control the seizures.
- To learn more about the different seizure types and actions to take to reduce the risk of having seizures, you can visit https://www.epilepsyottawa.ca/resources.
 Disponible en français aussi.

Changes to Attention and Executive Function

Attention/Focus

- Most people who have had a brain aneurysm can pay attention for less time than they used to and have problems focusing.
- This may be because of changes to your brain after the brain bleed as your brain is still repairing itself. Fatigue can also impact your attention and focus.

Executive Function

- Executive function includes our ability to plan, make decisions, think about things, organize our thoughts and multi-task.
- Most patients find it hard to make complex decisions, plan their days, or know how to organize themselves after the aneurysm. About three-quarters of people have these problems.
- Breaking up projects into short tasks, making a daily schedule, and avoiding lots of noise and crowded places with lots of people will help you feel less overwhelmed or stuck.

Memory

- Half to two-thirds of survivors have memory problems for over a year after the aneurysm.
- Making and keeping memories involves many parts of the brain, so memory problems are common in people who had an aneurysm.
- Many patients regain their ability to make new memories and remember old ones within a few months, but it takes longer for some people.
- Some people who had a brain aneurysm may not realize the difficulties they are having with memory or problem solving.
- Different parts of your memory may be affected. For example, you may remember things that happened a long time ago but have trouble making new memories. This may slowly improve over time as you recover and learn how to deal with it.
- You may never remember the day of your aneurysm or what happened in the hospital. This is normal. This memory loss can be a result of the aneurysm bleed or the treatments for it.

Social-Emotional Changes

After an aneurysm, you may feel more emotional or have difficulties interacting with people like you did before. This happens to a lot of people when they get serious news about their health. It is important to remember that you are not alone. If you're struggling with any of the changes listed below, talk to a family member or a health-care professional to get help.

Loss of emotional control/confusion

 Most patients have temporary loss of control over their emotions, including anger, frustration, and feeling tearful for no reason.
 This will get better with time. If it becomes too difficult to deal with then look for counselling as it may help you deal with your emotions.

Self-esteem/relationships

- You may have changes in your self-esteem and self-confidence because of physical and/or mental changes from the aneurysm.
 It is important to talk to your family, doctor, or therapist about how you feel and how to adjust to the "new" you.
- You can still have a normal life. But, it is going to take time to adapt and heal. Many

times, these changes are temporary and, as you recover, your relationships will return to normal.

Isolation

 You may feel different or isolated after your aneurysm. You are not alone. There are support groups where people who have had a brain aneurysm support each other. You can find some of these support groups listed in the Information and Support Groups section at the end of this pamphlet.

Depression and anxiety

- Depression 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 for depression, which is usually a combination of medication and talk therapy, is very effective in treating depression.
- Depression and anxiety are very common among people who survive a brain aneurysm. Half of patients have these feelings a year after their aneurysm, and one-third may have post-traumatic stress disorder (PTSD) after their aneurysm.

 These may be because of the aneurysm or by life changes since the aneurysm.

Returning to Your Normal Activities

Everyone is different. The following timelines are approximate and share what to expect in general:

First days:

 The health-care team focuses on stabilizing the patient and fixing the aneurysm.

First weeks:

 Most patients are in the intensive care unit at the hospital so that their health-care team can monitor them closely.

After first weeks:

 The health-care team focuses on preparing patients for leaving the hospital. Leaving the hospital may mean returning home, to a rehabilitation or a different care centre. The health-care team helps patients regain their ability to take care of themselves by doing activities of daily living including dressing, bathing and walking. If you are having problems doing activities
of daily living, or need more support for your
rehabilitation, ask your doctor for a referral to
an Acquired Brain Injury clinic. Ask to see a
Physiatrist or Neuropsychologist.

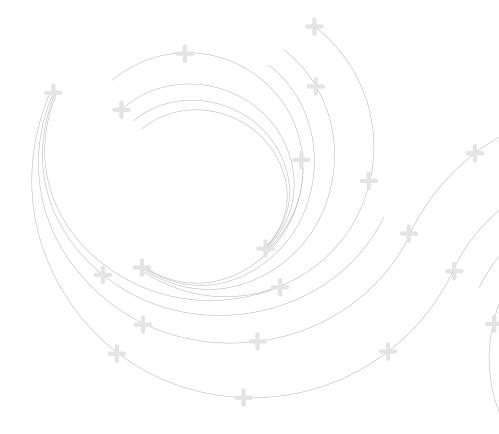
First 6 months and beyond:

- You focus on strengthening and recovery.
 This includes returning to your normal life roles such as living independently, parenting, social activities and return to school, work and things you like to do.
- Recovery can take a long time, sometimes several years. Sometimes it might feel like you are moving forward in some areas but moving backwards in others. This is normal.
- Other people may not be able to see and understand what you are going through and what you need.
- Be kind to yourself and your loved ones.
 Keep trying to take small steps forward.
- It can be difficult or scary to return to activities you did before your aneurysm, but it is important to try. It will help you focus on other areas of life, other than your aneurysm, and regain your strength and confidence.

- Try finding new interests and activities you can do. This will help you feel better and stop you from focusing on what you may be having trouble doing now.
- Instead of focusing on returning to work or school, try thinking of activities that you enjoy now as markers of your success in recovery. For many people, work is an important part of their life. In many cases, returning to work or school is a great goal. How you work after your brain aneurysm may be different from before. For example, it might be easier to go back to work parttime instead of full-time or try a different role. Two-thirds of people who have had a brain aneurysm are able to return to work between 2 and 4 years after their aneurysm. One-third of the people who return to work return to a different role or work less hours.
- Recovery after an aneurysm takes energy and practice. The more you practice towards your recovery goals, the more likely you are to reach them.
- Recovery is often faster and more obvious at the beginning and tends to slow down with time. But, things will keep improving for months and years afterwards. Try tracking

your progress in a journal to remind you of how far you've come. This is helpful for times when you feel like nothing is improving.

- Each person will recover differently depending on their type of aneurysm and treatment.
- You may not be able to do everything that you did before, but you can still reach your recovery goals and have a life you enjoy.



More Information and Support Groups



Brain Aneurysm Foundation (BAF):

The BAF is an organization that works on education and support for people with a brain aneurysm. They give information about and raise awareness of the symptoms and risk factors of brain aneurysms so that negative effects of aneurysm can be prevented. They work with medical teams to provide support for patients and families.



Website: https://bafound.org/



Brain Injury Association of the Ottawa Valley:

The Brain Injury Association of the Ottawa Valley is an organization that helps people with brain injuries to return to their environment.



Website: http://www.biaov.org/



Champlain Acquired Brain Injury System Navigation Services:

This is a service that provides clinical and community support for people who had a brain injury.

Website:

https://www.champlainhealthline.ca/listServices.aspx?id=10385



Neuro-Patient Resource Centre, Montreal Neurological Institute and Hospital:

The Neuro-Patient Resource Centre is a health information library to help you find the information you need to better understand neurological health and care. Disponible en francais aussi.



Website:

https://www.mcgill.ca/infoneuro/ online-resources/medical-topics/ aneurysms-brain-cerebral



Heart & Stroke Foundation:

National Canadian resource for information and support about heart health and stroke. Some of the information about stroke on this website is helpful for people who had a brain aneurysm.



Website: www.heartandstroke.ca



Brain Injury Canada:

This organization offers resources for patients with brain injury.

Website: https://braininjurycanada.ca





SAHaRA Research Program:

This website has information about research studies at the Ottawa Hospital that patients with brain aneurysm may be able to participate in.



Website:

https://www.saharaprogram.com/

Notes



Do you have any feedback about this education resource?

Is it welcoming and respectful of your background, culture, and identity? Your opinion is important to us. Please fill out this <u>survey</u> or contact the Patient Education team at <u>patienteducation@toh.ca</u>





Do you need this information in a different format?

Please tell a member of your health-care team so that they can provide you with this information in a format that works for you. This resource is available in English and in French. Cette ressource est disponible en anglais et en français.



Booklet information

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Source: The original version of this guide was written by the Medical Advisory Board of the Brain Aneurysm Foundation (BAF). With BAF permission it has been modified by aneurysm patients and family members to include the information that they think is most helpful to patients and their families as they begin their recovery. For the full original guide and other resources, please visit https://www.bafound.org/

