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McGill University Health Centre

Office d'éducation des patients
Patient Education Office

The MUHC Patient Education Office: Patient Engagement through Understanding

Nancy Posel N, PhD (Ed), Julia Thomas N MS c (a), Emily Churchill-Smith MA

Focus/Objectives

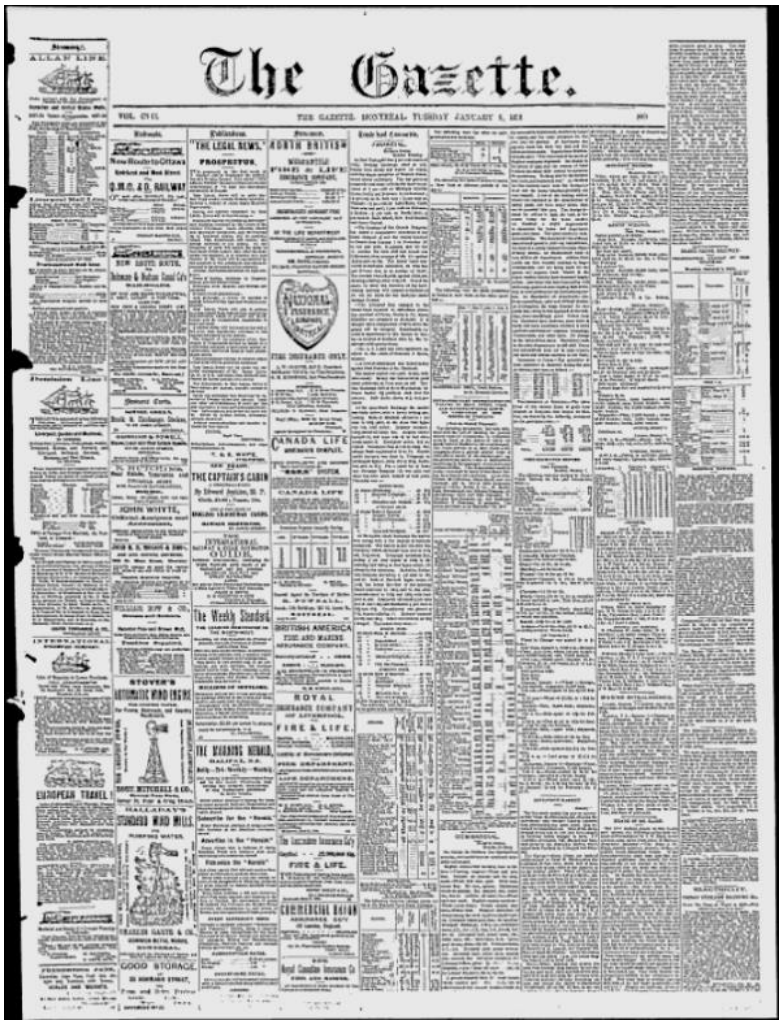
- ✓ Literacy
- ✓ Health Literacy
- ✓ The MUHC Patient Education Office
  - ❖ Rationales, mandates
  - ❖ Our development process
- ✓ Discussion

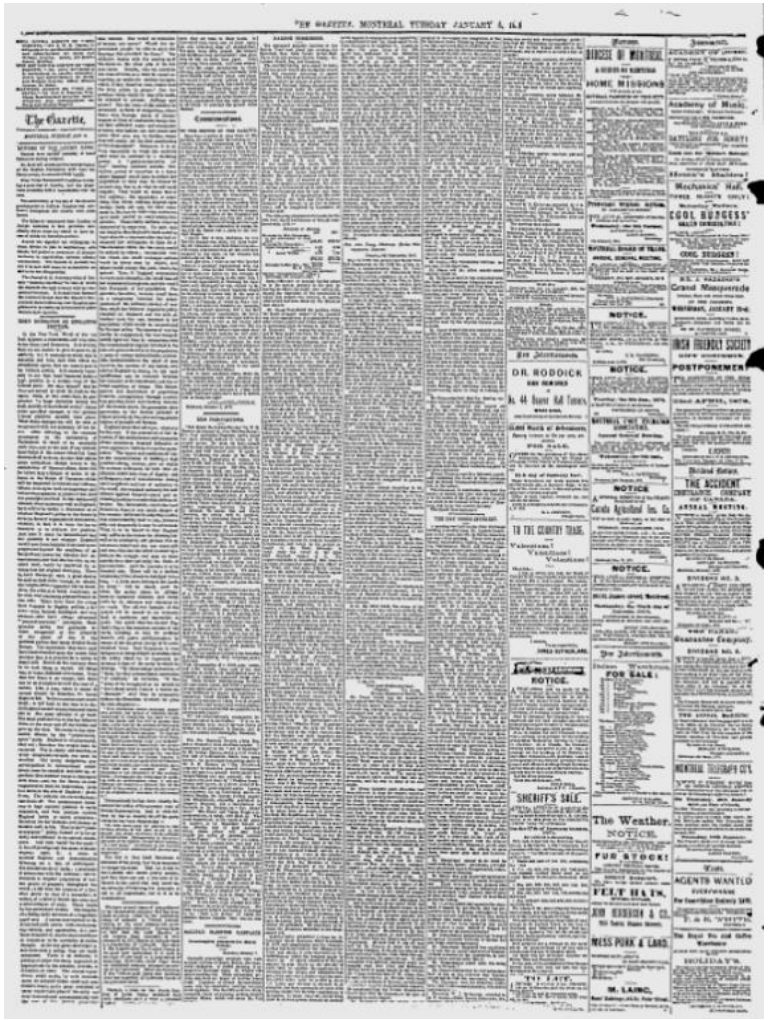
Literacy

". . . the ability to i***dentify, understand, interpret, create, communicate*** and ***compute***, using printed and written materials associated with varying contexts. Literacy involves a continuum of learning to enable an individual to achieve his or her goals, to develop his or her knowledge and potential, and to participate fully in the wider society."

United Nations Educational, Scientific and Cultural Organization (UNESCO) 2003

Situating Literacy:
The Montreal Gazette January 8, 1878


The Gazette.



Situating Literacy:
The New York Times September 23, 2016

NATIONAL COMMENTARY

Allison Jane Smith: Trump speaks like a sixth-grader. All politicians should.

By Allison Jane Smith

In March, a Carnegie Mellon University study confirmed what any casual observer of the primaries knows: Donald Trump uses the simplest language of the candidates, and Sen. Bernie Sanders the most complex.

The study received widespread media coverage. A Washington Post headline declared: "Trump's grammar in speeches 'just below 6th-grade level,' study finds," while New York magazine posted a video with the smirking caption "Donald J. Trump has the grammar of an 11-year-old. That's not opinion. That's research-proven."

New York magazine's video called Trump's low-level readability "a little bit mind-blowing." It also showed a clip of Clinton stating, "Tonight it is clearer than ever that this may be one of the most consequential campaigns of our lifetimes."

According to the Flesch-Kincaid index, the most widely used test to assess readability, Clinton's sentence is at a 10th-grade reading level. It has the same meaning if edited to "Tonight it is clear this may be one of the most important campaigns of our lives," a simpler sentence at a sixth-grade reading level. In this case, simpler language does not equal less meaning. It equals better comprehension.

Health Literacy

"Things should be made as simple as possible, but not simpler"
Albert Einstein

Complex material

Moving towards Clarity and Understanding

Health Literacy

The degree to which individuals can *(or have the capacity to)* **obtain, process and understand basic health information** and services they need to make appropriate health decisions.

Institute of Medicine's report Health Literacy: Prescription to End Confusion (2004)
The U.S. Department of Health and Human Services' Healthy People (2010)

Patients often misinterpret or do not understand information provided by their healthcare professionals.

Baker et al, 2000

Prevalence of Low Health Literacy

- In Canada:

  60% of adult Canadians do not have the necessary skills to manage their health adequately

  Canadian Council on Learning (2008)

- In the United States:

  12% of adults had proficient health literacy

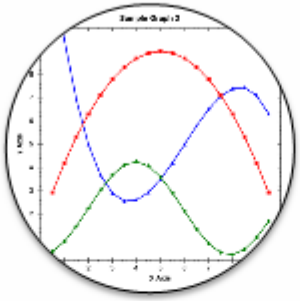
  47% could read instructions on a prescription label and determine what time a person should take the medication

  U.S Department of Health & Human Services

Health Literacy

Prose

Read, understand, and use information from printed material



Document

Interpret and use information from charts, graphs & forms

Numeracy

Apply mathematic operations to numbers in printed material

Problem-solving

Apply planning and analytical reasoning to reach a defined goal

Courtesy of E. Davis, N. MSN

The Cost of Low or Limited Health Literacy

- ✓ Health care costs are projected to be 4 times higher for people with low literacy skills than those with higher literacy skills.

- ✓ It is estimated that health literacy problems cost the US health care system between $106 and $238 billion dollars annually

- ✓ Patients with low literacy skills were observed to have a 50% increased risk of hospitalization compared with patients who had adequate literacy skills

National Patient Safety Foundation (2012). *Health Literacy: Statistics at-a-glance.*

The Impact of Low or Limited Health Literacy

Poorer health and increased risk of mortality among seniors

Higher rate of hospitalizations and medical costs, *increased use* of emergency and inpatient services

Lower uptake of preventive services, *reduced adherence* with treatment and medication errors, and higher incidents of *adverse* medical outcomes

Less effective management of chronic disease

The most vulnerable populations are seniors, immigrants and the unemployed

Our Clinical Reality

Our Patients

Aging demographics, chronic diseases, multi-morbidities, multilingual, multicultural

Need to synthesize complex information

Learning during crisis, stress, often higher anxiety and lower retention

Fewer 'teaching moments' and information as well as misinformation on the Internet

Low literacy/health literacy

Increased requirement for self-care

Changes to Healthcare Delivery

Fragmented health delivery models, dehumanisation

Technological advances in care

Austerity measures – no budget for education; staff shortage

Shorter or no inpatient stays ; same day or early discharge post surgery

The need to teach with less time and resources, lack of confidence

Increased complexity of home/community care

The MUHC Patient Education Office

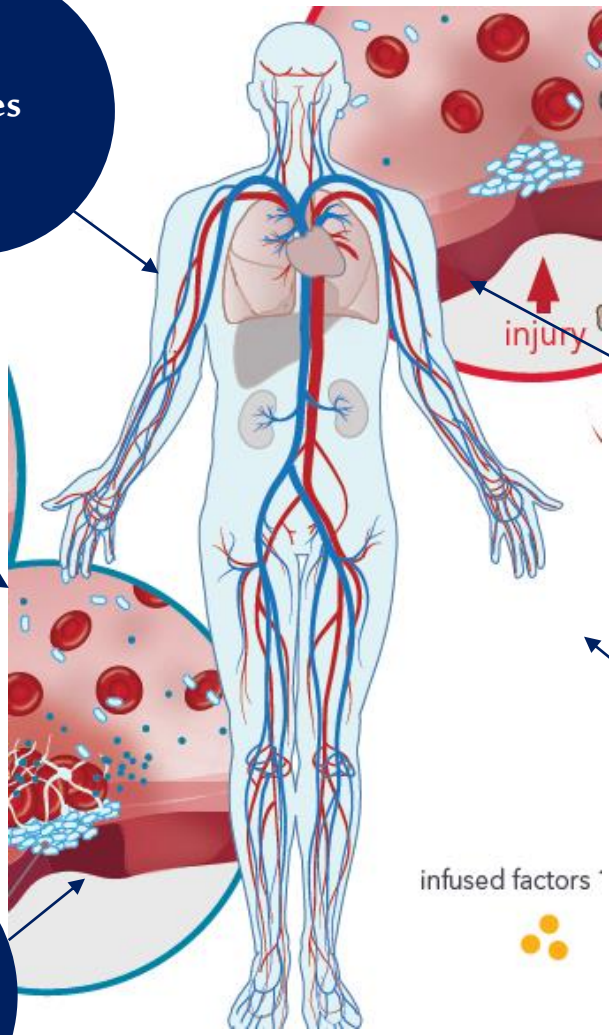
"Everyone has the right to understand."

- ✓ *Information* to support understanding of complex healthcare concepts
- ✓ Collaboration with the clinical team leading to *shared and informed decision-making*
- ✓ Knowledge to assure quality *self-care management*
- ✓ Ability to *determine when to call the healthcare team* and when to return to the hospital
- ✓ Awareness of the importance of *adhering to care regimens*
- ✓ Help *navigating the system*

The MUHC Patient Education Office

- ✓ Work with clinical care teams
- ✓ Design and creation of materials
- ✓ Health literacy consultation
- ✓ Writing resources
- ✓ Plain language and Readability
- ✓ Design, layout and image
- ✓ Multiple language versions

The MUHC Patient Education Office



Images

Evidence

Pedagogy

Clinical Experts

Patient feedback

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Our Development Process: The Clinical Expert

What causes Parkinson's?

Parkinson disease results from the gradual dysfunction and eventual death of nerve cells (also called neurons) in the brain. This process is often termed neurodegeneration, and is similar to aging. Perhaps a simple way to think of Parkinson's is that as ***all*** of us age, cells in our bodies work less efficiently, become unwell, and eventually die. In Parkinson's, some areas of your brain are aging faster than the rest of you.

In most people, the aging process of Parkinson's starts in certain areas at the base of the brain (called the brainstem), as well as olfactory areas and some nerve cells outside the brain. This can cause changes in your sense of smell, your sleep, or your bowels and bladder. Over time, the Parkinson's spreads to involve other regions. An area called the *substantia nigra* in the brainstem is the most critical region for motor symptoms. The cells in this area release a chemical called dopamine. Dopamine sends messages from the brain to other parts of the body to help start and maintain movement. As these nerve cells become sick, dopamine production decreases, and your movements become impaired. By the time you were diagnosed with Parkinson's, 30-60% of the cells in the substantia nigra were already impaired. Other areas of your brain might have had disease even longer. So, your disease has probably been with you for many years.

Although we understand a lot about the causes for Parkinson's, the exact cause for the faster aging of the brain in Parkinson's is not known. We do know that your affected brain cells contain an abnormal buildup of a protein called alpha-synuclein. These deposits are referred to as Lewy bodies. This is thought to result from the cell's inability to properly process this protein. An abnormal increase in levels (or impaired processing) of synuclein is clearly important in the development of Parkinson's, but is probably not the only factor causing disease.

Our Development Process: Pedagogical Expert

What is happening in my body?

Your body is made up of **cells**. These cells are the building blocks that make up the tissues and organs of your body. As all of us age, the cells in our bodies age as well. They do not work as well, become sick, and eventually die.

In Parkinson's disease, some areas of your brain are aging faster than the rest of your body. These brain cells (called **nerve cells** or **neurons**) stop working properly over time. Eventually, they die. We call this **neurodegeneration**.

For most people, Parkinson's aging starts in certain areas at the base of the brain (the **brainstem**), as well as in some nerve cells found outside the brain. Over time, Parkinson's spreads to other parts of the body. Aging cells in these areas can cause changes in your sense of smell, your sleep, or your bowels and bladder.

One part of the brainstem (called the **substantia nigra**) is an important area that controls how you move. The cells in this area release a chemical called **dopamine**. Dopamine sends messages from the brain to other parts of the body to help you move. As nerve cells become sick, the body makes less dopamine. This makes body movement more difficult over time.

By the time we know that you have Parkinson's disease, you would likely have had it for many years. For this reason, a good amount of the **substantia nigra** may no longer be working. Other areas of your brain may have also been affected.

Parkinson's disease experts have also noticed that brain cells, affected by Parkinson's, contain an unusually large build-up of a protein (**alpha-synuclein**). We know that these proteins are important in the development of Parkinson's. However, it is not clear why this build-up happens.

Comment [JT12]: We will definitely have images here, which will help enhance readability in this section.

Comment [JT13]: I felt I had to separate this content out from etiology. This pathophysiology content is more an extension of the "what is?" It seems.

Comment [JT14]: We need to take a step back. Not everyone may know what a "cell" (let alone neuron) is.

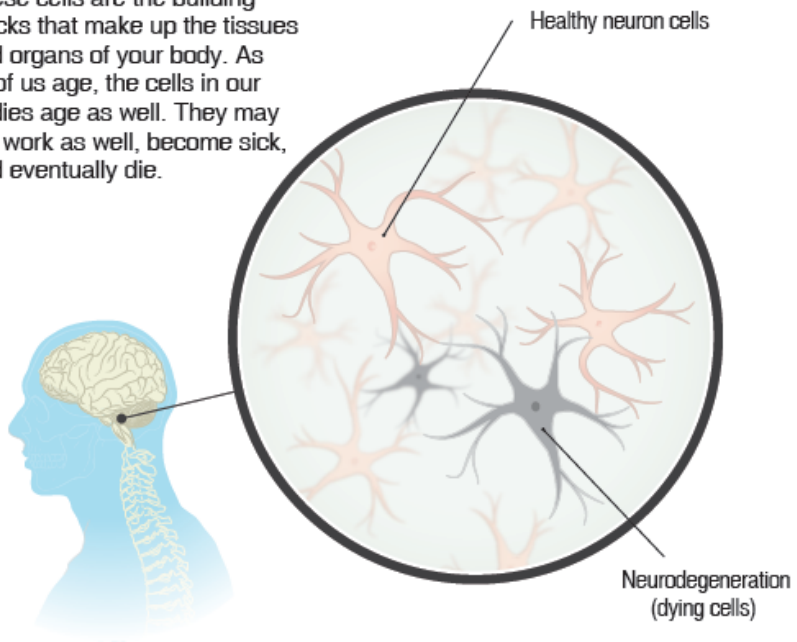
Comment [JT15]: Is this detail (30-60%) necessary?

Comment [JT16]: I took out the extra detail you had here referring to Lewy bodies. While this is your passion, patients/families may be overwhelmed by too many details at this point. With this in mind, especially in sections such as these, you need to parse out "nice-to-know" from "need-to-know" details. If understanding of Lewy bodies at this point is important to treatment adherence and patient disease management, I would suggest this is a "need-to-know" detail. Otherwise, you may want to exclude it.

Our Development Process: The Artist

What is happening in my brain and body?

Your body is made up of cells. These cells are the building blocks that make up the tissues and organs of your body. As all of us age, the cells in our bodies age as well. They may not work as well, become sick, and eventually die.



In Parkinson's disease, some areas of your brain are aging faster than the rest of you. So, certain nerve cells (also called **neurons**) stop working properly over time. Eventually, they die. We call this **neurodegeneration**.

For most people, Parkinson's aging starts in areas at the base of the brain (the brainstem), as well as in some nerve cells found outside the brain. Over time, it spreads to other parts of the brain.

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Our Development Process: The Artist

What movement changes might I see?

There are 4 main types of changes in body movement that we see in Parkinson's disease:

1. Slow movement
(We call this "bradykinesia".)

Your hand, leg, and face movements become slower and smaller than before. You or your family members may also notice that your voice is softer or quieter. You face may become less expressive (or "masked"). Your handwriting may become slow and small. You may have fewer spontaneous movements. (These are the many, natural movements that you make throughout the day, without much thought.) Routine activities, such as dressing and showering may take longer than they used to.

2. Shaking (tremor)

You may notice that your hands, legs or jaw are shaky. This typically happens when arms or legs are resting. (For example, your hands might shake when rested in your lap or while walking). Shaking often gets more noticeable during stressful situations or if you are tired. Not everyone with Parkinson's disease experiences shaking.

3. Stiffness (rigidity)

You might not be aware of this sign, but your doctor will pick this up during your check-up. Sometimes stiffness can cause muscle aches.

4. Walking and balance problems

Your walking may slow down. You may begin to take smaller steps or shuffle. You might feel unsteady. After some years with Parkinson's disease, some patients have episodes where their legs briefly get stuck in place, or they can lose their balance and fall.

Along with movement changes, **you may also notice other (non-motor) changes**. These could include difficulty sleeping, loss of smell, problems urinating, constipation, mood changes, trouble swallowing, pain, feeling tired, or troubles with memory. Many of these changes may have started before you notice changes in how you move. **(For more information, see Section 3 of this guide.)**

Parkinson disease is a chronic illness. This means that it continues over a long period of time, and develops slowly. The good news is that we know quite a lot about Parkinson's. While there is no cure yet, many of the changes and health problems that come with the illness are now treatable. Treatment can ease and help control many of these health problems.

Our Development Process: The Clinical Expert

What will happen when you get your RIG put in?

- A small needle will be used to place a small tube in your vein for medicine and fluid.
- A long thin tube will be placed through your nose into your stomach.

You will go to the X-ray department. Once in the X-ray department you may be asked again if you fully understand the procedure. **You will be asked to sign a 'consent' form.**

The RIG will be put in by a special doctor called an "Interventional Radiologist".

You do not need to be 'put to sleep' for this procedure. A medication may be used to help you relax and they may also give you some pain medication. . These are given through the small tube in your hand or arm.

You have to lie flat on your back on the X-ray table (insert picture of person lying flat). The staff will be checking your breathing. You might get oxygen through a small tube in your nose.

- The doctor will clean your skin, then freeze it with an injection.
- Your stomach will be filled with air.
- 2 or 3 buttons attached to stitches will be placed to keep your stomach in place.

Comment [jg3]: This concept consistently gets criticized-not clear. We either need a picture or need to elaborate.

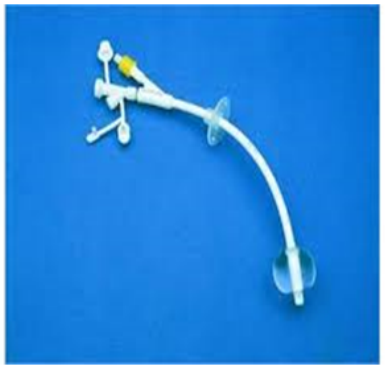
Our Development Process: Pedagogical Expert

MUHC logo to be inserted

Introduction

This booklet will help you understand the procedure of a feeding tube put in and how it is done. If there is any part of the booklet you do not understand, please ask a member of your healthcare team.

What is a RIG?



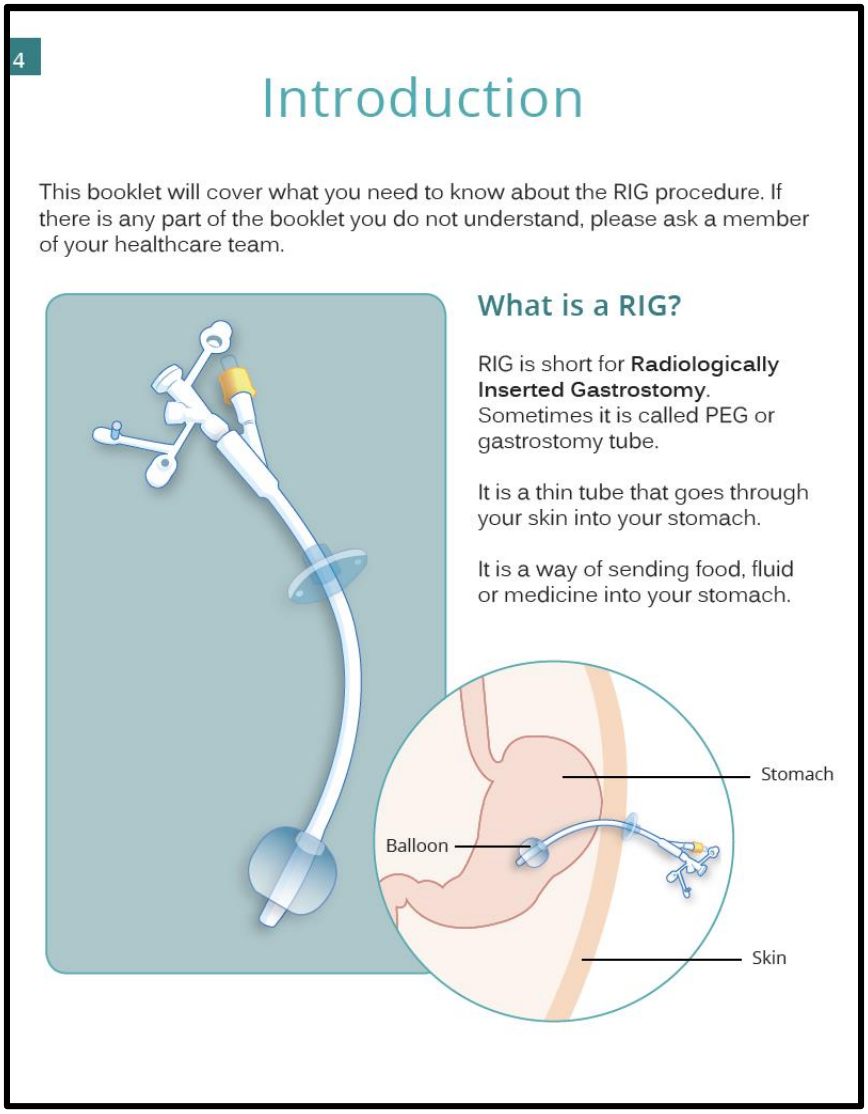
RIG is short for Radiologically Inserted Gastrostomy. Sometimes it is called a PEG or gastrostomy tube.

It is a thin tube that goes through your skin into your stomach. It is a way of sending food, fluid or medicine into your stomach.

Comment [jg1]: Several people suggested putting a picture of the RIG somewhere in document. Radiology suggested the same, with a picture of the balloon and emphasis on its purpose there.

Comment [PCI2]: We will need to put an example of the exactly the kind of illustration we want.

Our Development Process: The Artist



4

Introduction

This booklet will cover what you need to know about the RIG procedure. If there is any part of the booklet you do not understand, please ask a member of your healthcare team.

What is a RIG?

RIG is short for **Radiologically Inserted Gastrostomy**. Sometimes it is called PEG or gastrostomy tube.

It is a thin tube that goes through your skin into your stomach.

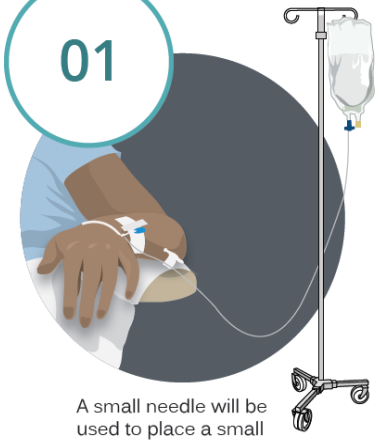
It is a way of sending food, fluid or medicine into your stomach.

Our Development Process: The Artist

15

What will happen?

01



A small needle will be used to place a small tube in your vein for medicine and fluid.

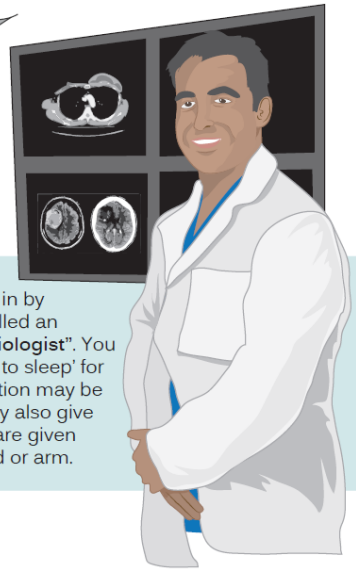
02

A long thin tube will be placed through your nose into your stomach.

16

03

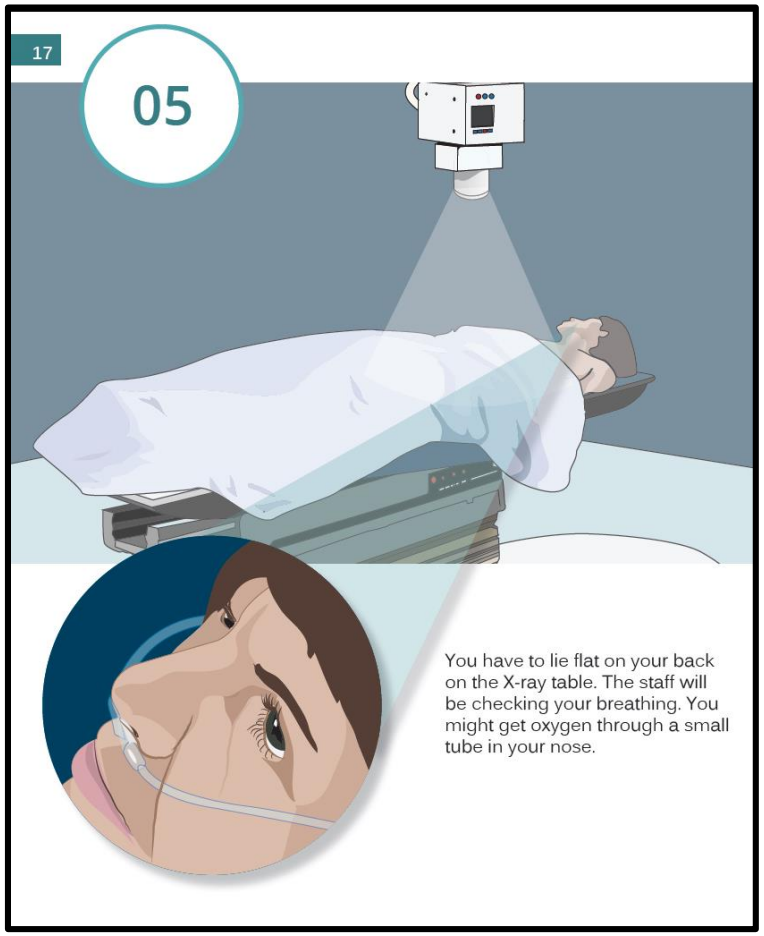
You will go to the X-ray department. Once in the X-ray department you may be asked again if you fully understand the procedure. You will be asked to sign a 'consent' form.

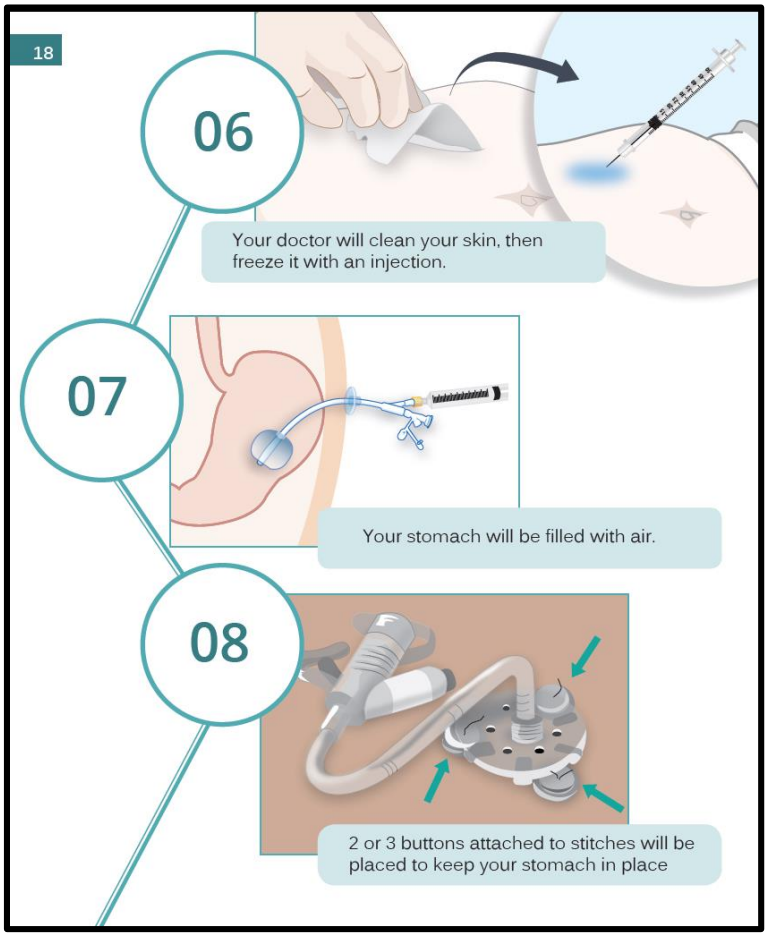


04

The RIG will be put in by a special doctor called an "**Interventional Radiologist**". You do not need to be 'put to sleep' for this procedure. A medication may be used to help you relax and they may also give you some pain medication. These are given through the small tube in your hand or arm.

Our Development Process: The Artist

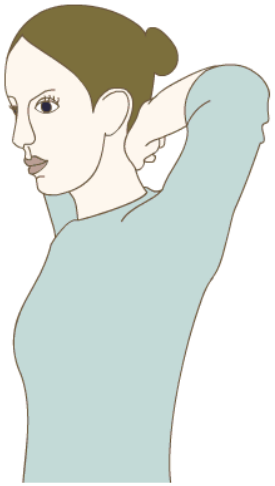




Our Development Process: The Artist

1) Elbows apart

Clasp hands behind your neck and bring your elbows together and then apart as far as possible.



2) Wall climbing

Stand one foot away, facing the wall with arm outstretched in front, use your fingers to walk up until you feel a stretch.

Try and move your arm further each time.

3) Side wall climbing

Stand with affected arm to the wall one foot away and sideways, with arm outstretched, use your fingers to walk up until you feel a stretch.

Try to get higher each day.

Use a pencil to mark your progress.

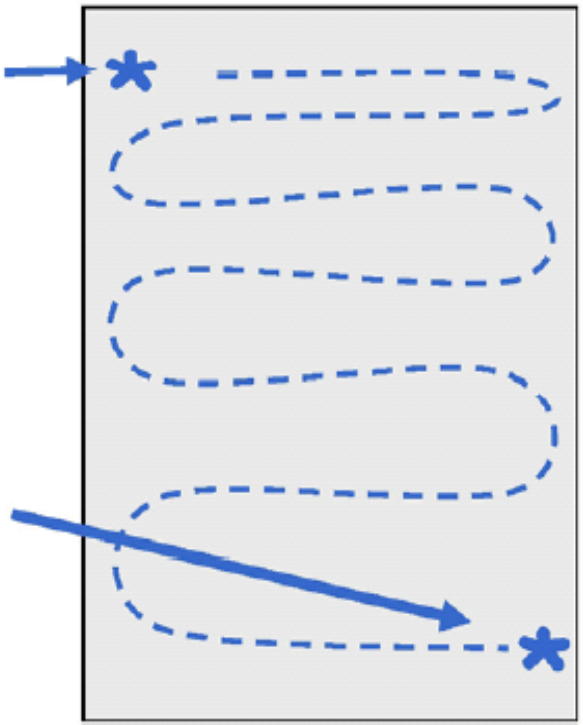
Other Instructional Strategies to Consider

- ✓ Reading Gravity
- ✓ Individualization
- ✓ Format(s)
- ✓ Target our learner
- ✓ Organization/navigation
- ✓ Title/headings
- ✓ Design and Layout
- ✓ Font
- ✓ Media
- ✓ Clarity – health literacy

Reading Gravity

To help readers to notice everything on the page, make your layouts consistent with "reading gravity"

Create a strong point of entry here with a main heading or strong visual.



Don't give readers a reason to jump down here first, or they may move on, overlooking other parts of the page.

Create a clear and obvious path through the page.

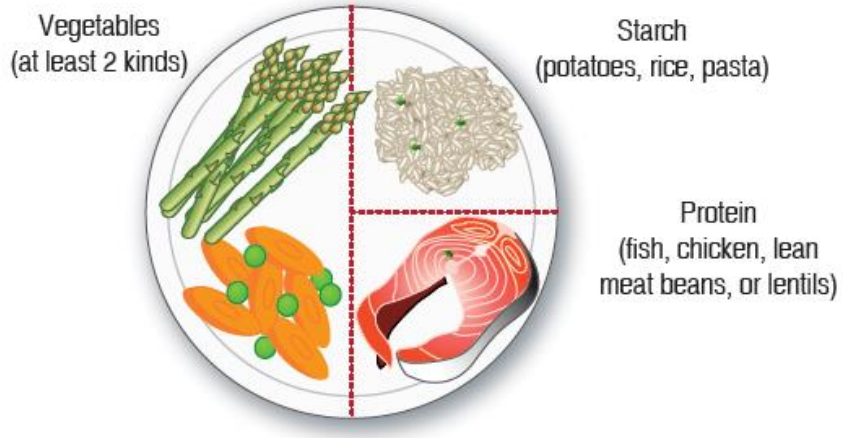
- Place the text and visuals in a way that fits with a reader's typical pattern of moving back and forth and down the page.
- Since strong visual elements draw readers' attention, creating a clear path helps readers notice the text as well as the visuals.

US Department of Health and Human Services (2010)

Reading Gravity

HEALTHY EATING IS A KEY FACTOR IN YOUR DIABETES MANAGEMENT

Your doctor will ask you to see a dietitian to come up with a plan just for you, and to follow up with you.



The glucose (sugar) in your blood comes mainly from carbohydrates in food we eat. You should not eliminate all carbohydrates

1. Make a healthy choice,
2. Spread carbohydrates evenly over at least 3 meals

Individualization

Use strategies to support individualization:

- ✓ Use empty spaces in the material so that you can fill in the blanks (for key information that is specific to a particular patient)
- ✓ Integrate a teaching notes pages
- ✓ Include places to add the patient’s name, the clinician's name, your contact information

Individualization

Members of your care team:

Your Neurosurgeon:

Name: _____

Office Phone Number:_____

Follow-up Appointment:_____

Location:_____

Your Nurse:

Name: _____

Phone Number: _____

Other specialists involved in your care:

Name: _____

Appointment date: _____

Name: _____

Appointment date: _____

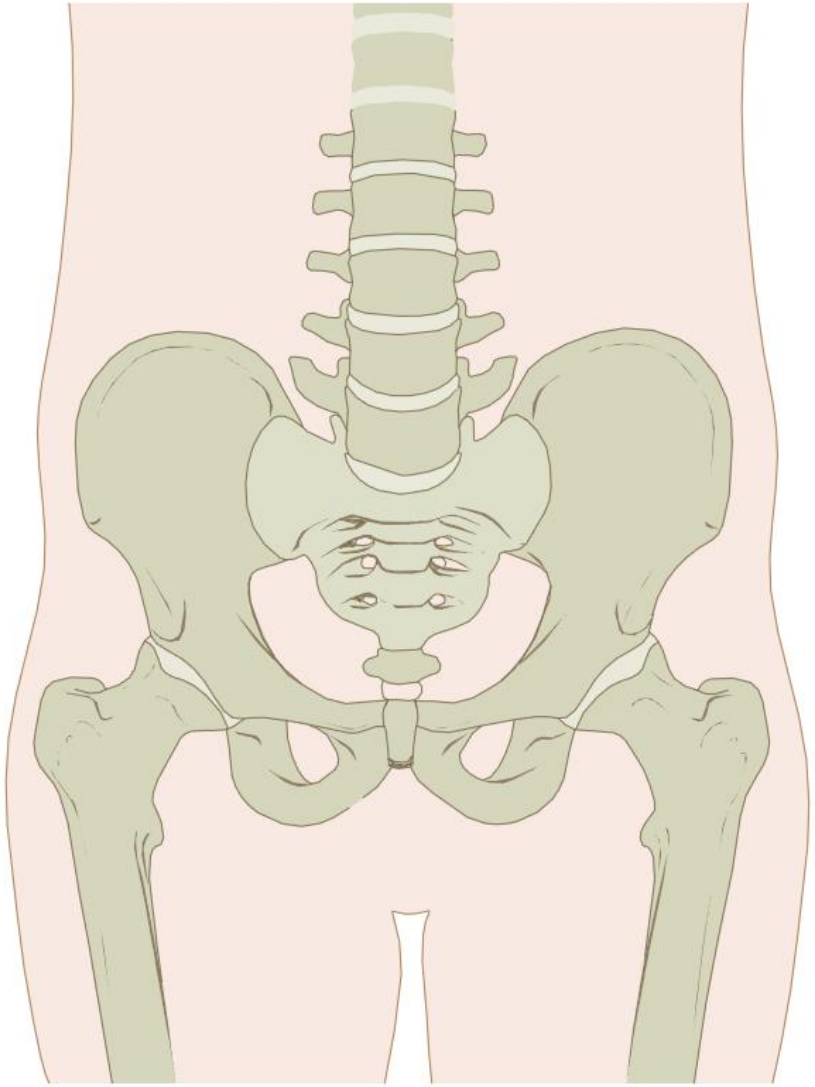
Name: _____

Appointment date: _____

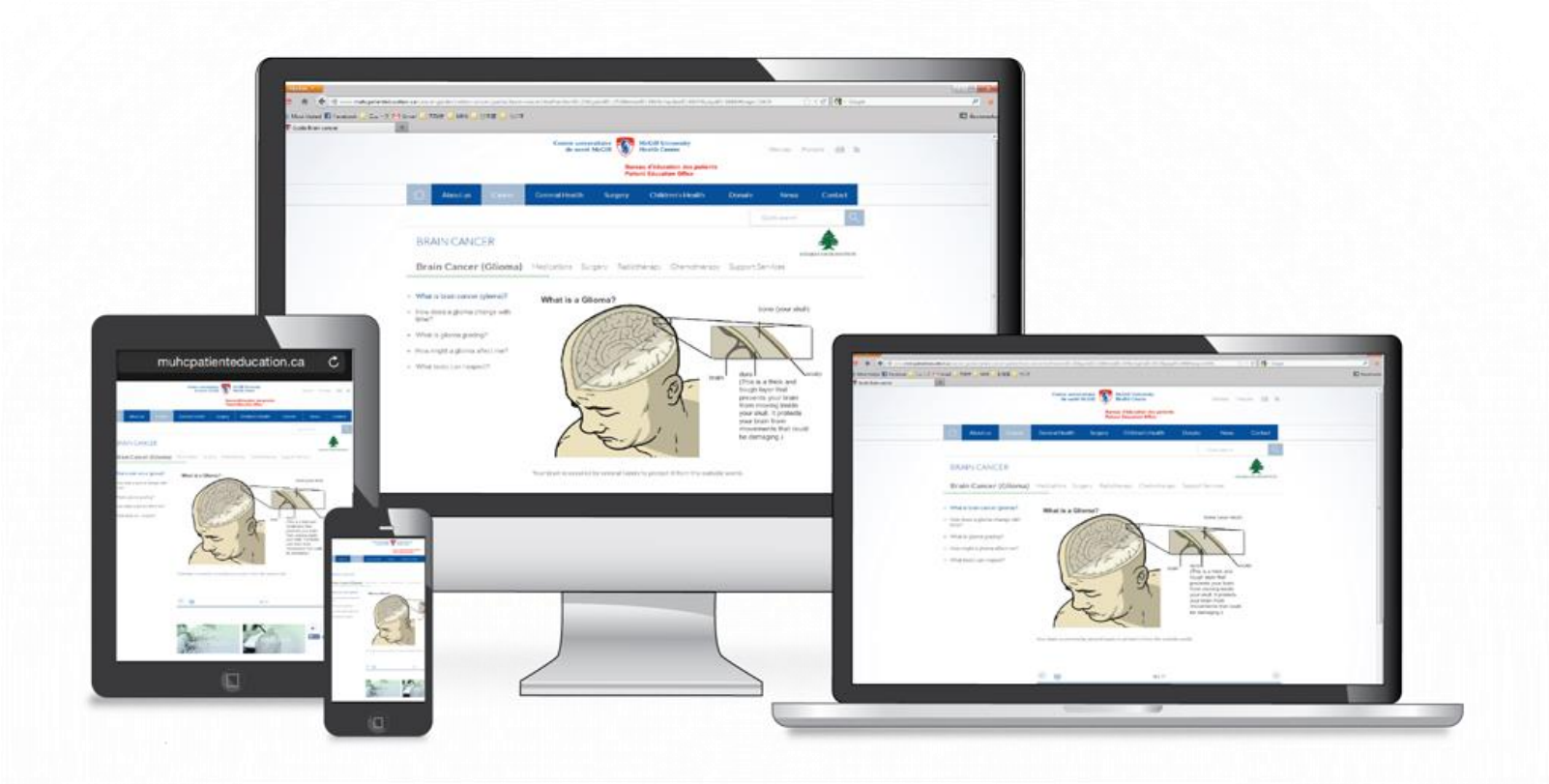
Individualization

NOTES :

Individualization



Formats
Examples: Interactive Module



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Examples: Patient Manuals

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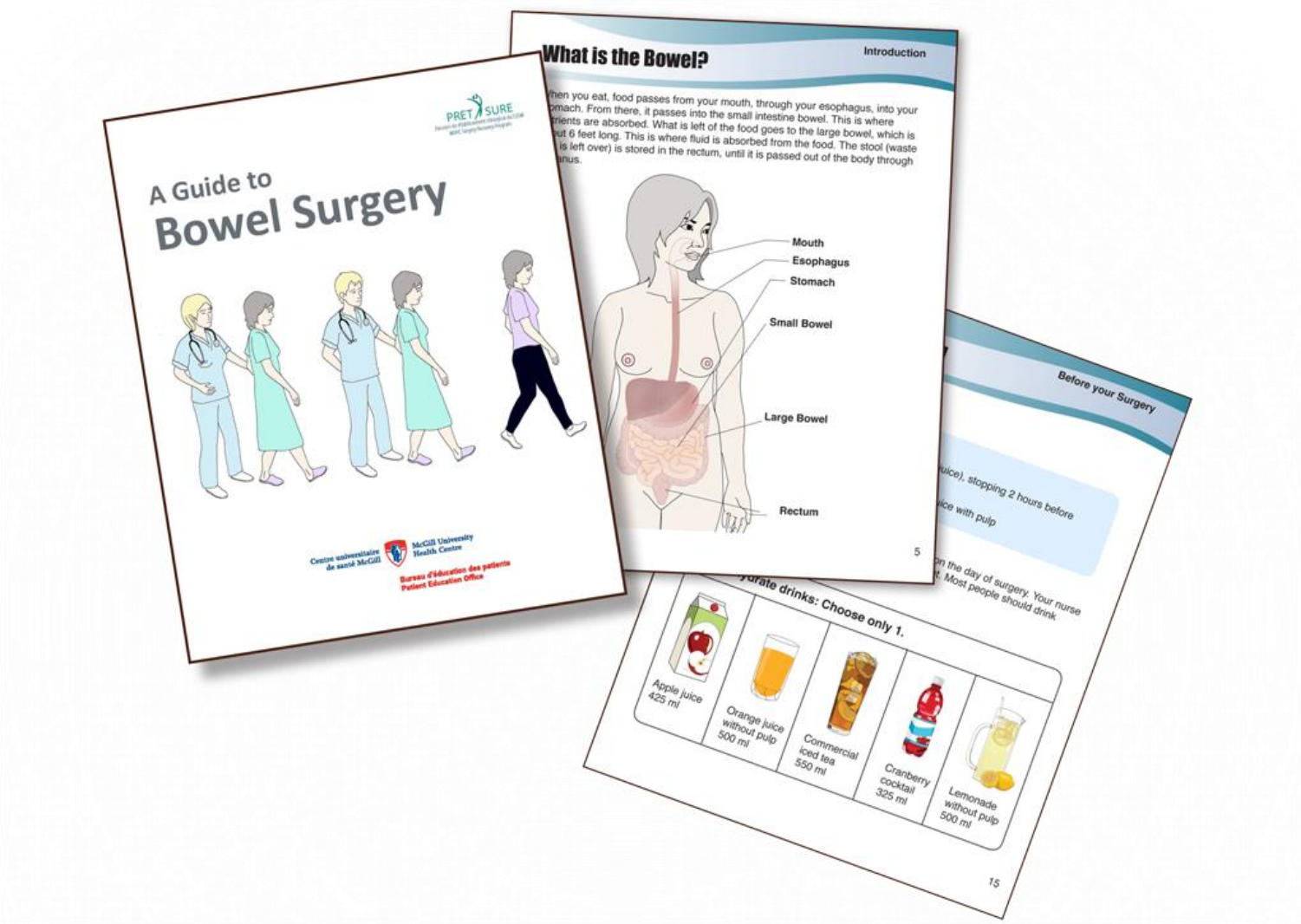
Examples: Booklets



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Examples: Small Booklets

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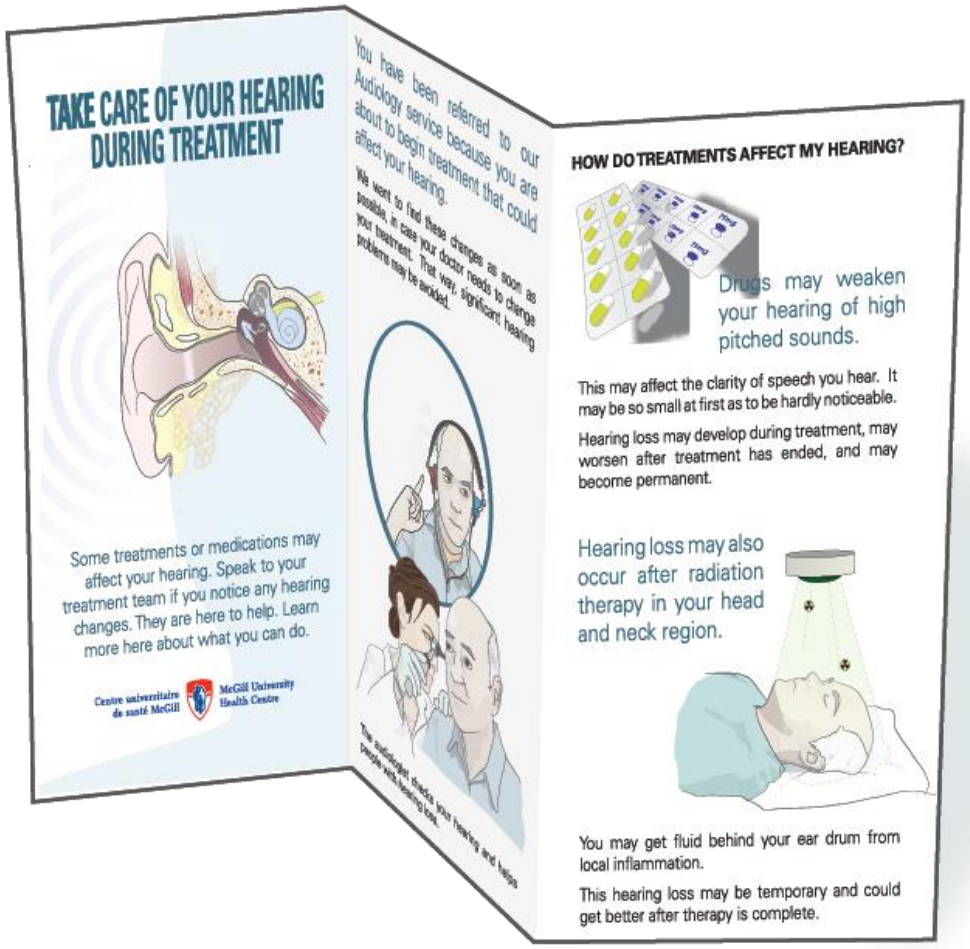
Examples: Pamphlets



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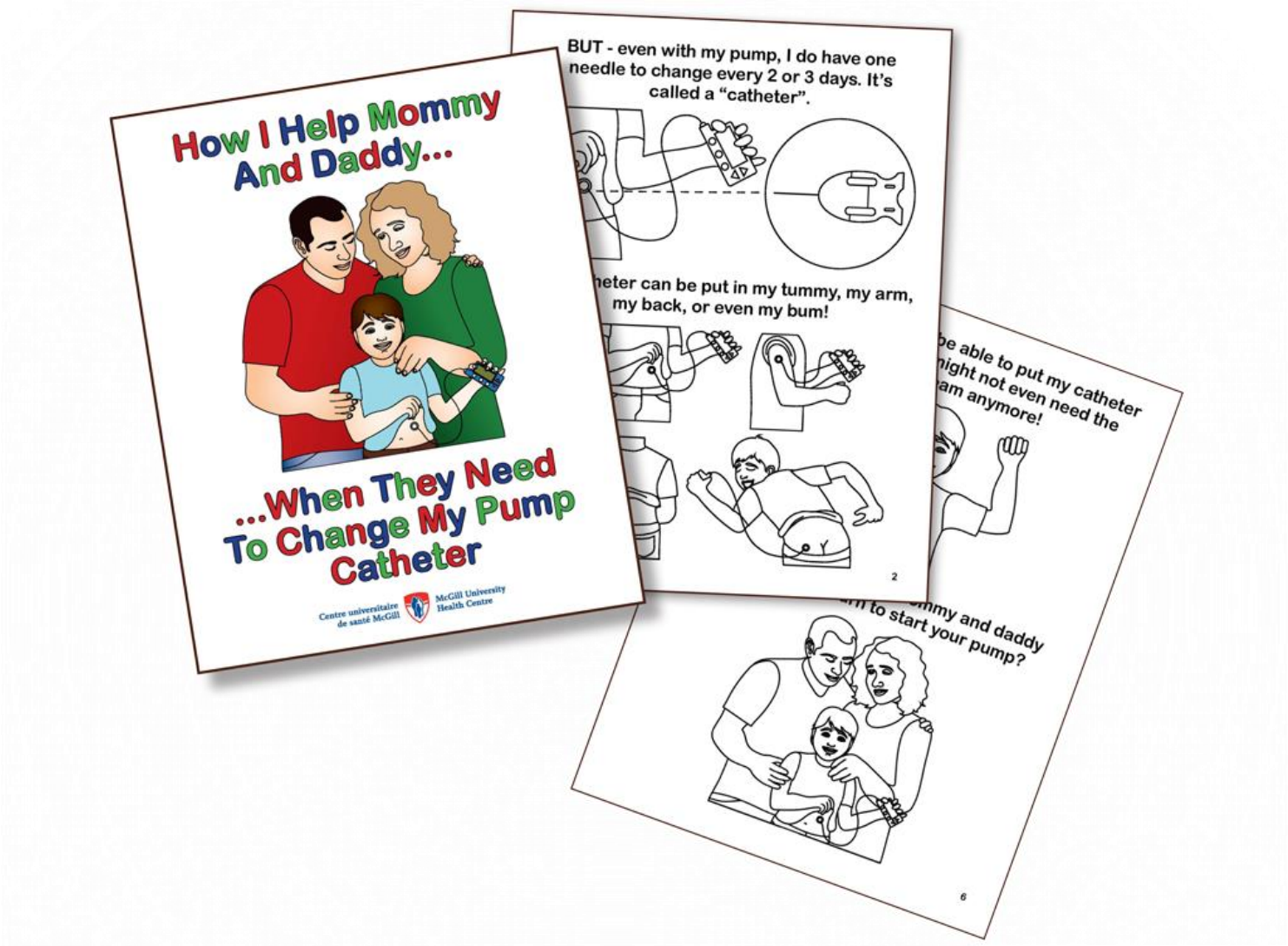
Examples: Colouring Books



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Examples: ER Information Sheets

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Vaginal Bleeding in early Pregnancy

Office d'éducation des patients du CUSM
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This material is also available on the
MUHC Health Education Collection (http://infotheque.muhc.ca/)
MUHC Patient Education Office (www.muhcpatienteducation.ca).

This material was developed by the McGill University Health Centre Emergency Department.

What is wrong?

It is relatively common for women to experience light vaginal bleeding (spotting) in early pregnancy. It often stops on its own but in certain cases, it may continue. The pregnancy might be the cause of the bleeding but the bleeding can also be due to other problems.

What should I do at home?

- Monitor the amount of vaginal bleeding you are having. Keep track of how often you change pads and how soaked they are.
- Do not use tampons and do not douche.
- Verify with your doctor if it is safe to have sexual intercourse.
- If you have pain, the emergency doctor might prescribe some medications. Use them as directed.
- Take medication for cramps only with your doctor's permission.

When am I going to feel better?

In most cases the bleeding stops on its own after a few days.

Should I see another doctor?

You will need a follow up with your obstetrician or family physician.

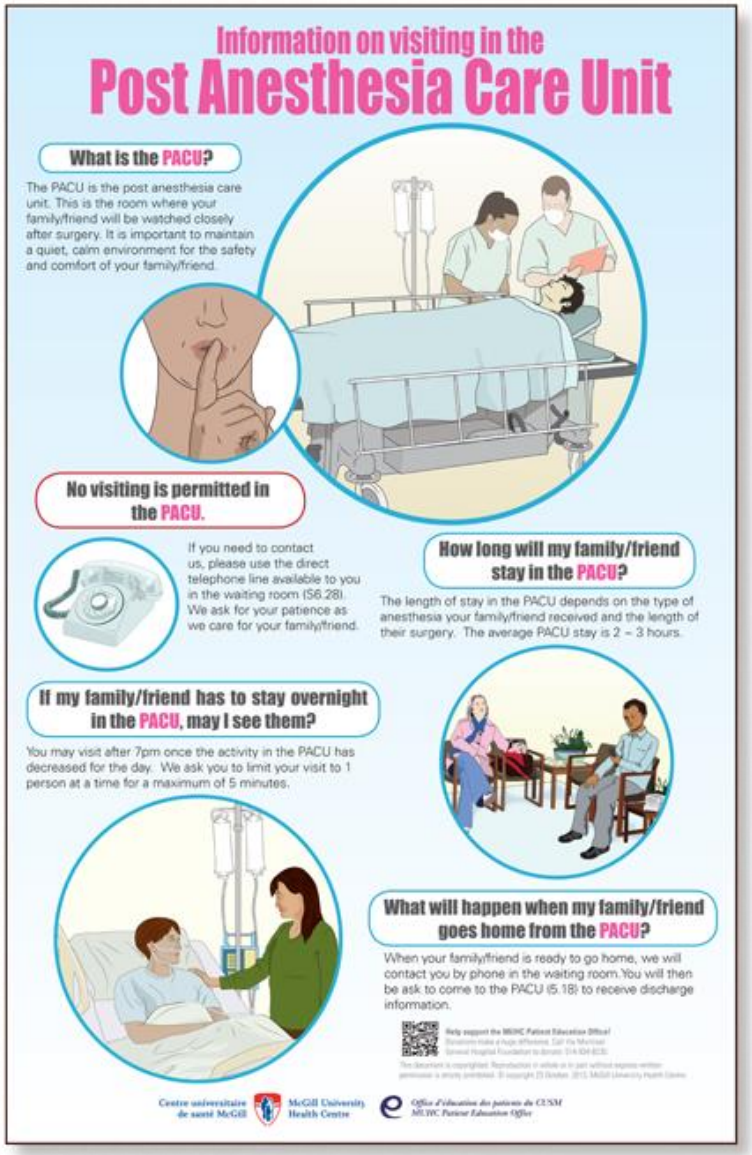
The emergency doctor might schedule you for an ultrasound in the next few days.

When should I come back to the Emergency Department?

You should return right away if you:

- You are experiencing severe abdominal pain or cramps
- You have to change your pads more than 3 times in 3 hours or you pass large clots
- You develop chills or fever (oral temperature above 38°C / 100.4°F)
- You become light-headed, weak or faint

Examples: Posters



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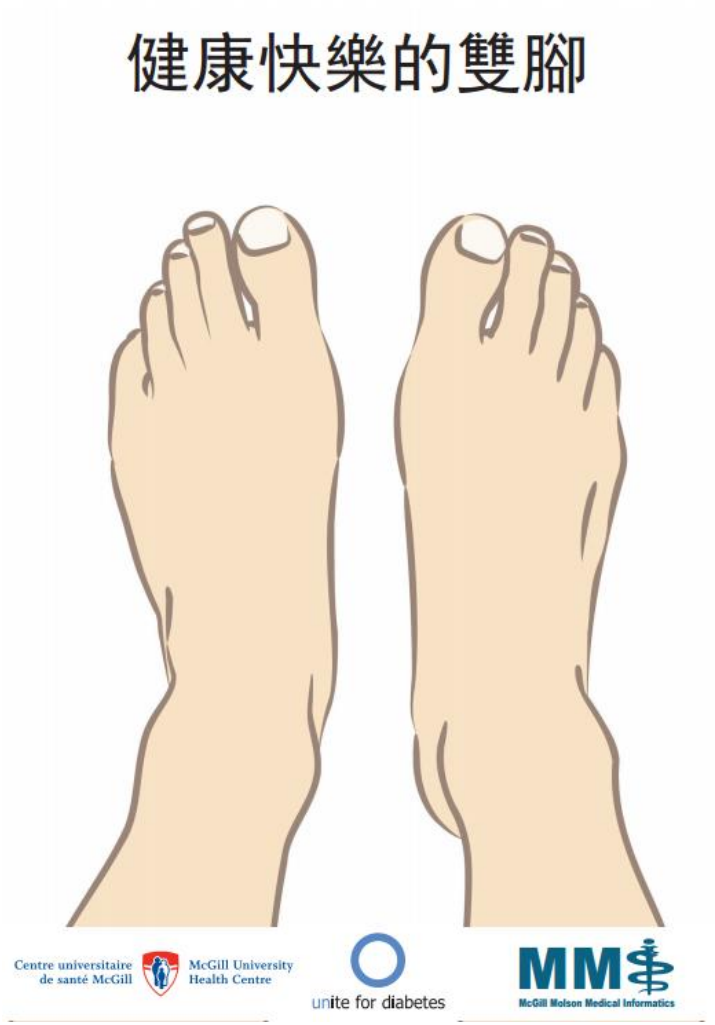
Who is our Learner?

LIVING SAFELY AT HOME

Fondation du Centre universitaire de santé McGill

McGill University Health Centre Foundation

Organization and Navigation



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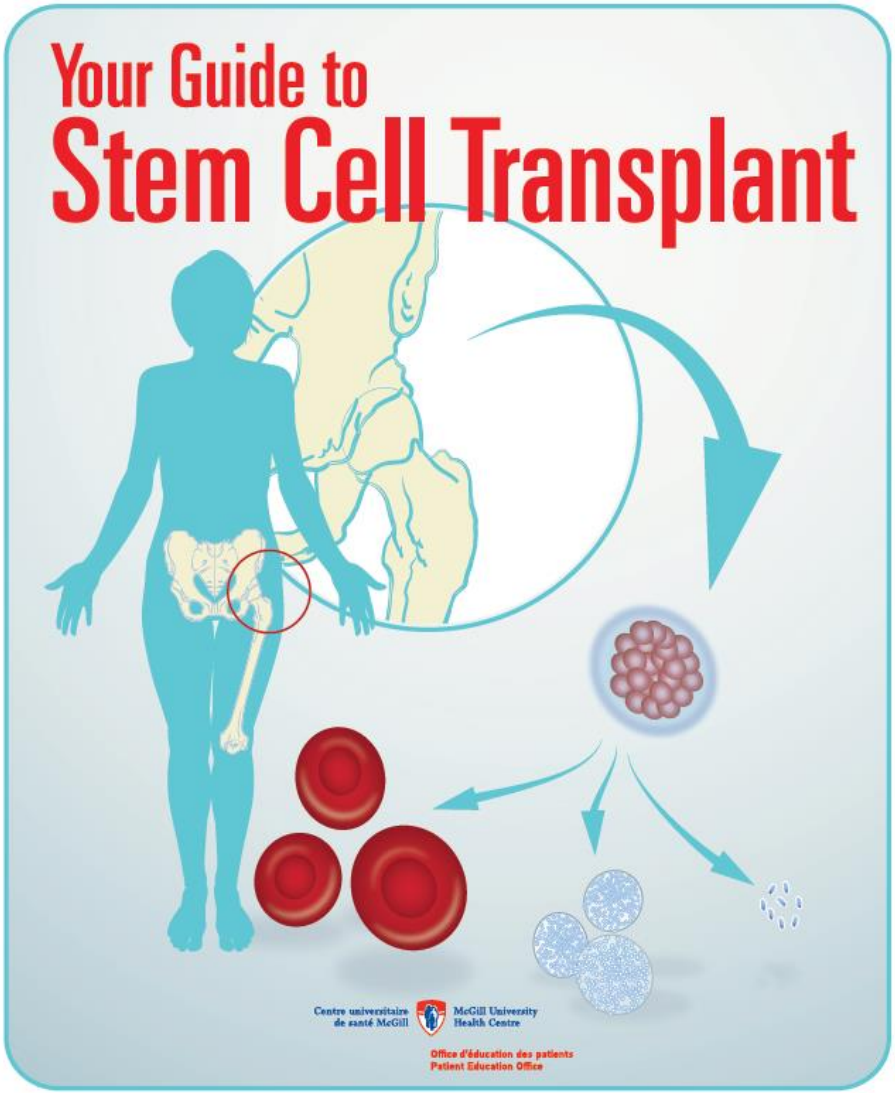
Your Guide to
Stem Cell Transplant
Centre universitaire de santé McGill
McGill University Health Centre
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Patient Education Office

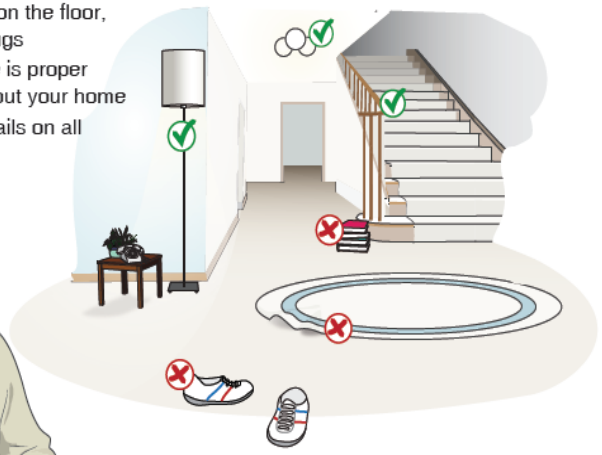
Headings/Design and Layout

What can you do to prevent a fall?

If you have osteoporosis, you are much more likely to break a bone if you fall, so the best way to avoid fractures is to prevent falls. You can prevent falls by:

Making your home safe:

- Remove clutter on the floor, such as loose rugs
- Make sure there is proper lighting throughout your home
- Use solid handrails on all stairways



Wearing sensible shoes:

- Sturdy shoes with non-skid soles are much safer to wear than
- high heels, slippers, or bare stockings

Using mobility aids and assistive devices:

- Consider using a cane or a walker
- Use rubber mats and grab bars in your bath or shower

Exercising regularly:

- Stay active to improve your balance and muscle strength
- You can do your doctor-approved exercises at home or in a group setting

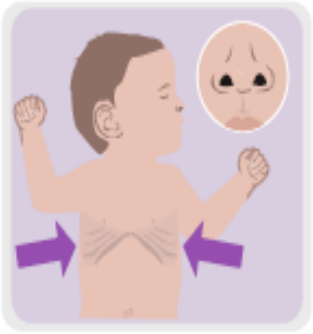
Speaking to your doctor:

- Ask your doctor or pharmacist if any of the medications you take can cause dizziness or sleepiness
- Have your vision and hearing checked regularly

Media

Distended or Enlarged Abdomen

...your child's belly becomes enlarged and feels hard to the touch. This might mean that the blood cells are getting trapped in the spleen, causing it to enlarge. Your doctor will teach you how to feel your child's spleen.



Difficulty Breathing

...your child has rapid breathing, shortness of breath, persistent cough, or chest pain.

Painful penile erection

...your child (boy) develops a painful, penile erection thatcan last a long time (more than 2 hours).

You should also contact us if...

...you notice any of the following symptoms in your child:

If you notice any of these symptoms, your child needs medical care as soon as possible.

Evaluation

- ✓ Evaluation by clinicians for content accuracy

- ✓ Evaluation by patients and families for understanding and clarity

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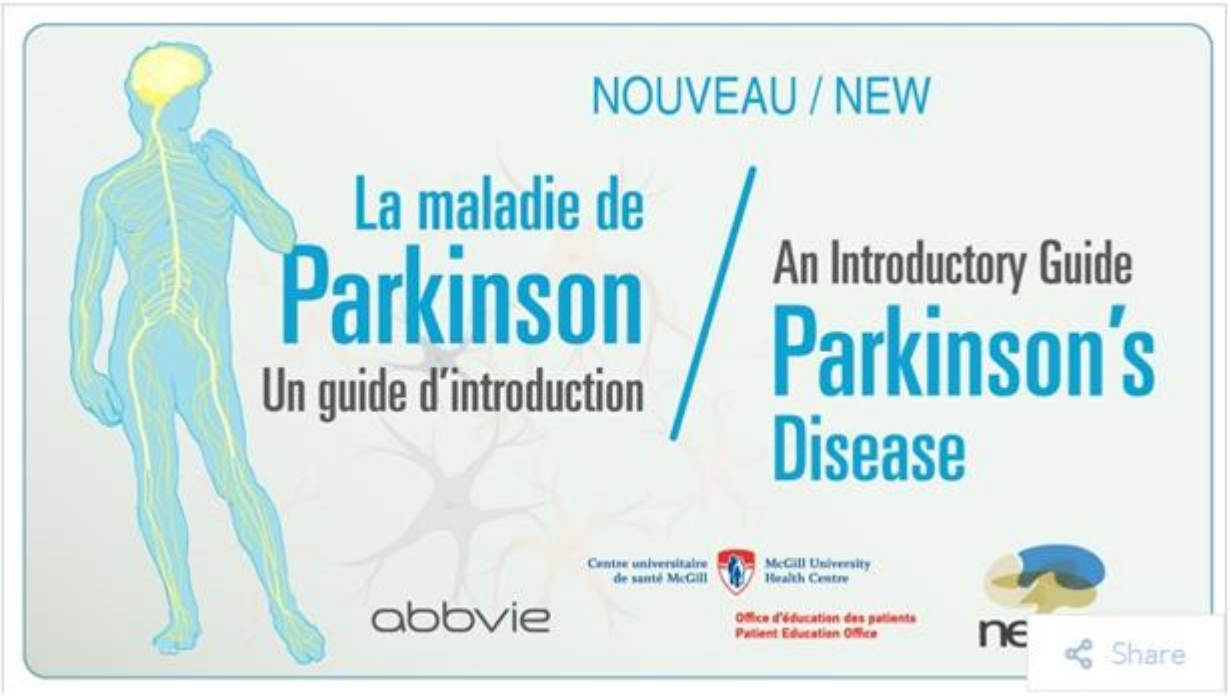

http://www.muhcpatienteducation.ca/

http://www.educationdespatientscusm.ca/accueil.html

Questions?