

Going to the hospital can sometimes feel like you're travelling to a foreign country. Seemingly simple things like knowing what to pack before leaving home or finding your way around once you arrive can be surprisingly complicated. On top of that, the language of hospitals can be confusing - knowing a few basic words can help you stay safe and out of trouble. And then there's all the new people you'll meet - knowing who they are and how to get what you need will make your next trip to the hospital a good one.

Think of this Handbook as your travel guide. It was crafted from the practical know-how of 25 Canadian seniors, who collectively have over 2,000 years of life experience behind them. Through this Handbook, they're passing their wisdom, tips and tools on to you.



FROM PATIENTS WHO KNOW: A HOSPITAL HANDBOOK

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FROM PATIENTS WHO KNOW: A HOSPITAL HANDBOOK

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In memory of June Cooney

Acknowledgements

Between December 2015 and July 2016, a remarkable group of seniors in an apartment building in Kingston, Ontario - affectionately known as Oasis - came together to share common hospital experiences, frustrations and workarounds. And with the help of OpenLab, their collective wisdom was packaged into a book, this book.

We would like to acknowledge the spirited contribution of the following people at Oasis: Mona Atkinson, Lorraine Brightman, Audrey Bucci, Tina Carson, June Cooney, Jane Culling, Jenny Dering, Val Dumais, Shirley Dumais, Norman Fournier, Shirley Greenwood, Mary Hyslop, Katherine Kroff, Pearl Larson, Jean McCready, Mary B. McGrath, Sheila McLeod, Christine McMillan, Tracy Pugh, Lois Richey, Paul Scudamore, Stella Stefan, George Van Vlack and Leota Van Vlack.

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Stuff Patients Want.

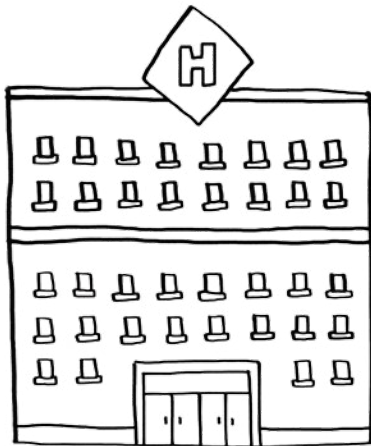
OpenLab is a design and innovation shop dedicated to finding creative solutions that transform the way health care is delivered and experienced. OpenLab brings together patients, clinicians, designers, artists, scientists, engineers and business people to understand health issues from multiple perspectives. Its approach strives to tap into the expressed and unexpressed needs of users to come up with products and services that are effective and a joy to interact with. OpenLab is located at the University Health Network, Canada's largest research hospital.

This Handbook is a product of OpenLab's *Stuff Patients Want* initiative. Stuff Patients Want is a participatory design initiative in which patients come together to share health care experiences they find frustrating. These patients are then armed with the tools (e.g. design, production) they need to bring their practical and inspired solutions to life. Stuff Patients Want is carried out in the Scandinavian participatory design tradition, driven by the idea that the people destined to use a product or service should play a critical role in designing it, and characterized by active collaboration between users and designers throughout the participatory process.



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Welcome

Going to the hospital can sometimes feel like you're travelling to a foreign country. Seemingly simple things like knowing what to pack before leaving home or finding your way around once you arrive can be surprisingly complicated. The wonderful people you meet during your stay can often sound like they're speaking Latin or Greek when describing your condition or treatment - knowing a few basic words can help you stay safe and out of trouble. And you might meet so many new people along the way that it's hard to know who's who, what they all do and how they're connected to one another.

We hope that this Handbook can be your companion during your next visit to the hospital. This Handbook was crafted from the practical know-how of 25 Canadian seniors, who collectively have over 2,000 years of life experience behind them. Through this Handbook, they're passing their wisdom, tips and tools on to you.

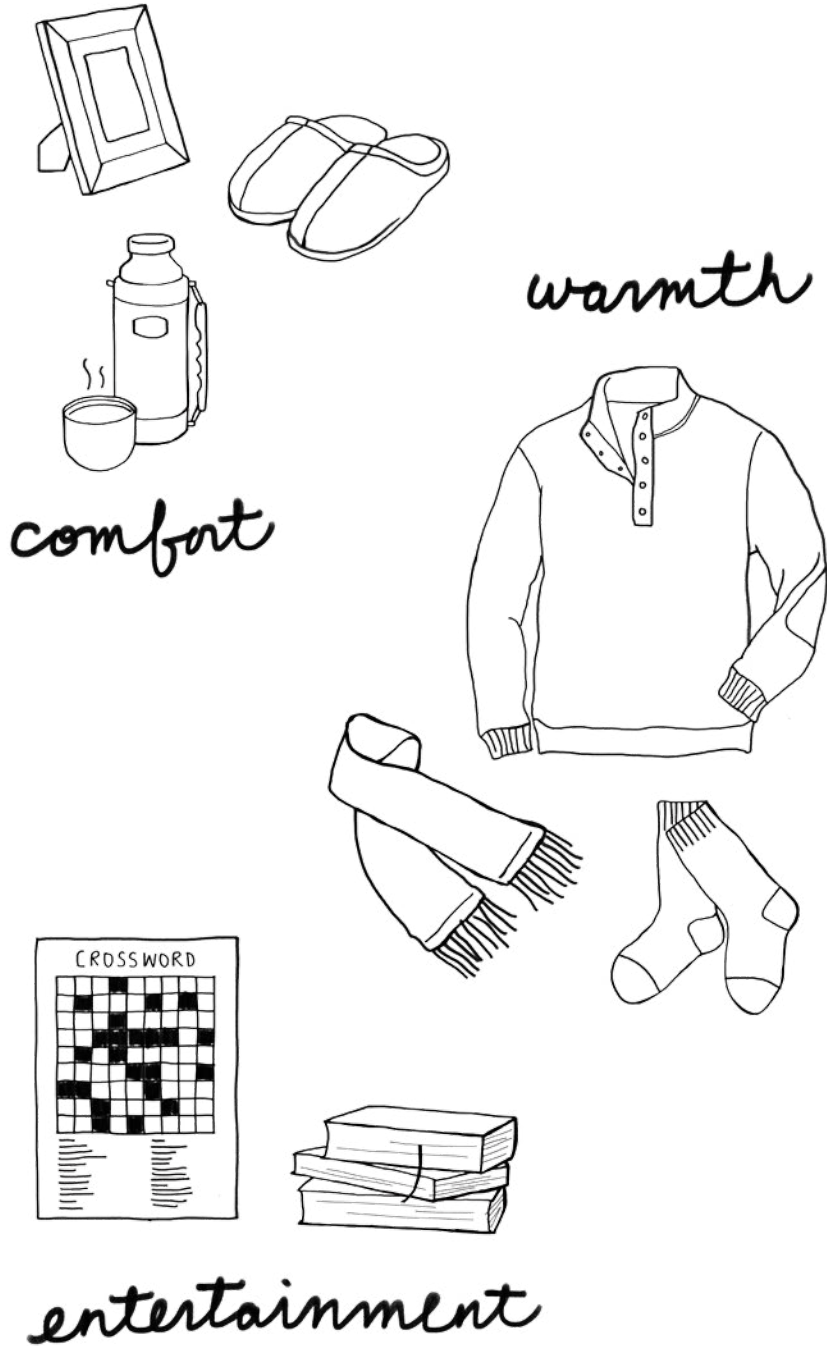


Travel Essentials: Things to Bring

Just like travelling, there are essential items you should consider bringing when visiting the hospital overnight. Experienced patients always try to bring something comforting, something for warmth, and a little bit of entertainment to help pass the time.

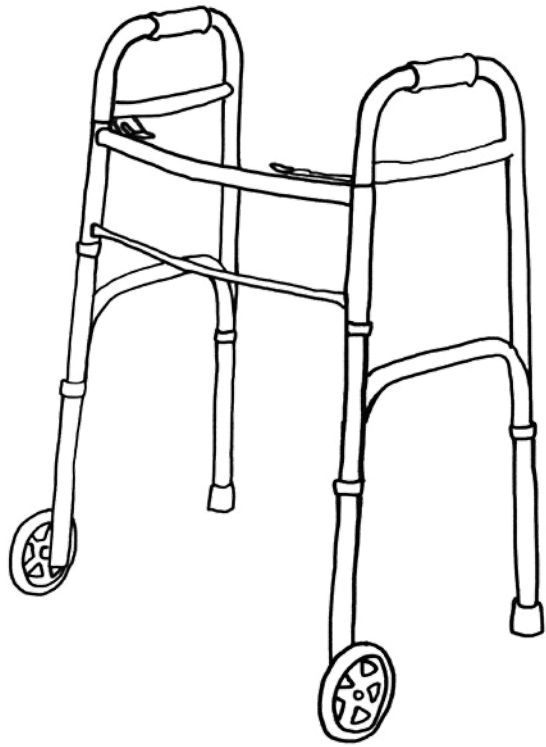
Consider pre-packing your travel essentials and setting them aside. This way, you will always be prepared. Use the accompanying checklist to help you pack.

P.S. Don't bring your valuables!



Things to Bring:

- Socks
- Slippers
- Books
- Medications (or a list)
- Hearing aid
- Toothbrush / denture care
- Pajamas
- Glasses
- Sweater
- List of phone numbers
- Hair brush
- Health card
- This handbook
- _____
- _____



“I would never take my walker to the hospital, it would be gone.”

How to be a good advocate.

As we age, it becomes increasingly important to bring a family member or friend along to our medical appointments. It can be a spouse, a child, a friend or a neighbour, just as long as someone is there to help ask questions, keep track of what's going on, and most importantly, to help voice your wishes and concerns. Below are some tips for how to be a good advocate for anyone taking on this role on your behalf. Share these tips with them.

The role of an advocate:

Be available.

It's hard to know when something unexpected might come up, but these are the moments when you are most needed.

Always ask if they want your direct help or only your suggestions.

Be sure the person wants you to advocate for them; sometimes they just want you to listen.

Do what they ask you to; don't do things on your own.

Obtain their permission to the action you will take on their behalf.

When advocating:

Stay objective.

Don't try to filter out information you think they don't want to hear, or interpret things based on your own feelings and opinions.

Don't lose your temper.

Staying calm under pressure is one of the most important qualities of an advocate.

Ask for help instead of demanding it.

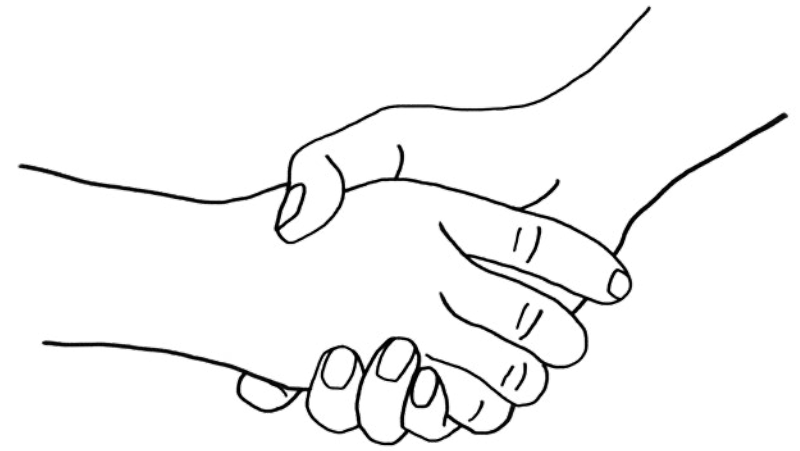
People are more likely to help if you outline your problem and make a request for assistance instead of demanding.

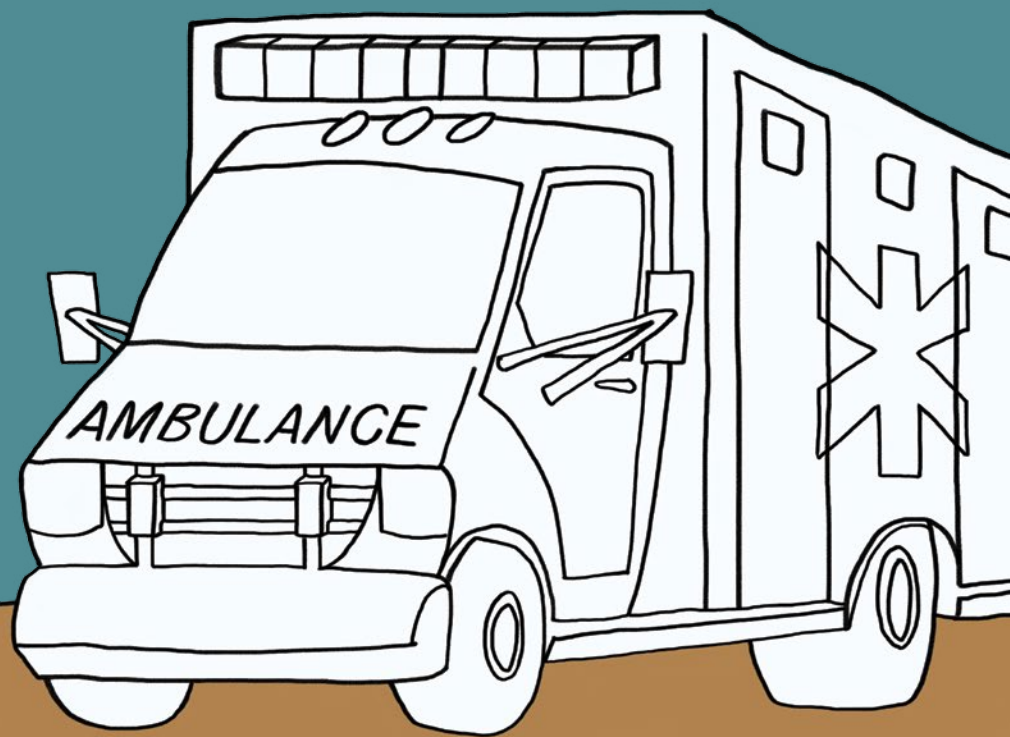
Say thank you to the staff.

Taking care of people when they are sick is a tireless job. It goes without saying that a well-placed thank you can go a very long way.

be assertive

“I don’t think you can train people to be assertive. You either are or you aren’t. But certainly if you aren’t, you need to have an advocate so you know somebody will look after your needs when you go into the hospital.”





Getting to the Emergency Department

Some people think that if they call an ambulance to take them to the emergency department, instead of going on their own, they will get seen quicker. This is only partially true.

Paramedics are trained professionals and can help you immediately upon their arrival. They also know which hospital to take you to, and have the right of way on the roads.

But once you're there, know that emergency departments see the sickest people first, not who arrives first or how they got there. On the next page is the scale emergency departments use to determine who has priority.

Levels of Urgency

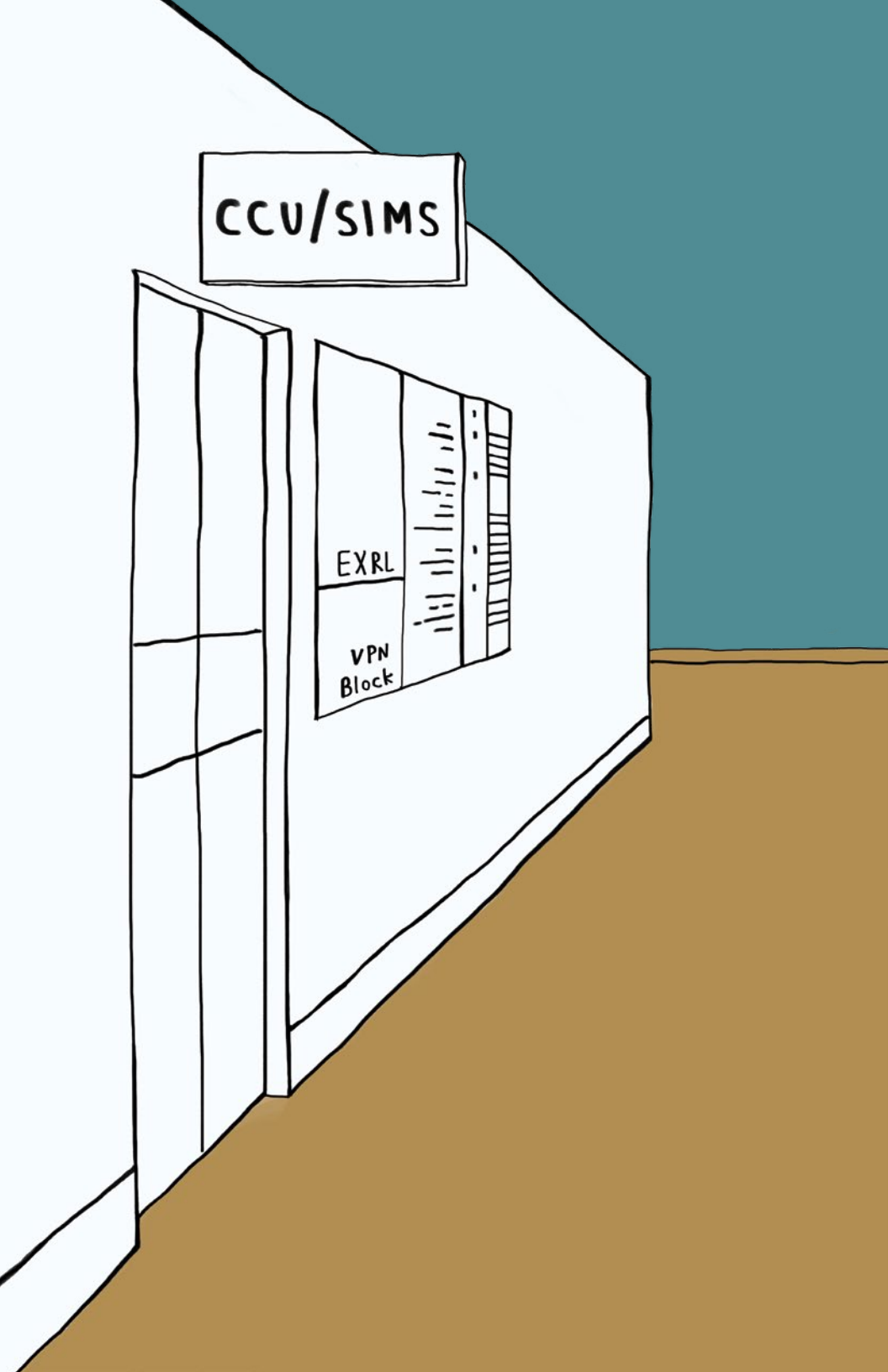
Level 1 patients get seen first and Level 5 patients get seen last.

Levels	Sample conditions
Level 1: Resuscitation	Heart attack, major trauma, loss of consciousness
Level 2: Emergent	Head injury, overdose
Level 3: Urgent	Asthma attack, broken leg
Level 4: Less Urgent	Headache, chronic back pain
Level 5: Non Urgent	Sore throat, vomiting, diarrhea

Tips: Getting What You Need

don't assume anything

“They charge you for the ambulance if they feel it was not necessary. So if you go in with a heart attack, always make sure that the person you are with asks them to sign off that you needed it because sometimes they forget and then you get a bill afterwards. It’s just an administrative thing.”

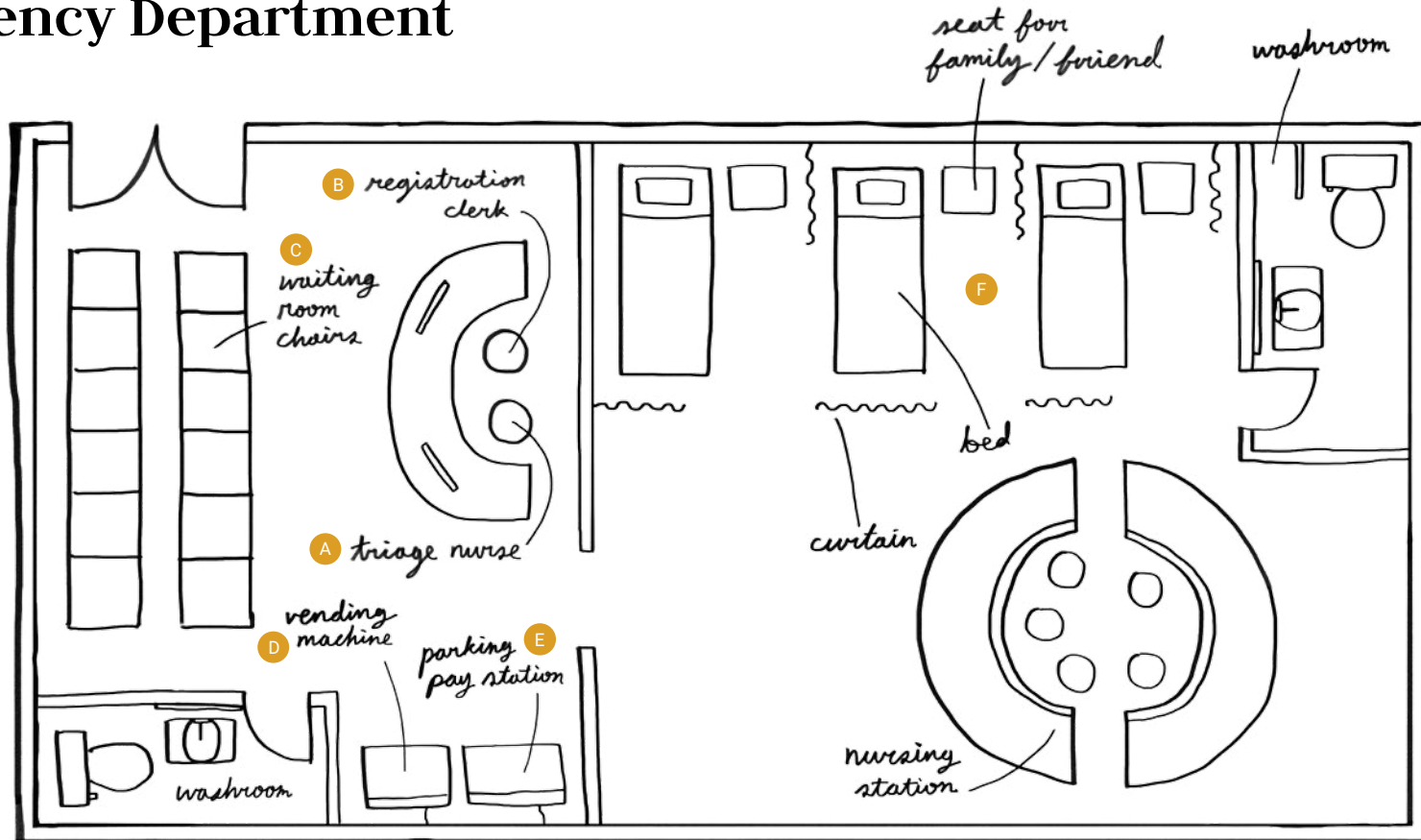


Knowing Your Way Around

It can be frustrating, confusing and even a little scary to not know where we are going when we visit a new place. So here are a couple of maps of the places patients commonly find themselves: the emergency department and the patient floor.

Although the layout might vary from hospital to hospital, we've detailed the essential features to look for no matter which hospital you visit. Just like landmarks in a foreign city you're visiting, look for these features to help you get your bearings.

Map of an Emergency Department



A The nurse will assess you and decide the order in which you will be seen. **Tip: Bring a list of all your medications.**

B The clerk will ask you for information such as name, address, contact info, etc. **Tip: Bring your health card.**

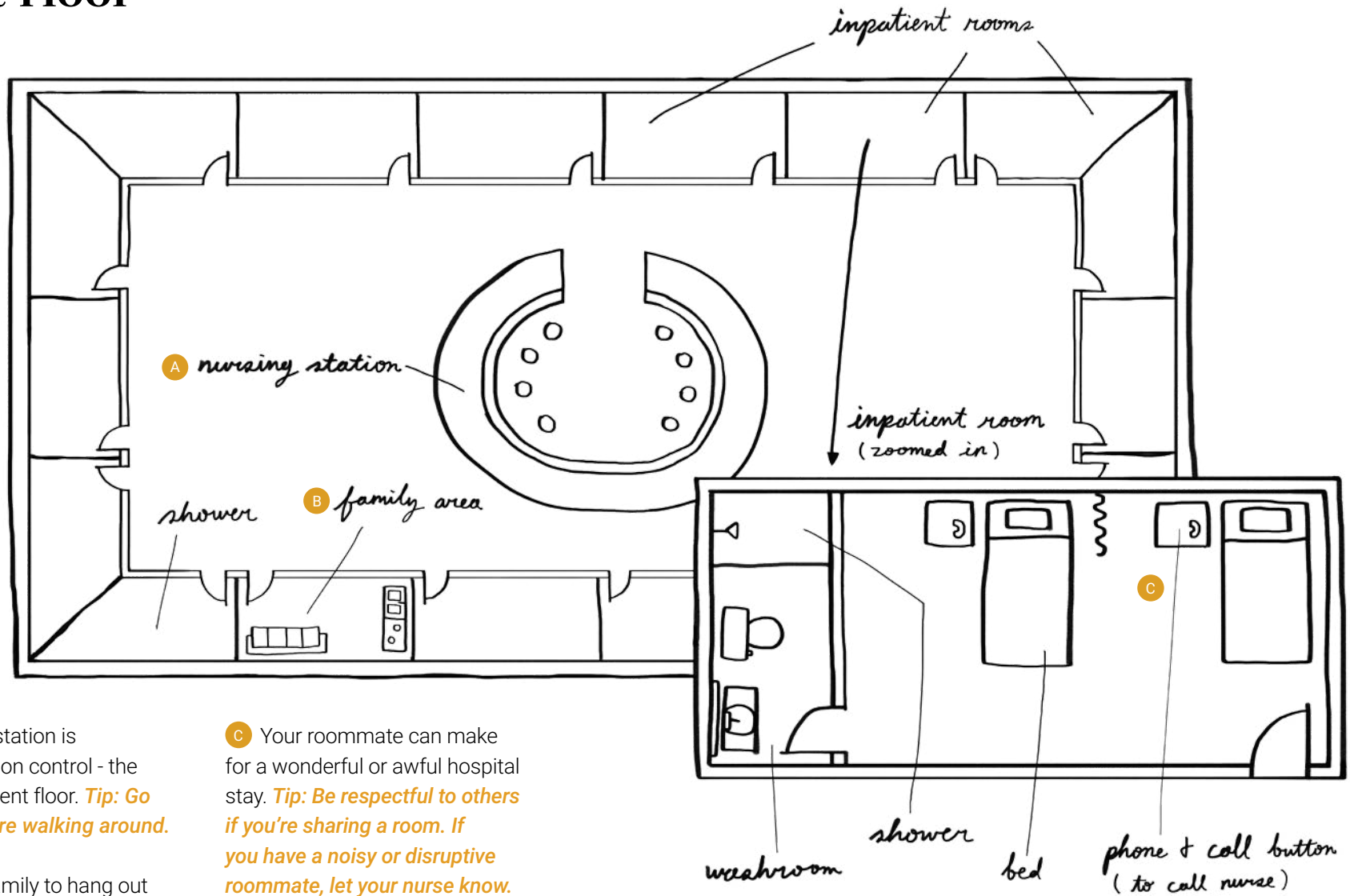
C You might have to wait a while. **Tip: Bring something to do (e.g. a book)**

D Snacks in case you're hungry. **Tip: Bring spare change.**

E Some hospitals have parking pay stations inside the building. **Tip: Don't forget to pay.**

F Treatment area - When it's your turn, you will be taken to this area. **Tip: Have your family/friend come in with you; you might be there for a while.**

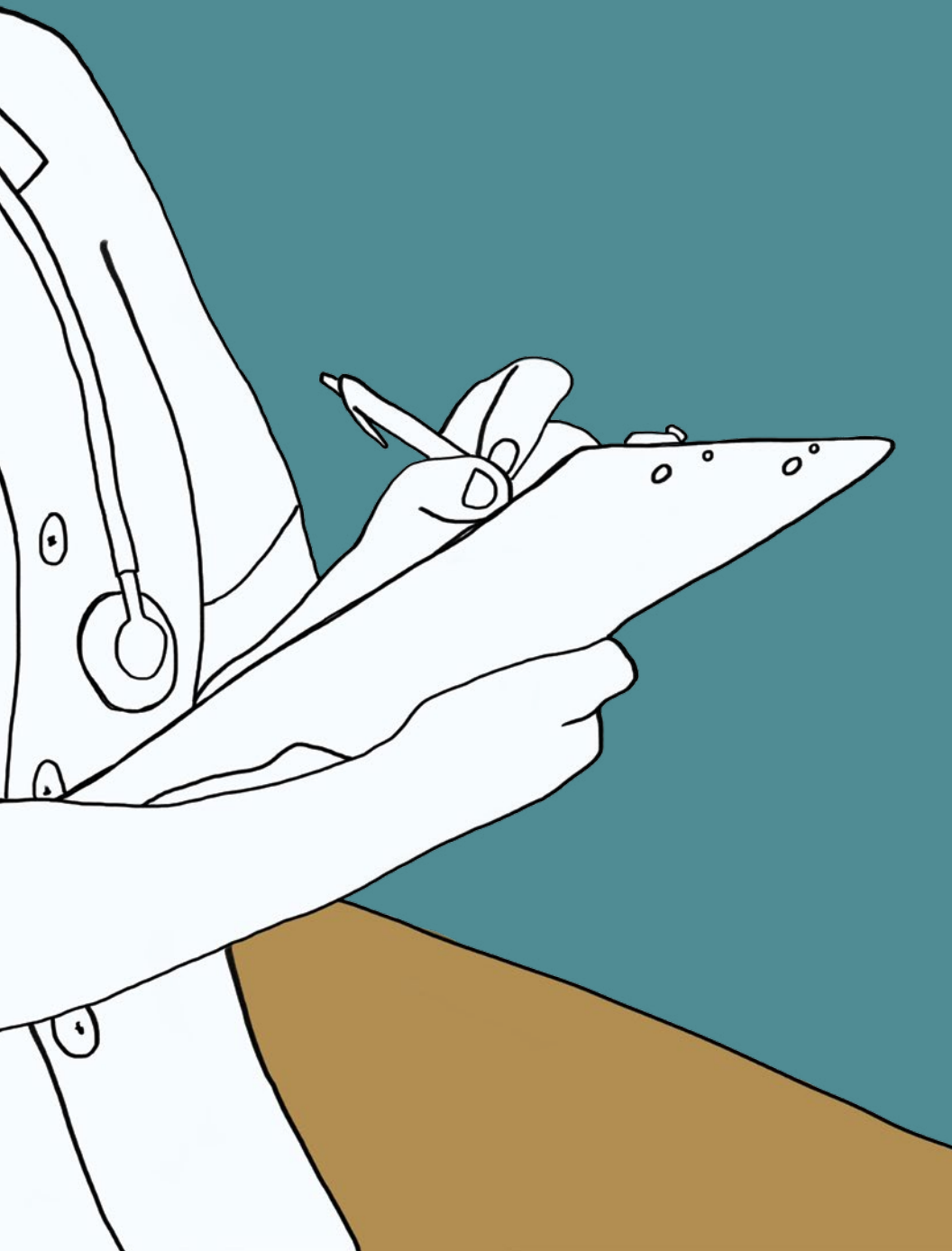
Map of a Patient Floor



A The nursing station is considered mission control - the centre of the patient floor. *Tip: Go say hi when you're walking around.*

B A place for family to hang out and not disturb you when you need privacy. *Tip: Don't be afraid to tell people to visit the family area when you need time to yourself.*

C Your roommate can make for a wonderful or awful hospital stay. *Tip: Be respectful to others if you're sharing a room. If you have a noisy or disruptive roommate, let your nurse know.*



The Language of Hospitals

Being in the hospital can sometimes feel like you're in a foreign country. That's because a lot of medical terms are derived from Latin and Greek. There's also heavy use of acronyms and shorthand that help to quicken communication among hospital staff. It takes years of training and practice to acquire this language. But you don't have to do that. Hospital staff are taught to use lay language when communicating with patients. So, if there is something you don't understand, don't be afraid to ask for a better explanation.

Having said that, there are times when you might think you understand something, but you actually don't. This can lead to embarrassing or even dangerous situations. Here are some words that are commonly misunderstood.

attending physician

noun /
at•tend•ing phy•si•cian /

You might think it means:
Doctor in attendance.

What it actually means:
Doctor in charge of your care.

"Let me go talk to the attending physician, and then we can decide."

congenital

adjective /
con•gen•i•tal /

You might think it means:
A disease of your genitalia.

What it actually means:
Something you are born with.

"The irregularity in your spine is probably congenital."

diet

noun /
di•et /

You might think it means:
Lose weight.

What it actually means:
Food and drink you normally consume.

"I want your diet to include more fibre."

discharge

verb /
dis•charge /

You might think it means:
Fluid that has leaked out of your body.

What it actually means:
You're leaving the hospital.

"You'll be discharged tomorrow morning."

formulary

noun /
for•mu•lary /

You might think it means:
Some kind of complicated calculation.

What it actually means:
Drugs covered by your health plan.

"This new drug is not on the formulary yet, so we're going to do some paper-work to see if your health plan will make an exception and help pay for it."

heart failure

noun /
heart fail•ure /

You might think it means:
Your heart has stopped working.

What it actually means:
Your heart isn't pumping hard enough.

"Because you have heart failure, I want you to limit how much salt you eat."

hypertension

noun /
hy•per•ten•tion /

You might think it means:
Stress.

What it actually means:
High blood pressure.

“I see that you’re taking beta-blockers for your hypertension.”

internist

noun /
in•ter•nist /

You might think it means:
A doctor in training.

What it actually means:
A doctor of internal medicine.

“Hi, I’m Dr. Abrams, your internist.”

med rec

noun /
med•rec /

You might think it means:
Medical record.

What it actually means:
Medication reconciliation (abbreviated). Making a list of all your meds.

*“Do you have your meds with you?
We’re going to do a med rec.”*

negative

adjective /
neg•a•tive /

You might think it means:
Something is wrong.

What it actually means:
You don’t have it.
(usually positive news)

“Your test came back negative.”

positive

adjective /
pos•i•tive /

You might think it means:
Everything is good.

What it actually means:
You have it.
(usually not positive news)

“Your test came back positive.”

pressure ulcer

noun /
pres•sure ul•cer /

You might think it means:
An ulcer in your stomach that’s pressing on vital organs.

What it actually means:
Bed sore.

“I’m going to help you change position so that you don’t get a pressure ulcer.”

prognosis

noun /
prog•no•sis /

You might think it means:
Test results.

What it actually means:
Likely outcome of your illness.

"Your prognosis is quite good."

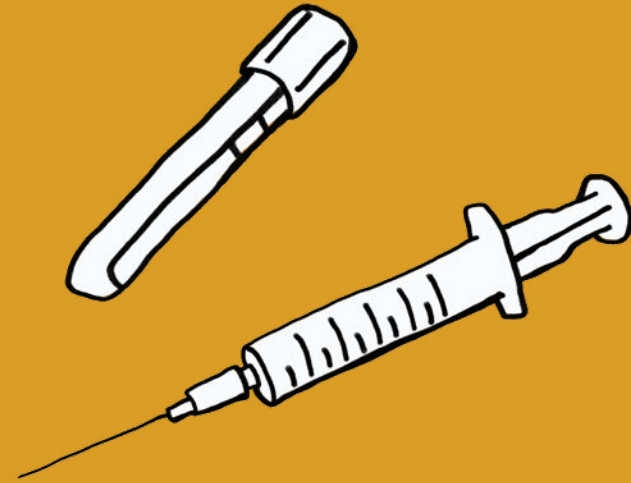
terminal

adjective /
ter•mi•nal /

You might think it means:
End of the illness.

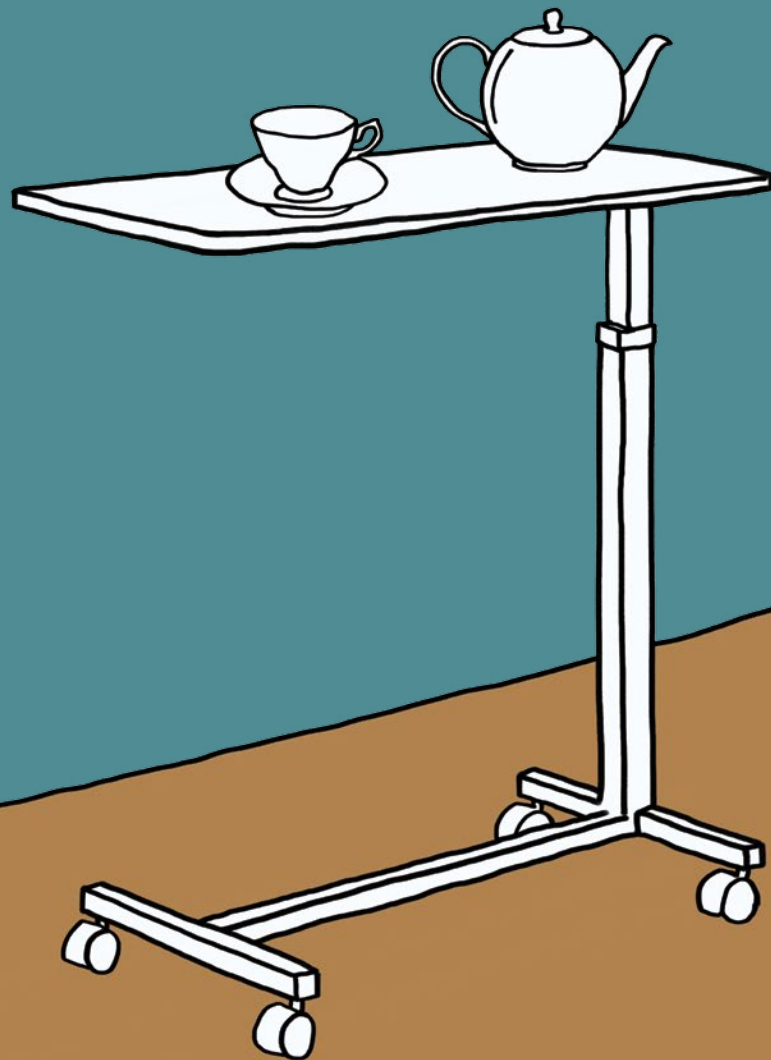
What it actually means:
Not curable.

"Your disease is terminal."



" They take a lot of blood at the hospital. Every time I turned around, there would be someone there saying, 'We're here to take a blood test'. If you have good veins you're lucky!"

Stella, 88



Food & Drink

Let's face it: hospitals are not known for their delicious food. Some hospitals do try to make food more appetizing, but generally speaking, don't expect a home-cooked meal.

On the following pages you'll find an extensive menu of comfort food ideas you can ask loved ones to bring.

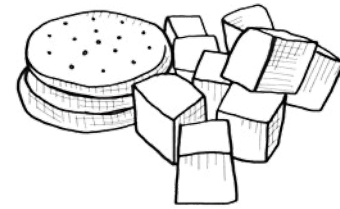
The menu represents food patients say make them feel better. Use it for ideas, but don't over-indulge! And check with hospital staff if you're not sure about what you can or cannot eat.

DRINKS



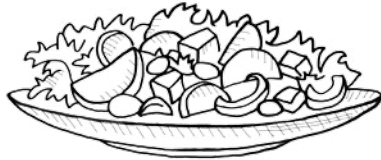
- Ginger Tea
- Camomile Tea
- Mint Tea
- Hot Lemon
- Power Shake
- Ginger Ale
- Vegetable Juice
- Lemonade
- Electrolyte Drinks Mix
- Water

SNACKS



- Crackers
- Bread
- Applesauce with Cinnamon
- Warm Baked Muffins
- Peanut Butter and Jelly Sandwich
- Toast
- Cold Cereal
- Bagel
- Nuts
- Granola Bar
- Animal Crackers
- Bread and Hummus
- Crackers and Cheese
- Crackers and Peanut Butter

MEALS



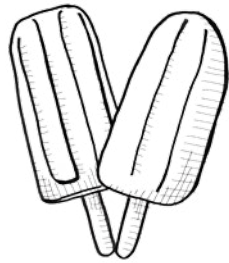
- Pasta
- Kitchari
- Salads
- Homemade Mac & Cheese
- Curry with Rice and Peas
- BBQ Chicken
- Meatloaf & Mashed Potatoes
- Polenta
- Burrito
- Good Hot Dog
- Homemade Fried Rice
- Chicken Tenders and Fries
- Cutlet
- Stir Fry
- Fish & Chips
- Pizza

SOUPS



- Chicken Noodle Soup
- Congee
- Pho
- Vegetable Soup
- Broth Based Soup
- Onion Soup
- Carrot Ginger Soup
- Minestrone Soup
- Miso Soup
- Wonton Soup
- Matzo Ball Soup
- Beef and Barley Soup
- Broccoli Soup
- Butternut Squash Soup
- Turkish Bridal Soup
- Homemade Lentil Soup
- Jamaican Beef Soup
- West Indian Yuk-Choy Soup

TREATS



- Popsicles
- Sweets
- Chocolate Pudding
- Jello
- Rice Pudding
- Potato Chips
- Chocolate
- Ice Cream



“If I go out and I buy some groceries, I usually just balance them on my walker and I hang on for dear life!”



People You'll Meet

There are many different health care providers working at the hospital. And as a patient you'll likely meet many throughout your stay. If you've ever visited a "teaching" hospital - one that is connected to a medical school - you'll know that there can be many providers involved in your care, including residents and trainees.

The following pages will help you know who's who, and what they each do. And to help you remember all the people on your care team, we've included a series of worksheets to help you keep track of faces and names.

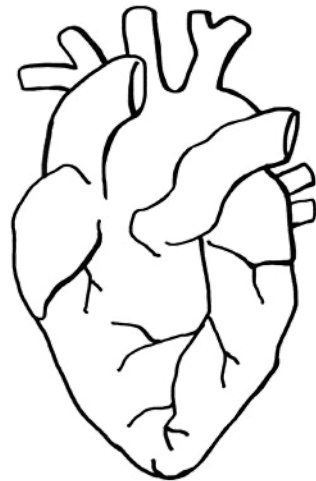
Types of Doctors

Anesthesiologist

This is the doctor that helps you to sleep through painful operations and medical diagnoses. They are responsible for administering the anesthesia and are present during surgeries to help in complications arising from anesthesia medications.

Cardiologist

A cardiologist is certified to treat any problem dealing with heart diseases and cardiovascular diseases.



Dermatologist

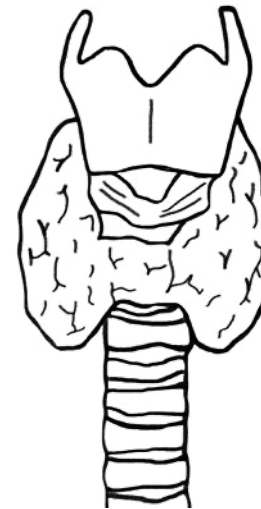
This is a doctor that treats any ailment related to the skin and its appendages such as hair, nails, etc.

Emergency Doctor

This is a doctor that works in the emergency department and is trained to deal with trauma patients. Emergencies treated may vary from poisoning to broken bones, burns, heart attack, concussions, accident trauma, etc.

Endocrinologist

Thyroid problems, hormone problems or any problems with the endocrine system is handled by an endocrinologist.



Epidemiologist

This is a doctor who specializes in epidemic illnesses which are highly viral. They are scientists who identify new diseases, virus mutations and develop cures and modes of prevention of diseases with vaccinations, etc.

Otorhinolaryngologist

Also known as ENT, this doctor treats problems with the ear, nose and throat. An ENT surgeon is a specialist who performs surgeries on these parts of the body.

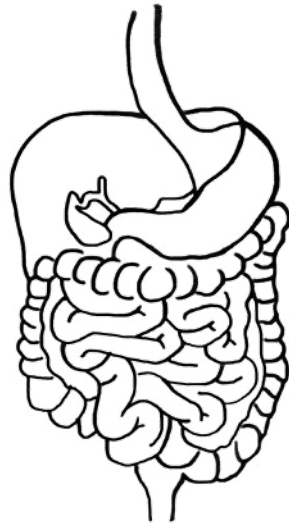


Family Physician

A family physician is the neighborhood doctor who treats illnesses and medical issues of all sorts, at all ages and in non-emergency situations. If the condition is serious they will refer you to a specialist.

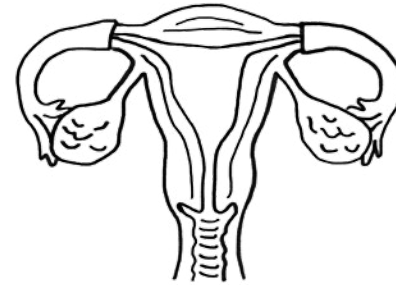
Gastroenterologist

A doctor for illnesses related to the digestive system including the common problem of acid reflux.



Gynecologist

Any problems with the female reproductive system is referred to and treated by a gynecologist.



General Psychiatrist

Any person with mental illness such as schizophrenia, depression or anxiety problems is treated by the general psychiatrist.

Hematologist

This is a doctor who specializes in blood and its diseases.

Hepatologist

This doctor is responsible for diagnosing and treating diseases of the liver.

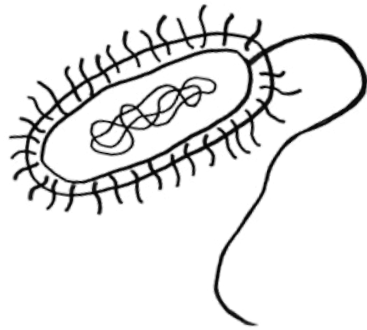


Immunologist

This is a doctor who specializes in diseases of the immune system.

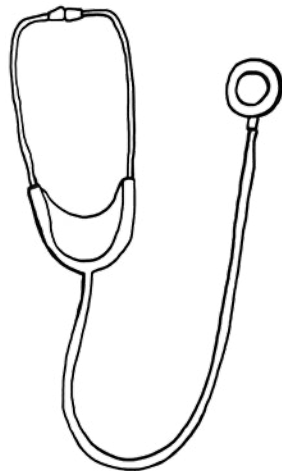
Infectious Disease Specialist

This is a doctor who studies and treats diseases caused by viruses, bacteria, fungi, parasites and will identify outbreaks of epidemics and pandemic situations.



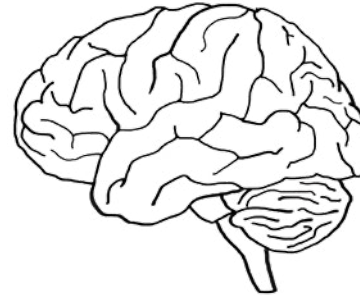
Internist

This doctor is specially trained to manage seriously ill patients suffering from advanced illness and/or diseases of more than one internal organ system.



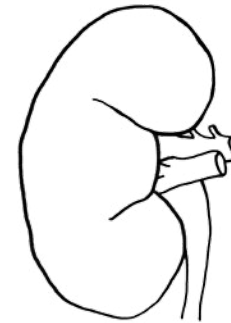
Neurologist

This doctor studies various brain disorders such as Parkinson's disease and Alzheimer's disease.



Nephrologist

This is a specialist doctor who treats kidney diseases and renal problems with treatments such as dialysis.

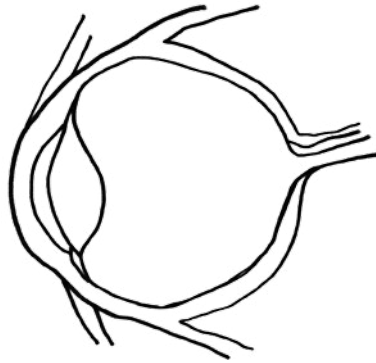


Oncologist

This is a specialist doctor who diagnoses and treats cancer patients with drugs, chemotherapy, radiation and where needed, surgical interventions.

Ophthalmologist

This is a doctor that treats eyes and various eye defects, blindness and performs different eye surgeries.



Orthopedist

Broken bones from falls or osteoporosis is treated by an orthopedist.



Podiatrists

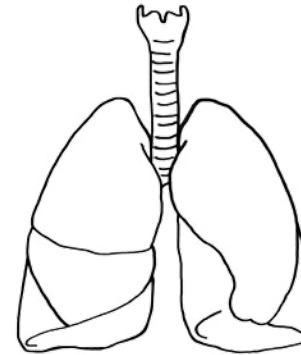
This is a specialist doctor who treats disorders of the foot and ankle.

Psychiatrist

This doctor specializes in mental illnesses and studies, diagnoses, counsels and treats mental illnesses such as bipolar, dementia, depression, Alzheimer's, etc.

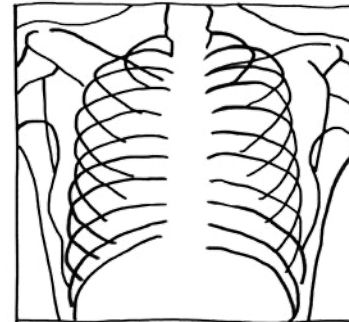
Pulmonologist

This doctor specializes in diseases of the lung and manages patients on mechanical ventilators in the intensive care unit.



Radiologist

A doctor who specializes in the use of X-rays or other imaging technologies in order to diagnose various illnesses.

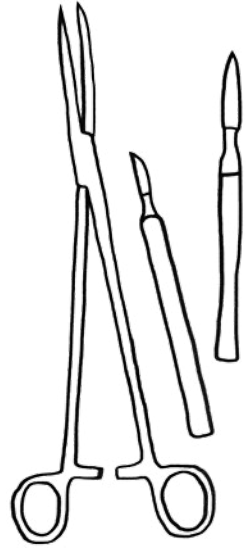


Rheumatologist

A doctor who specialized in autoimmune disorders and allergic conditions.

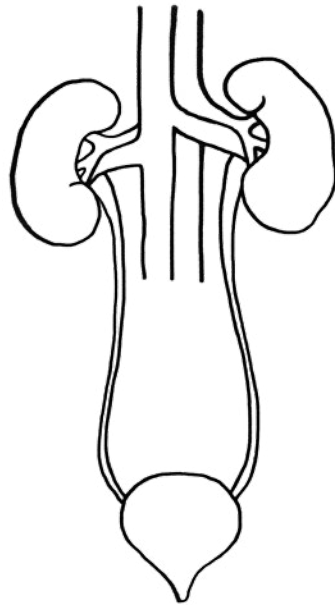
Surgeon

A surgeon is a doctor that specializes in surgical operations and will have their own specialties such as orthopedic, ENT, brain, nuro, cardiovascular, maxillo-facial surgery, plastic surgery and transplant surgery.



Urologist

Any urinary problems and urinary tract infections are treated by an urologist.



Tips: Getting What You Need

inform your family

“ Use your phone to record the conversation with the specialist (with permission) so you can share it with your kids later.”

Care Team Members

Attending Physician

Responsible for overseeing your care team.

Senior Resident

Coordinates the daily activities of your care team.

Residents & Students

In a “teaching” hospital, they visit you daily to address your concerns and assess how you’re doing.

Social Worker

Provides counseling to help access your right to care and coordinates resources you may need.

Pharmacist

Collaborates with your care team to manage your medication.

Occupational Therapist (OT)

Helps you safely manage everyday activities that you need to do at home and work.

Speech Language Pathologist

Assesses and helps you manage swallowing, speech, language and voice disorders.

Dietitian

Works with you to develop modified diets and good nutritional habits.

Physical Therapist (PT)

Helps you restore or improve mobility or function.

Nurse

Assists you and provides services essential to the promotion, maintenance, and restoration of health and well-being.

Community Care Planner

Arranges for home care services.

Putting a Face to a Name

Depending on your illness and which hospital you're at, there could be many providers involved in your care. Use these worksheets to help keep track of faces and names. As a fun exercise, ask hospital staff to draw a picture of themselves.

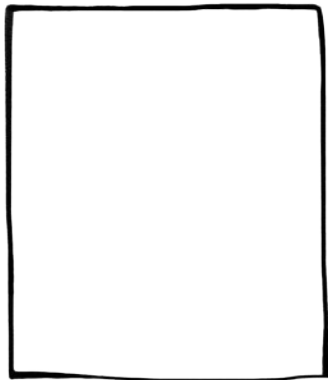
draw here ↴



Name: Karen

What they do: Physiotherapist
(gets me moving my hip again)

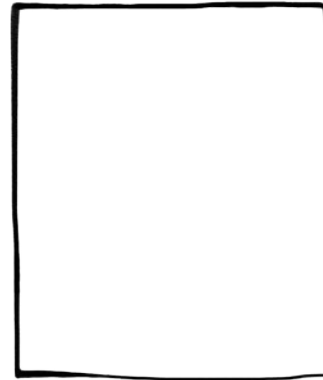
What they look like: _____
Straight blond hair, glasses,
brown eyes, friendly.



Name: _____

What they do: _____

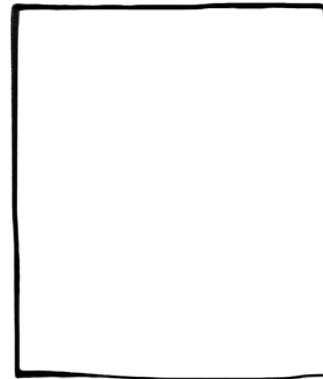
What they look like: _____



Name: _____

What they do: _____

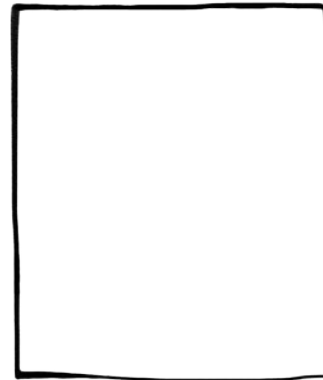
What they look like: _____



Name: _____

What they do: _____

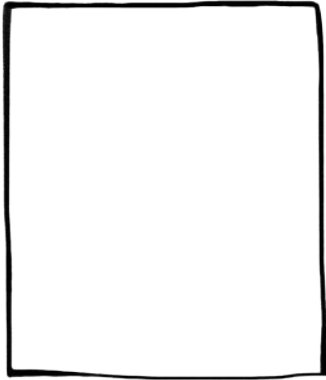
What they look like: _____



Name: _____

What they do: _____

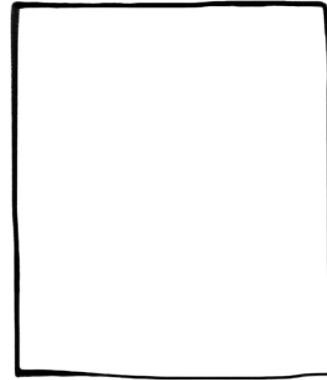
What they look like: _____



Name: _____

What they do: _____

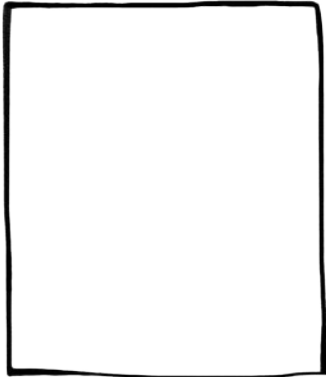
What they look like: _____



Name: _____

What they do: _____

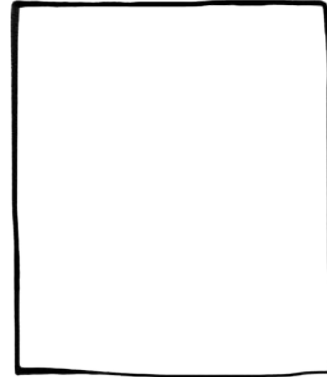
What they look like: _____



Name: _____

What they do: _____

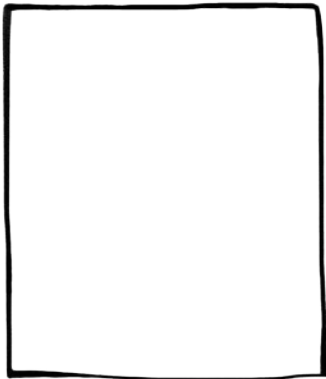
What they look like: _____



Name: _____

What they do: _____

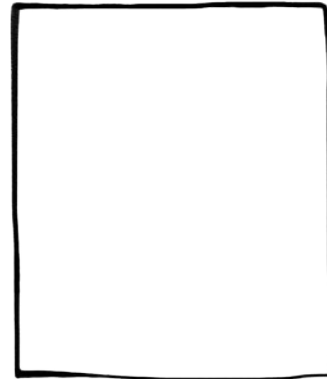
What they look like: _____



Name: _____

What they do: _____

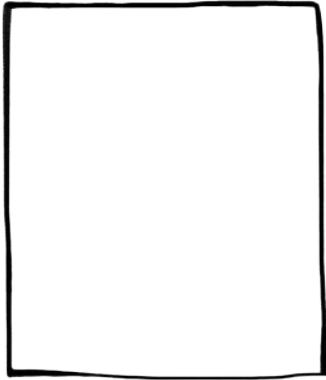
What they look like: _____



Name: _____

What they do: _____

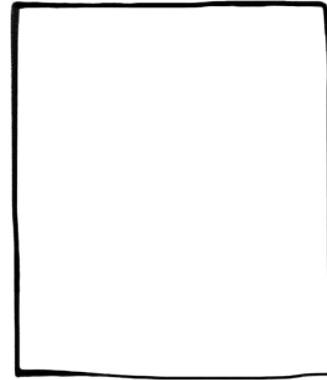
What they look like: _____



Name: _____

What they do: _____

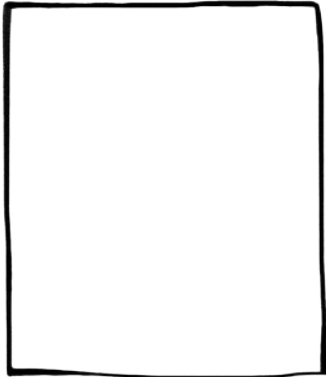
What they look like: _____



Name: _____

What they do: _____

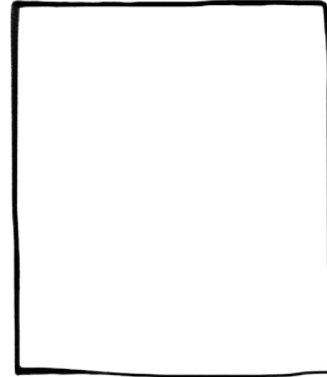
What they look like: _____



Name: _____

What they do: _____

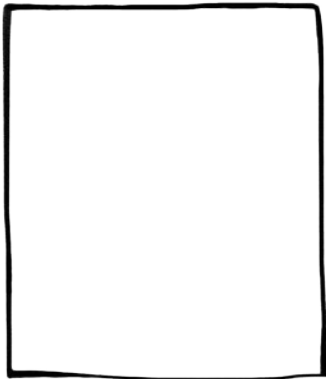
What they look like: _____



Name: _____

What they do: _____

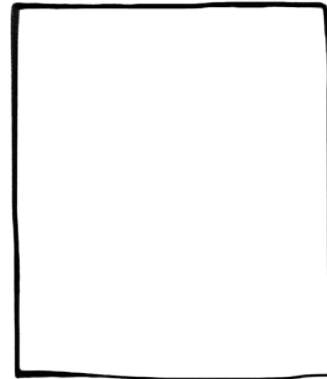
What they look like: _____



Name: _____

What they do: _____

What they look like: _____



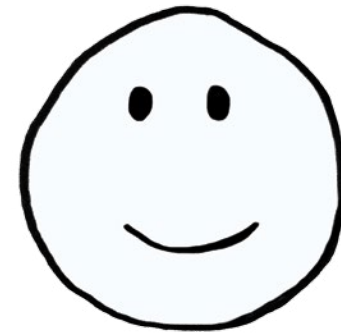
Name: _____

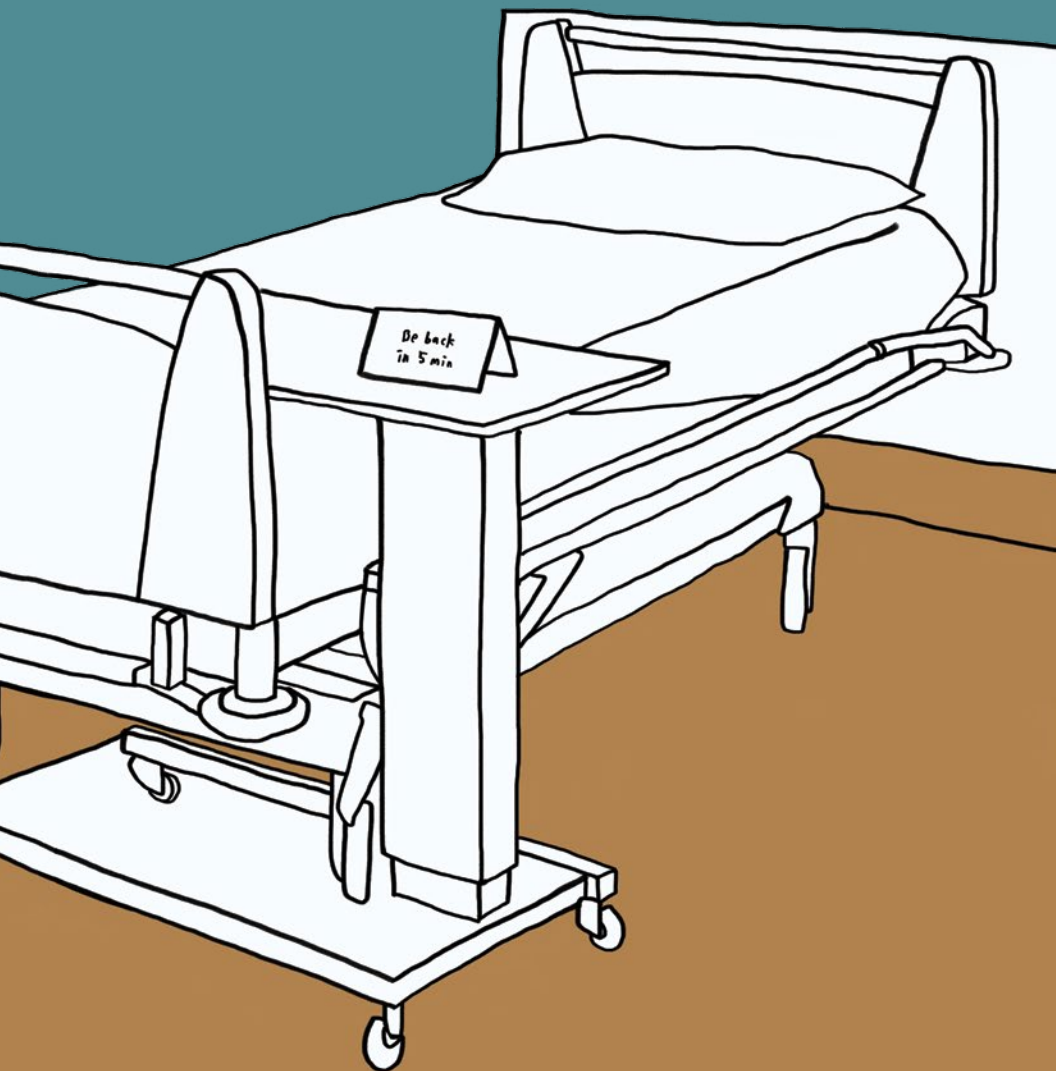
What they do: _____

What they look like: _____

be nice

“If I am being sincere about it, you have to put on a sweet looking face and be very polite, because most people are in a grumpy mood. It’s thankless job. If you are nice to people, they are going to return in kind.”





Courtesy Cards

As a visitor to a hospital, it can be difficult to get a sense of the rhythm and flow of how things work – when to ask for what, and whom to ask. It can all be quite overwhelming. For instance, if you need to get up and go down the hall for something, but are waiting on the doctor – who should you tell?

These types of situations are tricky. To make things run smoother and to alleviate unnecessary worry, we've included some tear-away signs that might help you better communicate with the people around you.

Instructions:

1. *tear*
2. *fold*
3. *leave by bedside*

tear along here →

My family will be
back at this day/time:

Phone #: _____

My family will be
back at this day/time:

Phone #: _____

Taking a rest.
Wake me if needed.

Taking a rest.
Wake me if needed.

tear along here ~

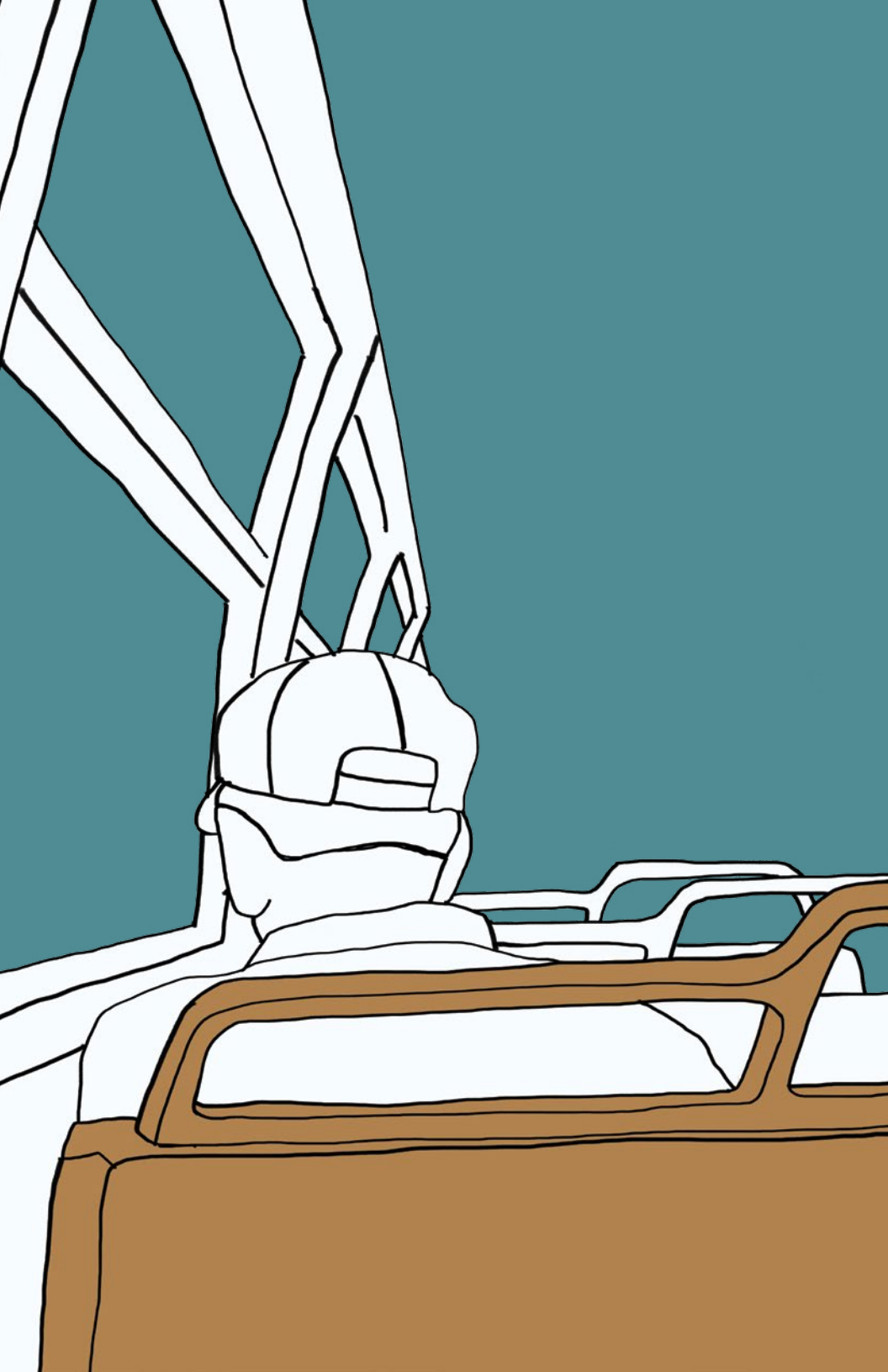
Gone sightseeing ;)
Be back by:

Gone sightseeing ;)
Be back by:

write your own ↴

write it down

“ Put it in writing. Never just ask. Bring a little note pad and a pen, and write it down. Then limp out to the nursing station and ask them to put it in your records. For example, if you have to have food 30 minutes before you take your medications, write down ‘Please can you arrange to bring me my medication 30 minutes before the meal.’ If you just tell them sometimes they are too busy and they forget.”



Going Home

Knowing exactly what you need to do once you get home from hospital will help with your recovery and avoid potential harm from doing the wrong thing. The problem is that hospital discharge can be a hectic period, and you might not be in the best mindset to absorb and remember care instructions, especially if there's a lot of it. And some hospitals do a better job of communicating such information than others.

5 Things to Know Before Leaving Hospital:

1. Medications I need to take
2. How I might feel and what to do
3. Changes to my routine
4. Appointments I have to go to
5. Where to go for more information

But don't put too much trust in your memory. Patients are often too stressed out or not in the right state of mind to absorb a lot of information. Use the accompanying worksheets to jot down all of this information. And if there is something you don't understand, don't be afraid to ask hospital staff.

It's also a good idea to notify your loved ones about when you'll be returning home so that there will be somebody there to help.

Tear along here →

My Care Guide

I came to hospital on _____ and left on _____

I came in because I have _____

Medications I need to take

My medication list has been provided to me and explained.

How I might feel and what to do

I might feel:

What to do:

_____	_____
_____	_____
_____	_____
_____	_____

Go to Emergency if:

Changes to my routine

Activity (e.g. diet, physical activity):

Instruction:

_____	_____
_____	_____
_____	_____
_____	_____



Rate Your Stay

Improving the patient experience is an important goal for most hospitals. But there's no way of doing this without hearing from actual patients, so we've designed a simple feedback form for you to fill out and leave behind. You can drop it off at the nursing station on your way out, or give it to the hospital's patient relations office.

Instructions:

1. *tear*
2. *write*
3. *leave behind*

tear along here →

Patient Experience Card

Thank you for attending to my illness. I hope you find my comments below helpful, and that you consider them in your quest to build a positive patient experience at your hospital.

Would I recommend this hospital to my family or friends?



Definitely No



Probably No



Probably Yes



Definitely Yes

Here are my reasons:

Tear along here →

Patient Experience Card

Thank you for attending to my illness. I hope you find my comments below helpful, and that you consider them in your quest to build a positive patient experience at your hospital.

Would I recommend this hospital to my family or friends?



Definitely No



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Tear along here →

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Definitely No



Probably No

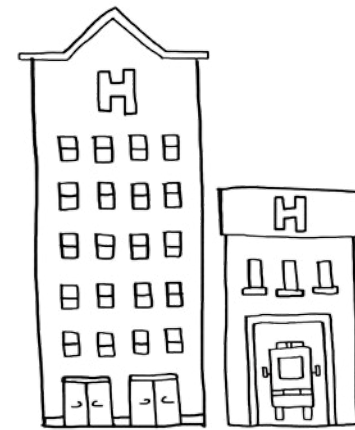


Probably Yes



Definitely Yes

Here are my reasons:



Safe Travels.