Cerebral Aneurysm

Information for patients and families

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Created: 11/2006
Form: D-5389 (04/2013)
Dear patient and family:

We are pleased to present you with this booklet. We hope it will be helpful to you and to those helping you in your recovery.

This booklet was created to give you and your caregivers information about your:

- brain
- aneurysm
- treatment and recovery

It also gives the answers to many general questions.

During your hospital stay, the Krembil Neuroscience Program is committed to offering you the highest quality care. Please contact any member of your health care team if you have questions or concerns.

We wish you a speedy return to a full and productive life.

Regards,

Pam McFarlane, Laura Gallant, Dawn Tymianski, and the TWH Aneurysm Peer Mentors
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Basic facts about your brain

What is the size, shape and function of the brain?

In an average adult, the brain:
  • weighs about 1.5 kilograms
  • is about the size of 2 fists
  • is grey
  • feels like firm custard to the touch
  • is divided into two halves that look very similar to each other

Some functions of the brain, like muscle movement and sensation, can be found in both sides. Other functions are found in only one side of your brain. Your speech centre, for example, is found only in the left side.

Cool facts

Your brain weighs about:
  • 1000 times more than a hamster’s
  • 100 times more than a rabbit’s
  • only ¼ that of an elephant!
How is the brain formed?

- The outside of your brain, known as the ‘grey matter’, is what allows you to be awake, alert and aware of your environment. The grey matter is between 1mm and 4mm in depth.
- Under the grey matter is the ‘white matter’ that passes information back and forth (like very complicated highways) to different parts of the brain for interpretation.
- Some conditions such as brain tumours, stroke, Parkinson’s Disease and Alzheimer’s disease affect both the grey and white matter.
- Other structures in your brain maintain your:
  - hormonal balance
  - appetite
  - temperature
  - sleep wake cycles
  - emotional system
  - response to fear
  - co-ordination of movement
- The brain stem is connected to the ‘bottom’ of the brain and joins it to the spinal cord. The brain stem controls most of the muscles and sensations in your face.
- The brain, brain stem and spinal column are all sealed in a tough protective covering known as the ‘dura mater’ (also known simply as the dura). This contains cerebrospinal fluid.

What is cerebrospinal fluid?

- Cerebrospinal fluid (also known as CSF) supplies your brain with a constant mix of nutrients (salts, sugars and proteins) and keeps it moist.
- About 3 tablespoons of CSF are produced every hour by small cells within the ventricles (cavities, or pockets, deep within the brain), to keep brain fluid pressure at a constant level.
- The CSF travels in this direction:
  1. out from the ventricles
  2. over the top of the brain
  3. down around the brain stem and spinal cord
  4. back into the brain where it goes back into the blood
How does blood flow?

• Almost everyone is born with the same arteries and veins but, just like other body parts, the length, width and shape of the blood vessels in the vascular system (the arteries and veins) are different from person to person.

• To keep your brain working, a constant blood supply is required to carry oxygen to it. Your brain receives about 1 litre of blood per minute, pumped from the heart through 3 main blood vessels to the head:

1. two carotid arteries, one running up each side of your neck, supply blood to the front and middle of your brain (either carotid artery can be used to check your pulse)

2. one basilar artery that runs up from the spinal cord and supplies blood to the brain stem and back of your brain

• The 3 arteries join together inside your brain to form a circle, known as the ‘Circle of Willis’. This circle allows your brain to continue to receive blood and nutrients even if one of the arteries is not working properly.

The veins in your brain take away the waste products and return them to the body.

Contrast Scan using dye to show the carotid arteries
How do brain lobes work?

The brain is divided into 4 different lobes:
1. Frontal
2. Parietal
3. Occipital
4. Temporal

**Frontal Lobe controls:**
- personality and behaviour
- muscle control and strength
- vision and expressive speech
- advanced thinking and reasoning

**Parietal Lobe controls:**
- sensation
- construction
- activities of daily living
- telling apart the left and right side

**Occipital Lobe controls:**
- vision
- spatial organization (figuring out how objects are arranged around us)

**Temporal lobe controls:**
- interpretation of sound (voice, music and more)
- emotion
- hearing
- memory

What does the brain do?

Your brain is an amazing organ and is considered the body’s ‘central control’.

It controls your:
- breathing
- speech
- vision
- hearing
- touch
- heartbeat
- muscle movement
- many other chemical activities.
It also helps you understand all body sensations and is the source of emotion and reason. Some of your brain runs automatically without you realizing it. For example, you are not normally aware of your heart beating or what your blood pressure is at any given time.

But, a lot of brain function is under your control.

You can:

- choose to move your muscles
- speak to others
- use your ability to think and reason.

**Cool facts**

The total length of your brain nerve fibres is between 93,000 and 112,000 miles.

Your brain's total surface area is about 2.5 sq ft.

**Why are nerve fibres or neurons important?**

Nerve fibres or neurons are nerves that travel back and forth using many connections through your brain, brain stem and spinal cord. These nerves come from the spinal cord, like branches of a tree, and reach all parts of the body to send messages from the brain to an organ or maybe from the skin, muscle or bone to the brain. If any nerve fibres along the way are cut or crushed by injury or damaged by disease, then messages do not get through and the part of the body affected does not react as it should.

For example, in the case of a bleed in the brain, the blood or the injured brain area can stop messages to-and-from different parts of the body. Depending on the area of the brain that is affected, this can cause:

- muscle paralysis
- swallowing and speech problems
- incontinence and other difficulties

Sometimes, if the problem is temporary, then function can gradually return as the brain heals. But sometimes, when the problem lasts longer or when there is a permanent injury, function may not return.
Aneurysms

What is an aneurysm?

An aneurysm (ann-yur-is-em) is a bulge, or balloon-like swelling, on the side of a blood vessel wall. Sometimes, this bulge can leak or burst and cause bleeding. An aneurysm in the brain is called a ‘cerebral aneurysm’. Aneurysms can be found on any blood vessel in the brain but are more common on those in the front of the brain.

The most common type of aneurysm, known as a ‘berry’ aneurysm, looks like a small blueberry. Another type of aneurysm, called a ‘fusiform’ aneurysm, can be shaped like a sausage.

Normal blood vessels in the brain (shown in white)

Aneurysm: a swelling of the wall of the blood vessel
Quick facts about aneurysms

Aneurysms:

- Happen to about 1% or 2% of people (in Canada, about 1 in every 350,000 people)
- Seem to develop more in areas with high blood flow, particularly where blood vessels branch or divide
- Seem to take many years to develop (they tend to be very rare in children)
- Are mostly found in people between the ages of 40 and 60
- Are more common in women than in men
- Are more common in smokers, people with kidney disease, and those with high blood pressure
- Can happen once or more than once
- May or may not burst and bleed depending on their size and location in the brain
- Are not always found since they do not always rupture and affect the health of the person
- Are not related to migraine headaches

Are there family connections?

Because of genes or inherited factors, about 15% of all aneurysms have a family link. If one or more relatives in the same blood family has an aneurysm, the other family members over 30 years old can be tested as an option. Family members under 30 years old are not usually tested because aneurysms can take years to develop and are very rare in younger people.

Your family doctor can order a Cat Scan (CTA), or Magnetic Resonance (MRA) to test for aneurysms.
What are the symptoms of an aneurysm?

- Most aneurysms are ‘asymptomatic’ (they give no symptoms).
- Usually, they are not found until there is a leak of blood from the aneurysm into the brain.
- Many patients only find out that they have an aneurysm when they have a brain scan for other reasons.

What is a subarachnoid haemorrhage?

Bleeding from an aneurysm in the brain is called a ‘subarachnoid haemorrhage’ (known as an SAH). Subarachnoid hemorrhage (SAH) is rare and happens when an aneurysm bursts. The brain is covered by 3 thin layers called the ‘meninges’. The names of these coverings are the ‘dura’, ‘arachnoid’ and ‘pia’. The blood vessels that supply the brain are between the pia and arachnoid layer. This space is called the ‘subarachnoid space’. When an aneurysm breaks, blood goes into the subarachnoid space; and this is what is called a ‘subarachnoid haemorrhage’.

What else do we know about SAH?

- It is rare and found in 1 out of 10,000 people
- Symptoms include a ‘thunderclap’ headache. This is a sudden, severe headache. It is often described as being the worst headache of a person’s life.
- There can also be nausea, vomiting, loss of consciousness, seizures or confusion
- Most people complain of neck stiffness
- It can happen at any time, for example, while watching TV or during exercise
- It is a medical emergency since about 15% to 20% of people die from SAH before they get medical attention
- It can be diagnosed through a Lumbar puncture, CTA (CAT scan with contrast or dye) or angiogram
- About 70% to 80% of patients who survive SAH have temporary or permanent disability.
Treating aneurysms

Your treatment team

You are in excellent hands!

The Krembil Neuroscience Centre has highly trained professionals from many fields of expertise. They work together as a team to give the best care possible for every patient.

Depending on how complicated your case is and how long your hospital stay is, you will meet some of the following people.

Neurosurgeons: medical doctors specially trained to diagnose and surgically treat people with brain and spine problems.

Neurosurgical Fellows/residents and Interns: qualified medical doctors finishing training. They are under the direct supervision of the neurosurgeons.

Nurse Practitioners: Registered Nurses (RNs) with advanced training who:
  - work with medical specialists
  - order diagnostic tests
  - assess and order medications
  - teach
  - help you and your family with treatment and when leaving the hospital

Nurse Managers: Registered Nurses (RNs) who provide leadership for all services on a hospital unit. They make sure care needs are met and can talk to you about any questions or concerns you may have. (Ask your unit nurse if you would like to meet the Nurse Manager).
Unit Nurses: Registered Nurses (RNs) who help with planning, providing and coordinating bedside care. They give you information and communicate with doctors and other staff to coordinate your overall care.

Social Workers: give emotional support and information about resources that you may need. They work with the entire team to coordinate your care plans and will arrange your transfer to other facilities if needed.

Physiotherapists: assess your physical ability and develop therapy plans to help with your movement or balance. They work with the team on discharge plans and may also help with treatment plans to help you become more independent.

Occupational Therapists: assess how well you handle everyday living and help you to become more independent. They suggest helpful services and equipment, as needed, and help with discharge plans. Occupational Therapy assistants may also be involved in your therapy.

Speech Language Pathologists: assess any communication or swallowing problems you may have. They also make recommendations for treatment and give education to help with discharge planning and any on-going treatment.

Dietitians: assess your nutrition needs and suggest any special food you may need. They give dietary education related to your condition and help with discharge planning.

Pharmacists: help the doctors manage your medications. They may meet with you to check your medication history, allergies, etc., and could also give medication counselling.

Spiritual Care: the hospital chaplains are from many faiths and can give emotional support and spiritual care for you and your family.

Hospital Volunteers: help patient or staff as requested.

Aneurysm Peer Mentors: past aneurysm patients who can provide friendship and support during, and after, your hospital stay.
How do you diagnose an aneurysm?

The doctors will decide how to test and diagnose you for an aneurysm. Testing will give your health care team information about where your aneurysm is found and the size it. Tests also help the team decide on the treatment options available.

More than one aneurysm may be found.

There are usually 4 diagnostic tests used to find aneurysms:

1. Lumbar Puncture
2. Computerized Tomography (CAT or CT)
3. Magnetic Resonance Imaging (MRI or MRA)
4. Angiography (Angiogram)

You may have one or more of these tests.

1. What is a Lumbar Puncture test?

If we think you may have bleeding in the brain or spinal column, the doctor or health care practitioner can do a lumbar puncture to check for it. Blood in the spinal fluid means there is a brain hemorrhage.

While you lie on your side, and after freezing the skin, the doctor will put a needle into your lower back and take a small amount of spinal fluid. The test takes about 20 minutes.

2. What is a Computerized Tomography (CAT or CT) Scan?

This test takes images or pictures of the inside of your head. Contrast materials, or dyes, are often used to take clearer pictures. The scan takes about 10 minutes.

3. What is Magnetic Resonance Imaging (MRI or MRA)?

This is a test that uses magnetism, radio waves, and a computer to create images of slices of your brain. For some procedures, contrast material, like gadolinium, is used to make clearer images. The scan takes about an hour.
4. What is an angiogram?

This test uses a special contrast dye and x-rays to show how blood flows through your brain. A thin, hollow tube called a catheter is inserted to an artery in your groin, then carefully moved up through the main blood vessels in the abdomen and chest, and into an artery in your neck. Dye is then sent through the catheter and into your brain where moving x-ray images help the doctor see any problems in blood vessels.

What are the treatment options?

The goal of all treatment is to stop or lower the chance of bleeding.

Some aneurysms only need to be watched carefully or maybe they need no treatment at all. This will all depend on the size of the aneurysm, where it is, the patient’s age and health or the patient’s own choice.

If your doctor says the aneurysm is not risky, he or she will recommend that you have follow-up appointments every year to make sure nothing changes. For example, they will check to see if the aneurysm has grown larger. After a few years of normal results, testing will probably no longer be needed.

If your doctor decides that the aneurysm needs attention, then there are 2 standard ways to treat it:

1. Clipping (done by a neurosurgeon)
2. Coiling (done by an interventional radiologist)

What is aneurysm clipping?

Aneurysm clipping means having brain surgery.

The surgeon places a small platinum ‘clip’ on the neck of the aneurysm. This clip, which looks like a tiny clothes peg, permanently blocks off the blood flow to the aneurysm. It prevents any future bleeding.
Your body will not reject the clip. It will stay in place for the rest of your life and never move. Platinum does not set off airport security alarms and you can usually continue to have MRI and CT tests.

If you have clipping done, you will be given a wallet card with full information about your clip before going home.

**What is aneurysm coiling?**

This is done through an angiogram.

The doctor inserts a very small tube into the femoral artery (which is in your groin area). The tube is threaded all the way to the affected area of the brain. When it reaches the aneurysm, a number of very tiny, soft, platinum coils are injected into the aneurysm from the tube. These tiny coils fill the space and create a solid clot of platinum and blood. This stops blood flow into the aneurysm and prevents future bleeding.

Depending on the condition of the aneurysm, some patients will need a ‘stent’ (or tube) during coiling. The doctor places the stent in the blood vessel to cover the neck or opening of the aneurysm. This will permanently stop the coils from falling out of the aneurysm back into the blood vessel. Once this stent is in place, the coils are then injected into the aneurysm to fill it, as described above.

**What are other treatments?**

There are two other, less common, treatment options that could be used when the aneurysm cannot be clipped or coiled:

- Balloon occlusion
- EC-IC by-pass

**What is balloon occlusion?**

This procedure is sometimes used when the size, shape or location of an aneurysm makes surgical clipping or coiling impossible. In this case the doctor may choose to block off
the artery that feeds the aneurysm with a tiny balloon. This stops blood from entering the aneurysm and lowers the risk of future bleeding into the brain. A test occlusion is sometimes needed at first to check the effects of this procedure and to make sure that the patient is safe.

Oclusions are most often needed if the aneurysm is at the base of the skull or is very large.

**What is EC-IC bypass?**

A brain bypass is the brain's equivalent of a heart bypass. It involves using a grafted-in artery to reroute blood flow around a giant aneurysm so that the part of the brain involved can continue to get a blood supply once the aneurysm is clipped. Graft arteries are usually taken from the scalp but can be taken from the arm or leg. This graft then goes around the clipped aneurysm and carries normal blood flow between healthy vessels.

If the artery is taken outside to inside the head, it is referred to as an extracranial-to-intracranial (EC-IC) bypass.

**Your elective treatment schedule**

**What to do before you are admitted to hospital:**

If you are having elective (non-emergency) treatment, such as clipping or coiling, you will go to a pre-admission clinic a few days before your treatment.

Here is what to expect:

- you will have blood taken for checking
- your medical history will be confirmed
- you will have the chance to ask a doctor any questions you may have
What to expect on the day of the procedure:

As an elective patient, you will be admitted to hospital either on the night before, or the morning of, your procedure. You will be admitted to a pre-surgical area, and from there will go to have your procedure.

- Do NOT eat or drink after midnight on the day of your procedure since you may have a general anesthetic.

What to expect after your treatment

If you have had coiling, your doctor will tell you to stay still, lying flat in bed for up to 4 hours. This rest period lets the opening in the femoral artery in your groin heal.

If you had surgery, you will spend the first 24 hours on a unit where you can be closely watched for any complications. If all goes well, you will be moved to a neuroscience floor the next day and discharged home from there.

Most patients treated for clipping or coiling will need either an angiogram, CAT scan (CTA) or magnetic resonance angiogram (MRA) before they go home and may also need to come back for a follow-up angiogram or magnetic resonance angiogram (MRA). Usually this is done a few months after the treatment to make sure that everything is healing properly.

Follow up

We will set up an appointment for you to be seen by one of the members of your TWH neurosurgical team about 4 to 8 weeks after you leave the hospital. Depending on the treatment you had and whether you have another aneurysm that needs to be treated or monitored, we may arrange long-term follow-up. A neurosurgical staff member will explain what is best for you at the time of your appointment.

If you give your permission before you leave hospital, a trained member from the TWH Aneurysm Peer Mentor program will contact you about 1 month after you leave the hospital. They will call to see how you are doing.
What is the risk of complications?

There are always risks with any procedure, but serious complications are rare. Most patients are able to go through their procedure very well and the aneurysm is usually completely fixed.

Watch for these possible complications:
- infection
- vision problems
- stroke-like symptoms such as:
  - weakness in one arm or leg
  - numbness
  - tingling
  - speech problems.

Your doctor will talk about the risks with you before your procedure.

Medications used to treat aneurysms

Your doctor or Nurse Practitioner may prescribe medication after your procedure, while you are in hospital, and for when you go home. A member of the health care team will tell you:
- what these medications are for
- any possible side-effects
- how long you are expected to take them.

You may receive medications to treat or prevent:
- Pain (most commonly the wound site or headaches)
- Infection
- Swelling (particularly of the brain)
- Seizures
- Nausea
- Other problems such as constipation (a common side effect of pain medications)

The hospital pharmacist may also talk to you about your medications and your medication history while you are in hospital.
What can I expect as I recover?

Any after-effects you may feel will depend on the location and size of the aneurysm, and amount of any bleeding that may have happened in your brain and the treatment you had.

- Some aneurysm patients are able to go back to normal life quite quickly after treatment.
- Some patients have temporary problems like:
  - tiredness
  - headaches
  - lack of concentration
  These patients usually take a short while to get back to normal.
- Other patients end up having more permanent and life-changing problems, called deficits (such as not being able to communicate properly, impaired judgment or problems with short- or long-term memory, etc.).

Your health care team will meet with you and your family to review your situation and find out what your needs are and how they can be met. You and the family will be part of the planning and decision-making process throughout your stay in hospital.

A member of the team will talk to you or your family if rehabilitation is needed. With rehabilitation, support and counselling, the effect of some deficits can be greatly reduced. Most patients also find they are able to make up for problems that they face and find new ways of doing many tasks.

Time, of course, is the greatest healer.
Some common problems

The most common problems that people go through are listed below. These problems can be short-term, minor problems. They can also be longer-term concerns where recovery can take some time. Your treatment team would be able to find out if they can help with some of these issues.

**Physical:**
- walking, balance
- loss of muscle strength
- lack of co-ordination
- loss of feeling
- strong sensation (such as tingling)

**Cognitive or thinking:**
- problems with long-term or short-term memory
- poor judgment
- trouble with managing everyday living skills

**Swallowing:**
- weakness or other problems with swallowing

**Communication (aphasia):**
- problem understanding what is being said
- problem putting speech together

**Vision:**
- ‘frozen’ eye muscles leading to changes in vision
- poor vision quality
- double vision
- altered colour sensations

**Hydrocephalus:**
- blockage of spinal fluid in the ventricles (can be caused by a brain haemorrhage)
- can cause headaches, changes in memory and difficulty walking
• for some people, it resolves itself over time; for others, a ‘shunt’ is needed (a tube placed into the ventricles in the brain and run down into the abdomen to drain extra fluid from the brain and restore normal pressure)

Some patients tell us that they suffer from one or both of the following conditions after an aneurysm bleed:

**Fatigue and feeling ‘blue’:**
- Many patients tell us that they feel tired when they get home. This fatigue can last for a few weeks or months. Others feel ‘blue’ or ‘down’ right after they go home and this can last for several months after the aneurysm event.
- Fatigue and feeling ‘down’ are normal stages of recovery for some patients and for most people these feelings pass in time. If they don’t, talk to your family doctor about possible medications or getting a referral for counselling.
- Rest and take time to recover!

**Headaches:**
- Some people get headaches after their treatment but others do not. Post aneurysm treatment headaches can last for a while, but they usually stop after some time.
- Most headaches are not a problem. If you are really worried about your headaches, talk to your family doctor.

Most of your after-effects will either go away after some time or you will learn to live with them. But, you should call your doctor if:
- You still feel tired after 2 months
- Your feelings of ‘blueness’ do not get better after 1 month or if they get worse
- You still have headaches everyday after a considerable time
- You have any concerns about your general health

**What about therapy?**

You may need therapy for one or more deficits. Once your doctor says that you are medically stable, you will be discharged from TWH. Different options are available and these will depend upon your needs.
Your options could include any of the following:

- Go home with no therapy needed
- Go home with a referral to a Community Care Access Centre (CCAC) or Homecare for help with personal care (bathing, dressing, medications) or for therapy in the home
  - Homecare doesn’t include cleaning, laundry or making meals
  - CCAC could also give care in the home while you wait for a bed at an In-Patient Rehabilitation Hospital
  - If you need Homecare or CCAC, somebody from CCAC will see you to help set up the services before you leave the hospital
- Go home with a referral to an Out-Patient Rehabilitation Clinic
- Transfer to another hospital that specializes in In-Patient Rehabilitation
- If you came to TWH from another hospital and still need more time for recovery, you will be taken back to that hospital when you no longer need specialized neurosurgical care

Some patients with serious deficits from a haemorrhage, or those who need a longer time for recovery, may be taken to facilities that can continue to give higher levels nursing care. These include Long Term Care facilities (Nursing Homes) or Complex Continuing Care facilities (Chronic Care).

When you leave the hospital

For you, the patient

Patients have told us about 6 areas where they had to make changes during recovery. You may face one or more of the following challenges:

1. Speed of healing
2. Setbacks
3. Dealing with the ‘new normal’
4. Getting back to work
5. Your family
6. Relationships
1. Healing

Every brain is different. So, every patient recovers at a different pace. Some patients bounce back to their previous activities in no time. Others take longer to heal and may need rehabilitation therapy.

Some people feel discouraged if recovery is not coming along as quickly as they hoped. If this happens to you, remember that many patients who have dealt with aneurysms have, in one way or another, recommended, “Have patience and give yourself the gift of time.”

2. Setbacks

As in any recovery process, you may sometimes think that your recovery has:

• Stopped
• Hit a plateau or even
• Slipped backwards in some way

This is normal as the brain recovers. Most patients find that, even after a setback, healing moves forward again and progress becomes noticeable. Trying to keep a positive attitude does wonders for the body and the mind.

3. The ‘new normal’

While some patients recover quickly from their aneurysm treatment, others have to live with new realities and challenges. You may have physical challenges but you may also notice that you feel emotional and have changes in your thinking. Maybe you are just not used to spending so much time at home. This is especially hard on people who are real ‘go-getters’. So, you may think about your life differently than you did before. This is true with many patients who experience any kind of medical problems, not just aneurysms.

Your family and those close to you may also notice differences in your attitude, priorities and sometimes even in the way you relate to others or think about yourself. Some patients tell us that they feel like ‘a different person’. This is often called the ‘new normal’. Although this can be an odd and unexpected situation for you and those close to you, you will learn to adjust to it over time.
All of us change over time depending on how life rolls out. You have been through a serious medical situation and, of course, crises and challenges in life often change the way we function or think about ourselves. Going through a brain injury may cause a more sudden or unexpected change, but, it may also be something that you might have had to face later on in life anyway. Interestingly, patients and family members often say that a ‘new normal’ person is just as interesting and lovable and, in many ways, even better than the old one!

If you have such changes and find it difficult or quite a problem to adjust, there are resources that can help you. Some resources are the TWH Aneurysm Support Group, family counsellors and psychologists. Talk about your needs with your family doctor if you feel that you need help.

4. Going back to work

Going back to work is a decision that you and your doctor must make together.

You might not feel ready to go back to work even though the healing of the brain and body has gone well. Maybe you are anxious to get back to work as a sign of returning to normal but still have challenges. You will need to think about what is best for you and what feels right.

Although going back to work can be an important step in recovery, nobody can predict for sure when you will be ready for it. This is why it is important to talk about this decision with your family and with your family doctor. The doctor can help you if you decide to take more time to recover. They can also provide a letter for your employer to ask for changes in the workplace to:

- Adjust your work hours
- Change your responsibilities
- Provide special equipment

Make sure that you apply for all the financial benefits that you are entitled to, such as Employment Insurance or Short-term Disability Employee Benefits. For patients with no insurance, benefits or savings, Ontario Works is a government program that can help to support you through the time off work.
5. Your family

Sometimes, patients are more concerned about the reactions and worries of their family members than they are about themselves. Of course, when someone suffers an aneurysm, everyone who loves and cares for them is affected – a spouse, partner, children, siblings, and friends.

Sometimes, returning to loving relationships and social activities can be difficult:

- Family members may treat you as though you are fragile or not able to do many things for yourself (sometimes this might be true but, usually, you can do much for yourself)
- Often, when providing care, family members become tired and emotionally drained themselves

In these situations, try to understand that your family members have also had a difficult experience and they, too, need reassurance and support.

6. Relationships

Having sex again may be awkward or concerning. If your aneurysm burst while having sexual relations (or while having a bowel movement, which is not uncommon) please know that, if you were clipped or coiled, your problem has been fixed and you are no longer at risk during either of these activities!

If you need help in dealing with these types of issues, it is important to speak to your family doctor, a TWH Peer Mentor or other health care worker.

A closing thought

In closing this section, we would like to leave you with two quotes from aneurysm patients. We often refer to them as a source of inspiration for recovering patients:

“My recovery….continues to be the….success story that I first thought it was.”
[aneurysm patient after several setbacks]

"The word 'recovery' seems to suggest looking backwards. Instead, I think a more appropriate word might be 'discovery'."
[double aneurysm patient]
For your caregiver

For an aneurysm patient, a caregiver is anybody who provides help, support and encouragement. This can include a:

- Spouse or other significant partner
- Relative
- Friend
- Professional caregiver

Caregivers are great support and can really be very helpful in recovery.

It is always wonderful for the patient to be able to go home but, as a caregiver, you may have already felt stress during the patient’s hospitalization and you need to know your limits, both physically and emotionally.

Be ready with as much information as possible. Before discharge from hospital, the health care team will discuss the patient’s medical needs with you. It is important that you understand these needs and feel sure that you can help the patient properly.

Trusted friends and family are always a solid resource for both the patient and the main caregiver. There are also professional resources for caregivers if times become difficult.

For example:

- The Self-Help Resource Centre of Toronto can connect you with other caregivers and supportive resources. www.selfhelp.on.ca or call 416-487-4355
- AVM/Aneurysm Peer Mentor Program and Support Group (see section on TWH AVM/Aneurysm Support Group)
- Krembil Neuroscience Website: brainavm.com (no ‘www’ needed)
TWH Aneurysm Support Group and Peer Mentors

What is a support group?

Since 2000, we have provided a monthly Support Group for patients, their families and friends. This group gives everyone a chance to come together to:

- celebrate successes
- discuss concerns
- look for advice
- find friendship
- enjoy empathy

Our group members find the experience very helpful. There is no minimum or maximum number of times that anyone has to attend. Some people just come once, others attend month after month. The format is informal, low key and not intimidating. Anyone may take part freely or just listen and learn if they feel that they are not yet ready to share their own experiences.

Some months, there are presentations on different topics about aneurysms, usually with a guest speaker, then followed by enough time for questions and personal input by the group members. Other meetings are free and informal discussion.

What is peer mentoring?

Other than the Support Group, several patients who are on the path to recovery volunteer their time and act as Mentors to give a friendly and supportive voice to others. We hear again and again that only someone who has first-hand experience ‘can truly understand’.

All our Mentors are accredited to TWH and have had full training through the hospital. They can really make a difference.

They are available by phone, by e-mail or in person to provide friendship, advice and support through the process of recovery. They can also meet with the families of patients.

For more information on the Support Group and Peer Mentoring, please see the pamphlet that comes with this manual for times, locations and contact information.
Other useful information

For families and visitors from out of town

Toronto Western Hospital staff will be happy to help with any questions you might have. Here is a short list of what’s most important:

- If you need help finding a place to stay while in Toronto, ask the social worker or ward clerk for our list of places to stay near the hospital or check our website www.uhn.ca.
- Visit the Patient & Family Library on the 1st floor near the West Elevators. A computer is also available there for short-term use. Visit www.uhnpatienteducation.ca.
- Visitor parking is located in parking lots off Leonard Ave. and Nassau Street.
- A free shuttle bus service between Toronto Western and Toronto General Hospitals leaves each location every 15 minutes between 8:15 a.m. and 5 p.m. and every 30 minutes between 5:30 a.m. and 7:30 a.m. There is no service on weekends or holidays.
- There is a free phone in the main lobby for calling taxis.
- The TTC street car passes the hospital door. It is a single fare system that can get you just about anywhere you might want to go in Toronto. Any TTC subway station can provide you with (free) detailed transit maps.
- Commuter and main line (VIA) trains run from Union station.
- There are places of worship for many denominations within a short distance of the hospital.
- Other hospital services include:
  - Patient Relations (compliments or complaints) at 416-340-4907 or patientrelations@uhn.on.ca
  - Security and Lost Items at 416-340-4111
  - Volunteer Services at 416-603-5800 ext. 6125 or email volunteering@uhn.on.ca

What if I have other questions?

- Talk to your family doctor
- Call Tele-health Ontario (1-866-797-0000) or go to their website www.health.gov.on.ca/en/public/programs/telehealth
- Talk to our Toronto Western Hospital Nurse Practitioner
- Talk to your neurosurgeon at your follow-up visit
- Ask to be connected to a TWH Peer Mentor (details in the enclosed pamphlet)
- Come to our monthly AVM/Aneurysm Support Group at TWH (details in the pamphlet)
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Visit our website at: brainavm.com (no ‘www’ needed)