

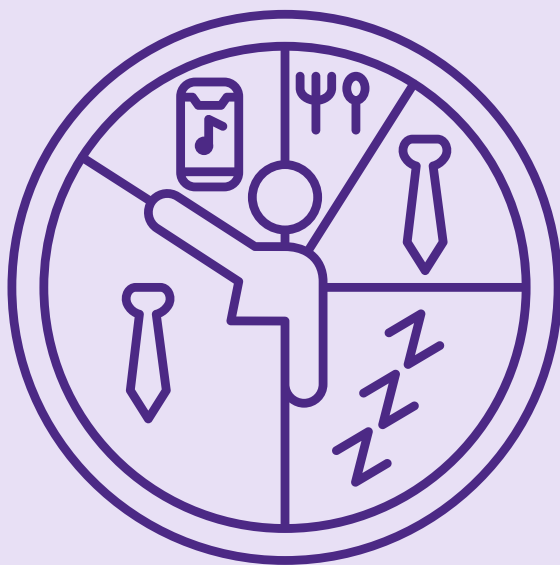
Empower

Understand

Thrive



EMPOWER
MY CONGENITAL HEART



*Living Your
Best Life:*

Your CHD Lifestyle Guide

Section 1

DIET AND HEALTHY EATING





DIET AND HEALTHY EATING

A **well-rounded diet** helps your body work at its best. If you have a chronic (*long-term*) condition like CHD, what you eat matters even more for your long-term health and to **help prevent other conditions from developing**.

Let's focus on diet information that supports your heart and covers special considerations for CHD.

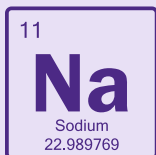
What to Eat?

A Heart Healthy Diet consists of balanced nutrition, which includes:

- ◆ A wide variety of fruits and vegetables
- ◆ Whole grains
- ◆ Plant-based protein (legumes, soy products)
- ◆ Fish and seafood
- ◆ Lean proteins (low fat percent)
- ◆ Minimize processed foods and added sugars
- ◆ Low sodium (salt)
- ◆ Limited or no alcohol

Heart Healthy Recipes

bit.ly/AHA-recipes



SODIUM INTAKE

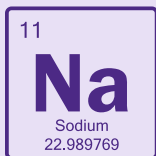
Sodium (*salt*) is an important mineral your body needs to work properly, but it's important to keep it in balance. It helps control fluid levels in your body, supports healthy blood pressure, allows your muscles and nerves to work, and acts as an essential electrolyte needed by your cells.

If you have too much sodium, you may experience:

- ◆ High blood pressure.
- ◆ Excess sodium can cause fluid to build up in your blood vessels.
- ◆ You may develop fluid in your lungs, which can make it harder to breathe or cause shortness of breath.
- ◆ Your heart may have to work harder to pump blood.
- ◆ Too much sodium can also lead to heart failure.

If you don't have enough sodium, you may experience:

- ◆ Nausea
- ◆ Headache
- ◆ Muscle cramps



SODIUM INTAKE

Many people eat more salt than they realize because some foods are high in sodium even if they don't taste salty. If you have trouble keeping your sodium intake low, your doctor may recommend cutting back on sodium.



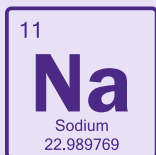
Common foods that are high in sodium include:

- ◆ Canned goods and frozen/ready-to-eat meals
- ◆ Bacon and cured meats
- ◆ Pretzels, chips, nuts (salted), cheese, and pickled foods.
- ◆ Many condiments/sauces (soy sauce, ketchup, etc.)



Tips for how to find sodium info on food labels:

- ◆ Check the sodium listed **per serving**, and account for how many servings you eat.
- ◆ You should not consume more than 100% of the Daily Value for sodium, which is about 2,300 mg per day.



SODIUM INTAKE



Medications can also impact your sodium levels, making them higher or lower than they should be.

Examples Include

- ◆ Vasopressin / Antidiuretic Hormone
- ◆ Diuretics (*lasix*, “*water pill*”)
- ◆ Mental health medications: SSRIs, SNRIs, MAOIs
- ◆ Steroids or Hormones
- ◆ Mannitol
- ◆ Narcolepsy medications (Xylem, Lumryz) can be high in sodium. Some (Xywav) are lower in sodium.

Special CHD Considerations

- ◆ Low sodium diets (*1,500–2,000 mg daily*) are often recommended for those with heart disease
- ◆ For Fontan patients, staying well-hydrated is especially important, but is dependent on each person’s unique heart function and circulation.
- ◆ If you experience fluid retention, your ACHD doctor may recommend taking a diuretic and/or a low sodium diet to help your body get rid of extra fluid



MEDICATION & DIET CONSIDERATIONS

Some medications need to be taken with food to prevent side effects or help them work better. Others are most effective when taken on an empty stomach. Certain foods, such as acidic ones, can interact with your medicine and make it less effective or cause side effects.

Immunosuppressant Drugs: avoid grapefruit and pomegranate

Coumadin (warfarin): Vitamin K—thickens your blood—keeping your vitamin K intake consistent is key to keeping your INR levels in range.

- ◆ **Foods high in Vitamin K:** Green leafy vegetables (i.e., kale, spinach, brussel sprouts, cabbage, lettuce), broccoli, green beans, soy beans, cashews
- ◆ **Watch alcohol consumption** because alcohol thins your blood

Warfarin, Diet,
& Vitamin K

bit.ly/warfarin-diet



PROTEIN-LOSING ENTEROPATHY (PLE)

PLE is a condition that **can develop** among patients with some CHDs. It is seen often among those who have had a Fontan.

Diet Considerations

It is beneficial to maintain a high protein, low fat diet when you have PLE since you are not able to retain as much of the protein you consume.



- ◆ **High Protein:** At least 0.9 grams of protein per pound of weight per day. Lean meat, fish, tofu, nuts/seeds, lentils.
- ◆ **Low Fat:** Less than 25% of calories from fat. Lean meat, fruits, vegetables, whole grains.

Signs of PLE

- ◆ Water retention (swelling)
- ◆ Bloated stomach
- ◆ Weight loss
- ◆ Abdominal pain





POST-TRANSPLANT DIET

All your food **must be cooked through**, especially meat. Tip: use a thermometer to check!

USDA-Recommended Safe Minimum Internal Temperatures

165 F

Meat (cut up or ground): Beef, pork, veal, lamb, turkey, chicken

160 F

Eggs: Egg Dishes (160), for eggs cook until yolk and whites firm

145 F

Fish

145 F (with a 3 minute rest time)

Roasts and Chops: Beef, Pork, Veal & Lamb Steaks

Food Safety Guide

bit.ly/tch-food-safety

Other Considerations

- ◆ Avoid unpasteurized foods, raw foods (sushi, oysters, muscles, etc.), seed sprouts, raw honey
- ◆ Eat more protein than usual for first few weeks

Section 2

NON-PRESCRIBED SUBSTANCE USE



WHAT ARE NON-PRESCRIBED SUBSTANCES?



Non-prescribed substances are anything you **take without guidance from your doctor(s)**. This can include tobacco products, alcohol, caffeine, other legal and illegal drugs, and even herbal supplements. These substances can affect your heart by impacting things like your blood pressure, breathing, and heart rate.

Learn About Different Substances
bit.ly/substance-info

If you take anything that is not prescribed to you, **including herbal supplements**, talk to your ACHD doctor about how they could be affecting your CHD condition.

TRANSPLANT CONSIDERATIONS

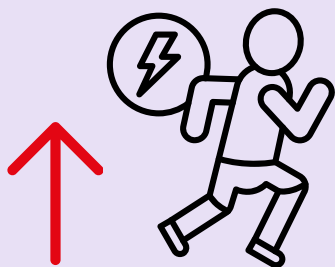
It is VERY important to **be aware** of how **taking illegal and even legal substances** may impact your ability to be listed or receive a transplant, if you need one. Before you are listed—and again when you're admitted for transplant—your team will do blood, urine, and other tests. If any of your results are too high, too low, or contain things they shouldn't, **you may not be able to be listed or have your transplant** even if an organ match has become available at that time.



STIMULANTS VS. DEPRESSANTS

Many substances can be separated into two main categories based on how they affect the body.

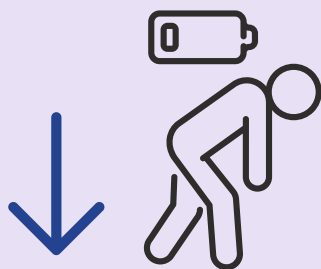
Stimulants



Speed things up, increasing heart rate and blood pressure. Can cause sudden cardiac arrest, heart failure, and arrhythmias

Examples: cocaine, meth, cannabis/marijuana, amphetamines (Adderall, Ritalin), nicotine, caffeine

Depressants



Slow things down, decreasing blood pressure, heart rate, respiratory rate (breathing), which can be slowed TOO much causing oxygen deprivation

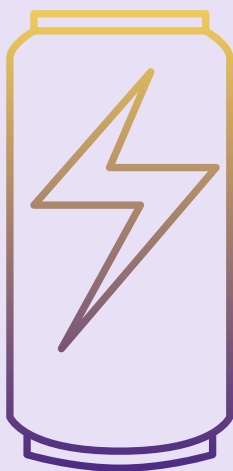
Examples: opioids, benzodiazepines (Valium, Xanax), sleep medications (Ambien), alcohol, GHB

STIMULANTS VS. DEPRESSANTS

People use different substances for many different reasons. Some people might use stimulants to help them stay awake or focus. Others may use depressants to help them relax.

The possible risks of using a substance depend on several different factors.

- ◆ The specific substance you use.
- ◆ The amount you use and how strong the substance is.
- ◆ The way you use the substance.
- ◆ How the substance might interact with your own body or other medicines you take.



MARIJUANA



Marijuana products come in various forms and may use the terms “**cannabis**” or “**THC.**” THC products may also come from hemp plants, rather than cannabis plants.

Examples

- ◆ Smoking and vaping products
- ◆ Edible products
- ◆ THC-infused drinks
- ◆ Topical creams, ointments, etc.
- ◆ Tinctures

**Those with compromised lungs, including Fontan patients, should take extra care to NOT smoke.*

It is important to note that **legal usage varies by location**. Some places have no legal options for using marijuana, while others may allow medically prescribed and/or recreational use. If you have a prescription your doctor can help you find the best method and dose for you.

OPIOIDS

Opioids are a type of drug/medication often used for severe pain management. They may be provided through prescription or used illicitly without prescription.



Examples

- ◆ Morphine
- ◆ Oxycodone
- ◆ Hydrocodone
- ◆ Norco
- ◆ Fentanyl
- ◆ Heroin

If you've ever had major surgery, you probably received a prescribed opioid to help manage pain during and after the procedure.

Safe Opioid Use Information

bit.ly/opioid-safety

OPIOIDS



Opioids are NOT typically recommended for long-term/ chronic pain management (3+ months) due to development of physical dependence that occurs naturally over time

Considerations

- ◆ If taking an opioid prescribed to you by your doctor, **never take more than prescribed.**
- ◆ **Talk to your doctor** about how **to slowly reduce** how much you are taking so you do not experience withdrawal symptoms
- ◆ **Do not use** other depressants, such as **benzodiazepines** (*Valium, Xanax*), that could decrease your breathing too much or completely when **combined with opioids.**
- ◆ If you have been taking opioids for a **long time**, do not try to reduce your dose on your own. Your doctor may prescribe you other **medications to help you reduce your dose safely.**

ALCOHOL



Most people can safely drink small amounts of alcohol, but **your CHD condition** and overall health **may require extra precautions.**

Binge drinking (*having more than 4–5 alcoholic drinks within 2 hours*) is not recommended for anyone.

Considerations

- ◆ Alcohol can harm the heart by changing its **rhythm and weakening the heart muscle.**
- ◆ Many **medications**, including those used to treat CHD, can have harmful and sometimes very **serious interactions with alcohol.**
- ◆ If you have **CHD and a condition that affects your liver**, you should avoid alcohol.
- ◆ People with **Fontan circulation**, for example, **are at very high risk for liver disease** and should not drink alcohol because it can further damage the liver.
- ◆ If you have been drinking heavily (multiple drinks per day) and begin to feel **withdrawal symptoms** such as shaking, sweating, fast heartbeat, or irritability, you should **see a doctor** to help you reduce drinking safely.

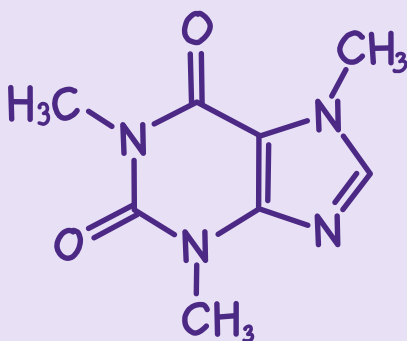
CAFFEINE



While caffeine may have some benefits, patients with CHD need to be aware of how it increases your heart rate and blood pressure, and is also a diuretic (see fluid management info in previous section).

Considerations

- ◆ Caffeine can negatively impact sleep and anxiety.
- ◆ You may need to limit use of caffeine, whether it be coffee, caffeinated tea (green and black tea) or soda (Coke, Pepsi), supplements, energy drinks, etc.
- ◆ Sometimes we don't realize we are consuming something that contains caffeine. Make sure to read labels!



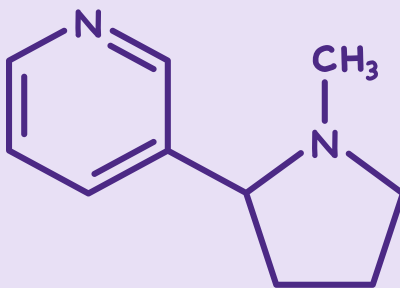
NICOTINE



Nicotine **increases** your **heart rate and blood pressure**, and can cause heart attacks and stroke. Using nicotine can also cause oral/dental health problems, which can in turn cause problems with your heart (*see dental care section*).

Examples

- ◆ Cigarettes & cigars
- ◆ Electronic cigarettes (“vapes”)
- ◆ *Smokeless Tobacco*: chewing tobacco, dip, snuff
- ◆ *Nicotine Products*: gum, lozenges, snus, patches



SMOKING



Smoking tobacco products has been shown to cause serious **harm** to both the **heart** and **lungs**.

Considerations

- ◆ People with **lung problems**, including those with **Fontan** circulation, should be **especially careful not to smoke**.
- ◆ To learn how to quit smoking, visit *Smoking and Your Heart* and *Your Guide to a Healthy Heart* listed below. Although these focus on heart health, they also include helpful information about quitting smoking.
- ◆ For free help and support to stop smoking, call the National Cancer Institute's Smoking Quitline at 1-877-44U-QUIT (1-877-448-7848).

Smoking and Your Heart
bit.ly/heart-and-smoking

Your Guide to a Healthy Heart
bit.ly/health-heart-guide

HERBAL & OTC SUPPLEMENTS



Supplements are readily available at many stores. Even products like these that don't require a prescription **can have unintended effects**, especially since they are not tested and regulated like other medications are.

If you are taking any over-the-counter (OTC) **supplements, herbal supplements**, or even **vitamins**, you should **let your doctors know** in case there is any reason you shouldn't be taking them or if they have negative interactions with your prescribed medications.

EMPOWERMENT

Supplements are not regulated the same way as medications, and providers **may not** have specific training or knowledge about supplements.

Supplement Considerations

bit.ly/supplements-info

HOW TO TALK TO YOUR DOCTOR ABOUT SUBSTANCES



It can be **hard to talk to your doctor** about substances (legal or illegal), especially if you think they may judge you in some way, but it is important for your overall health to make sure nothing you are taking or consuming is **causing unexpected harm** or has risks you aren't aware of.

We Will Go Over How To

- 1 **Build Trust**
- 2 **Focus**
- 3 **Ask for Clarity**
- 4 **Make a Plan**

Note: You don't have to discuss everything with one doctor. If you'd prefer, you can speak with another provider who's a better match for your needs and comfort level.

HOW TO TALK TO YOUR DOCTOR ABOUT SUBSTANCES



1

Build Trust: Being up front can help you build a trusting relationship with your doctor and allow them to better manage your health with you. You may not feel comfortable sharing right away, and that is okay.

2

Focus: Ask your doctor to explain how using the substance(s) relates to the issue you came to see them for. This can be helpful if you feel like your doctor is getting off topic and overly focused on your substance use, rather than your health concern.

3

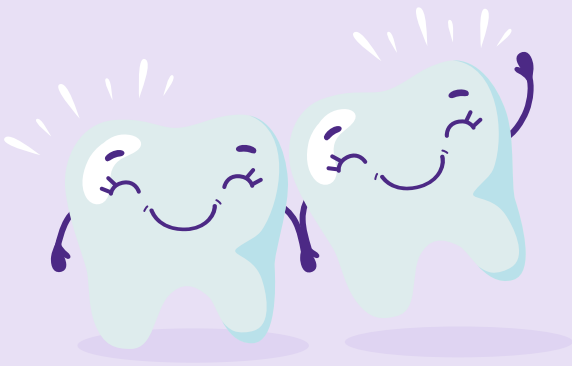
Ask for Clarity: If your doctor isn't explaining the risks or potential effects of the substance in a way you fully understand, ask them to explain it in a different way.

4

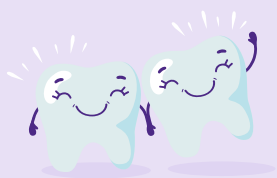
Make a Plan: Your doctor should work with you to make a plan that is realistic for you. Try to work together to come up with something that will be doable for you, even if it's a first step. Take notes or ask them to write things down for you that you need to remember.

Section 3

DENTAL CARE



DENTAL CARE



Dental care is **extra important** for those with **heart conditions** because of the risk of developing endocarditis.

What is Endocarditis?

An **infection** of the inner lining of your **heart's** chamber or valves. It is caused by a bacteria that enters into your bloodstream.

Symptoms

Symptoms can include: *fever, muscle aches, new/changed heart murmur, chest pain, fast heart rate.*

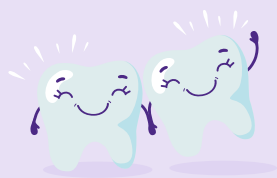
How Do You Get Endocarditis?

You can get **endocarditis** from bacteria entering through skin sores or small cuts in your mouth. This becomes **more likely when having a dental procedure** or when you develop a **build up of bacteria** in your mouth/gums.

Prevention

Your cardiologist may recommend taking **antibiotics before** your **dental appointment** to help prevent endocarditis ahead of time.

DENTAL CARE



Always **ask your adult congenital cardiologist** if you need to take antibiotics before your dental appointment — **recommendations may have**

changed since you last heard them. Your doctor may recommend taking **antibiotics 30 to 60 minutes before** your appointment to lower your risk of endocarditis.

Tips for a Healthy Mouth

- ◆ Have regular dental check-ups/cleanings (preferably every six months)
- ◆ Floss daily
- ◆ Brush twice a day
- ◆ Switch out your toothbrush every 3 months

Preventative Antibiotics Q&A

bit.ly/antibiotics-dental

When to Contact Your Dentist

- ◆ If your gums are excessively bleeding
- ◆ If you have mouth or jaw pain
- ◆ If you have mouth sores that don't heal

Section 4

SLEEP



SLEEP HYGIENE



Getting **good sleep is extremely important** for your overall health and wellbeing. It helps your body with regulation of hormones, metabolism, brain function, circulation, respiratory system, and immune system function.

Adults generally need between **7-9 hours of sleep** per night, consistently. Along with how long you sleep, you also need to get good quality sleep (minimum interruptions).



PEER-EMPOWERMENT

Joe Valente, *Tetralogy of Fallot*

“After my open-heart surgery at 6 years old, I could not feel my heart beating anymore because the repair had fixed my near-constant arrhythmias. Not understanding what had happened, I never wanted to go to sleep because I thought my heart was not beating anymore. These sleep issues have plagued most of my life, and it was not until I saw a **sleep psychologist** that I was able to get proper sleep.”

SLEEP HYGIENE TIPS

- ◆ Set aside time before bed to “**wind down**” from the day.
- ◆ Create a **bed time routine** to let your body and mind know it is time to sleep.
- ◆ Try to wake up and go to bed at the same time **every day**.
- ◆ Make sure your sleep environment is **comfortable** for you.
- ◆ If you have trouble falling or staying asleep, a **sound machine** may help you sleep more soundly.
- ◆ If you have a hard time falling asleep, you may find a **guided meditation** or other calming sound helpful in getting your body and mind to relax.
- ◆ Turn your phone on “**do not disturb**.”



SLEEPING WELL WHILE YOU HEAL



Sleep problems are common for people with CHD, especially during recovery. Pain, discomfort, and medication side effects can make it hard to rest when your body needs it most.

Considerations

After a procedure, you might have more trouble sleeping because of pain or discomfort.

- ◆ Noise-canceling headphones can help block unwanted sounds.
- ◆ Use extra pillows and an eye mask.
- ◆ You may need to sleep on your back, which can feel uncomfortable.
- ◆ An adjustable bed or recliner can help you find a more comfortable position.



PEER-EMPOWERMENT

Lindsay Alano, Heart and Liver Transplant Recipient

“After my transplant, I couldn’t sleep on my side and needed extra support. My OT suggested a pregnancy pillow. The pillow was a total game changer for easing hospital discomfort.”

SLEEP APNEA



Sleep apnea is **very common**, and many people don't know they have it. Getting checked is important because untreated sleep apnea can affect your **energy, mood,** and **heart health**.

Considerations

- ◆ People with sleep apnea often **snore loudly, choke or gasp** for air while sleeping, wake up with a **dry mouth**, and **feel tired** during the day.
- ◆ To find out if you have sleep apnea, or what type you have, your doctor may order a **sleep study**.
- ◆ If you have sleep apnea, it's important to get treatment so you can **breathe properly and sleep well**.
- ◆ Many people use a **continuous positive airway pressure (CPAP)** machine while sleeping to help them breathe more easily.
- ◆ CPAP machines have **different mask options**, and you may need to try a few before finding the one that fits you best.
- ◆ There are also other treatments available that you can ask your doctor about.

Section 5

TRAVEL

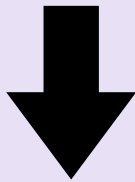


TRAVEL TIPS & CHECKLIST



Traveling, especially with a chronic condition like CHD, can sometimes feel stressful and bring unique challenges, but planning ahead can help you stay **prepared and confident** along the way.

- 1 **Plan for Emergencies**
- 2 **Prepare Your Medications and Equipment**
- 3 **Air Travel and Special Considerations**
- 4 **Stay Comfortable and Healthy**



**HAVE
FUN**

PLAN FOR EMERGENCIES

1

Before you travel, find out where the nearest Adult Congenital Heart Disease (ACHD) Center is located at your destination. You can search the ACHA provider directory below.

Download Travel Directory

bit.ly/acha-pdf-directory

Consider buying **travel insurance** in case you need medical care while away from home.

Wear an emergency **medical ID** that lists your heart condition, allergies, and emergency contacts. You can find examples at [GetMyID.com](https://www.getmyid.com).

Carry a Heart Passport—such as the **EmpowerMyCH Medical Passport** and emergency information in your phone. *This should include:*

- ◆ Most recent History and Physical (H&P) from your ACHD cardiologist
- ◆ Diagnoses, surgeries, procedures
- ◆ Medications and doses
- ◆ Names and contact information for your doctors and emergency contacts

PREPARE YOUR MEDICATIONS AND EQUIPMENT

2

- ◆ Bring all your medications, plus extra in case of travel delays.
- ◆ Keep your medications in your carry-on bag—never check them in your luggage.
- ◆ Know the location of a local pharmacy at your destination.
- ◆ If you have a device (like a pacemaker or defibrillator), carry your device ID card and information.
- ◆ Get your device checked or optimized before your trip, and bring any remote monitoring equipment with you.
- ◆ Bring other medical devices you use regularly, such as your CPAP machine. For battery-powered devices (like LVADs), bring extra batteries, chargers, and extension cords.
- ◆ Pack a pulse oximeter and blood pressure monitor so you can check your readings if you feel unwell.

AIR TRAVEL AND SPECIAL CONSIDERATIONS

3

- ◆ Ask your cardiologist if you need oxygen while flying, especially if you have cyanotic CHD or Eisenmenger syndrome.
- ◆ If you need help at the airport, request wheelchair assistance in advance.
- ◆ Bring your cane or other mobility aids if you use them.
- ◆ If you have a pacemaker or ICD, let TSA know you cannot go through the metal detector
- ◆ People with cyanotic CHD can read more about special travel precautions in this study: [**bit.ly/aha-travel**](https://bit.ly/aha-travel)



Read More

CHD & Air Travel

bit.ly/chd-air-travel

STAY COMFORTABLE AND HEALTHY

4

- ◆ Avoid traveling to **high altitudes** or very remote areas without checking with your doctor first.
- ◆ **Compression socks** can help reduce leg swelling and lower your risk of blood clots.
- ◆ Bring your **own snacks, water, and electrolyte drinks** to stay hydrated and avoid sudden changes in diet.
- ◆ **Avoid traveling soon before or after a major surgery** unless your doctor says it is safe to do so.

MOST OF ALL
have **FUN**