A Teen's Guide to Medical Transition

Put a selfie here!

Your Name:

_____

Your Age:

_____

Your School:

_____

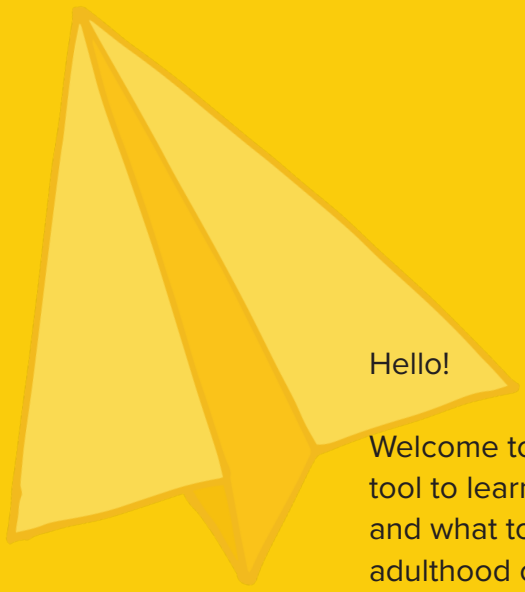
Your Favorite Things to Do:

_____

_____

_____

_____



Hello!

Welcome to your health care transition guide. Your tool to learn about the coming years in transition and what to expect along the way. Transitioning to adulthood can be confusing for everyone, but we're here to help you explore some ways to navigate through all the changes.

Take this book and make it yours by completing the activities in each section. Use this guide to learn how to be a self-advocate, schedule appointments, talk to your new doctors, and ask great questions so that you can keep getting the best care from your new doctors and their staff.

Let's get started!

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Section 1

Me and Myself

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What to Expect in Transition

Transition happens to everyone. Your body starts growing and developing. You experience new emotions. You start taking on new responsibilities. And eventually it will be time to see a new doctor so you can keep getting the best care.

It's OK if it feels overwhelming sometimes, but it's nothing to be scared of. The more you know and practice new skills, the more prepared you'll be by the time you reach adulthood.

Here are a few tips to help you get ready to visit your new doctors.

1. First things first, your doctor's visit is about you! If you don't understand what the doctor said, ask questions.

2. Make sure your doctor is talking to you, and not just your parent. If your doctor is only talking with your parent, ask your parent to help redirect questions to you. Practice asking your questions at home or in the car before you get to your appointment.

3. As you get older, you deal with new things. Be ready for your doctor to ask you some embarrassing questions about your friends, drugs, alcohol, and even sex.

Starting at age 16, you have the legal right to have your parent leave the room to talk to your doctor in private. This is a safe place to ask your doctor about your changing body or the things going on. These topics are a part of growing up!

4. Your new doctors might have different expectations for you at the appointment. For example, adult doctors often have less time for each appointment. So don't take it personally if they ask you more questions with yes or no answers or if they seem in a hurry.

It doesn't mean you shouldn't ask all of your questions. It just means you need to be more prepared and ready to speak up!

5. Take notes; it'll help you stay in charge! Bring a pen and paper, or use the back of this book to write down reminders, future questions, or to-do lists. Your future self will say "Thank you!"

New Words

Growing up means getting to do new things. Stay ahead of the game by learning these new words!

"Age Out": means you can no longer keep seeing that same doctor or receiving that service because you are 'too grown up.' This happens at different ages for different services, but will start at age 18

Family Doctor: Doctor who is trained to take care of patients of all different ages. You can see a Family Doctor no matter your age

Provider: Another way to say "doctor"

Primary Care Physician ("PCP"): The main doctor you visit for regular checkups

Referral: A referral is when your doctor tells you to see another doctor, like a specialty doctor. There are many speciality doctors, such as for your leg, heart, back or head

Pediatrician: Doctor who only sees kids. Depending on the doctor, you can see that doctor up until you turn 18 or later

Prescription: Your doctor has to write to a pharmacy to say you're allowed to take this medicine. When you "fill" a prescription, you go to a pharmacy counter and pay them for the medicine

Medical History: Medical conditions you've had in the past and what medicines or treatment you took for them. Your doctor keeps track of your medical history at their office, and you can ask to have your own copy

Medical Summary: The diagnoses you have now, the medicines you are taking now, any allergies you have, and any important parts of your medical history

Insurance: Something that you or your parents get to help you pay for medical care

Medicaid: is one 'brand' of insurance. It is free or low-cost insurance for people with disabilities, the elderly, or people who are "low-income"

Medicaid Waiver: Services and supports that some people with disabilities get to help live and work in their home and community

Medicare: is another 'brand' of insurance. It is also free or low-cost, typically for the elderly or people with certain disabilities

Insurance Card: Your card that says which company your doctor should bill for your medical care. Always bring this to your doctor's appointments

If you come across some new and confusing words - write them down in the open space and ask an adult to explain them to you!

Your Strengths

Sometimes transition can feel like a lot of new things you have to learn how to do. But don't forget that you are already great in so many ways! Your strengths can be something you naturally do well or it could be something you work to achieve.

Name 3 things you think you're *good* at:

1

2

3

Name 3 things you have done that you feel *proud* of:

1

2

3

Work with someone else, like a friend or parent, to remember 3 moments where your strengths stood out!

Write them in the spaces below!

Find Your Strengths

Strengths don't have to be things you do but can be qualities you have.

Circle the traits you think describe you!

Bravery
Facing challenges and difficulty even if people oppose you

Creativity
Imagining new and different ways to think and do things

Honesty
Speaking the truth and being sincere in your actions

Hope
Expecting the best in the future and working to achieve it

Fairness
Treating all people the same and giving everyone an equal chance

Social Intelligence
Being aware of the feelings of others and knowing what to do

Spirituality
Having beliefs in a higher purpose and meaning in the universe

Perseverance
Finishing what you start and continuing to try despite obstacles

Judgement
Thinking through all sides and not jumping to conclusions

Precaution
Being careful about your choices, not doing things you will regret

Teamwork
Working well as a member of a group or team and being loyal

Forgiveness
Forgiving those who have done wrong and accepting others' faults

Enthusiasm
Approaching life with excitement and energy

Curiosity
Taking an interest in different subjects and exploration

Appreciation of Beauty
Noticing and appreciating beauty in the things around you

Gratitude
Being aware of and thankful for the good things that happen

Kindness
Doing favors and good deeds for others, thinking of others

Love
Valuing close relationships with others and being close to people

Humor
Liking to laugh and bring smiles to other people

Leadership
Encouraging a group to work together and get things done

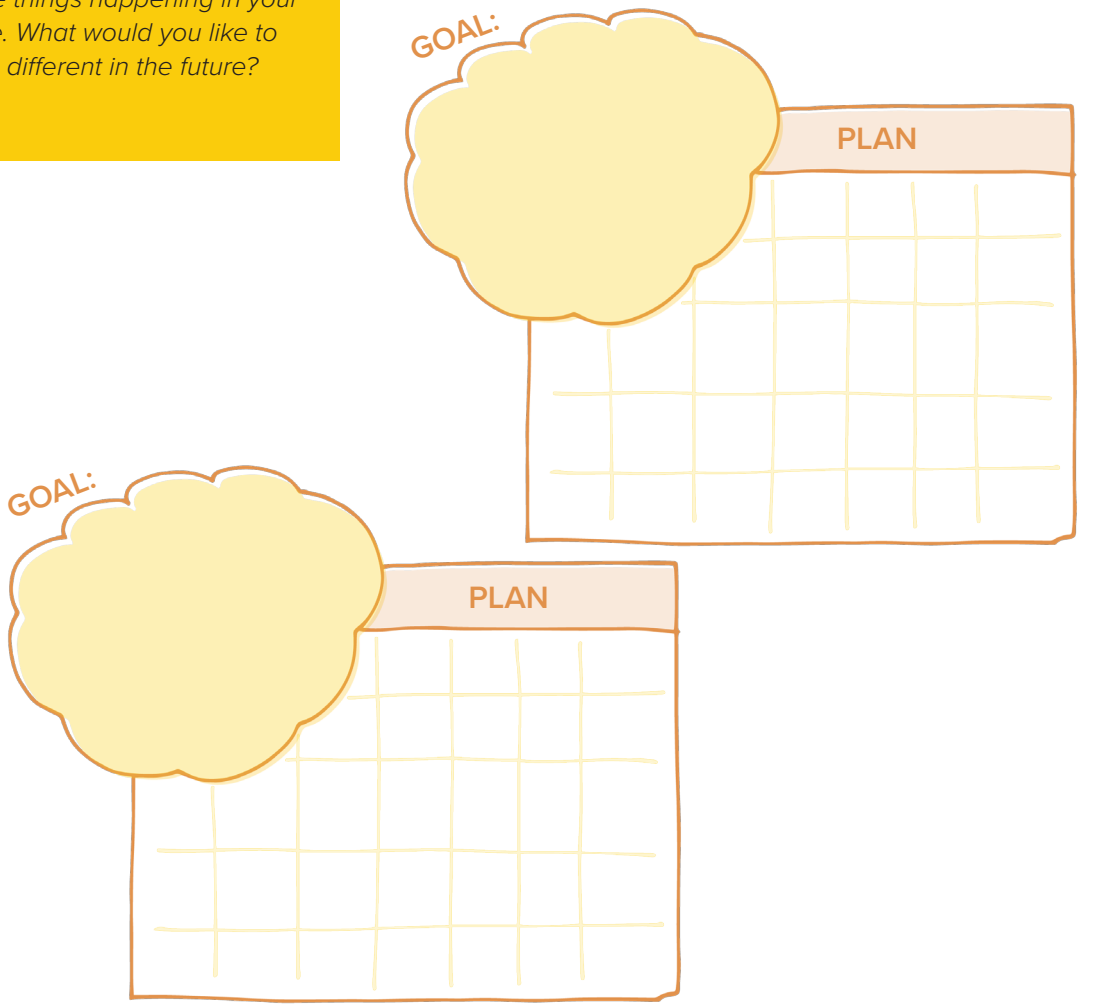
Adapted from the VIA Institute of Character.

Goals

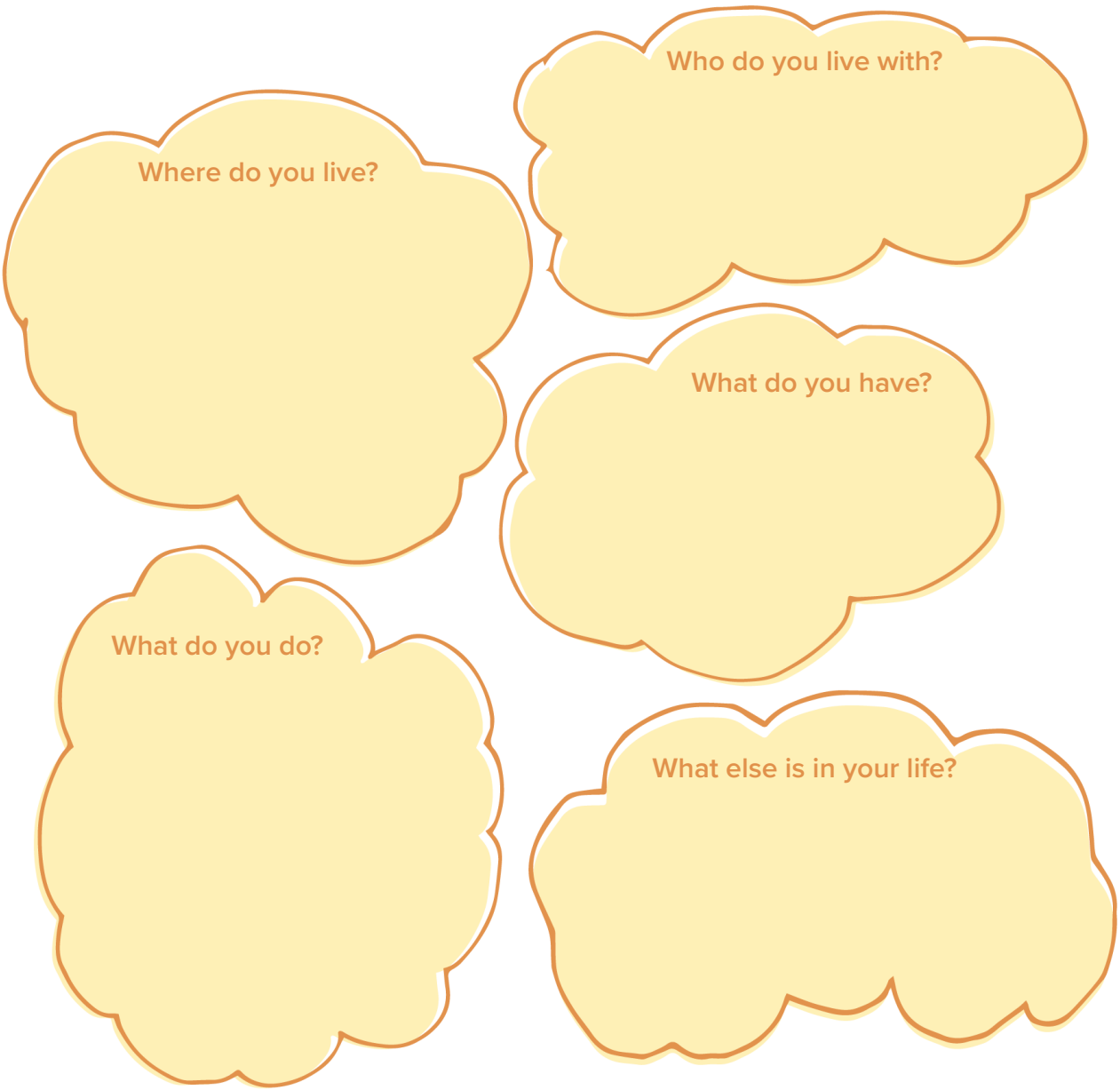
Transition is all about growth. You can shape your future by making goals and working towards them. Setting goals will help you choose where you want to go in your life.

Take a minute and reflect on who you are right now, and the things happening in your life. What would you like to be different in the future?

What are 2 goals you have for the next year?



Imagine yourself in the far-away future. What does your life look like?



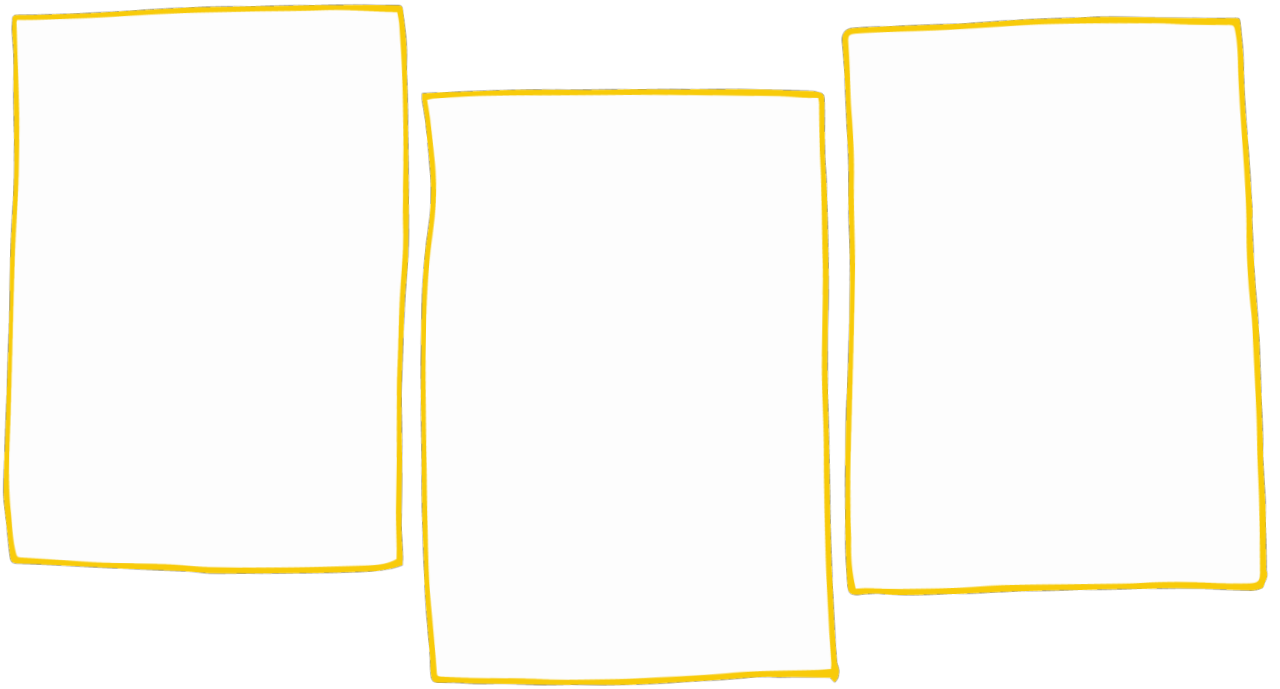
Take Care of Your Emotions

Transition and growing up can be really hard! If you're feeling stressed, anxious, or upset, remember to stop and take care of yourself. In the moment, try to do something that you know calms you down. Take this time to prepare tools for yourself that will help you throughout life.

What are 3 ways that help you to calm down?

Write or draw 3 specific things that have helped you.

(Ex. Listening to music, texting a friend, journaling alone)



Assess the Situation

Use these questions each time you get upset. They will help you understand yourself and what you need.

1. What is the feeling you have? What happened?

2. What do you want to be different about the situation?

3. What do you want to ask for from others?

I've been feeling _____ recently. Can I talk to you about it?

_____ happened to me the other day. What do you think I should do?

When you did _____ , t made me feel _____.

Next time, can you please do _____ instead?

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Family

As you start to feel more like an adult, you might want to be treated differently by your parents. As you get older, you can do more things for yourself, but adults might have a hard time letting you grow up. They've known you since you were little, and to them you might always be their "baby." Even if they can be annoying, your parents really do want the best for you.

Communicating with your parents calmly and confidently will show them just how mature you are. Even when you feel frustrated, try not to use an angry voice.

Try some of these statements to the right!
Circle the ones you want to use with your parents or other adult family members. Try each one by saying it out loud and seeing how it feels.

"I think I can do it on my own. Please believe in me."

"Thanks for trying to help me, but I want to try to do this by myself."

"I want to learn how to do this. Can you do it with me until I think I can handle it alone?"

"I know this is something I am working on, but I think trying it by myself is the best way for me to practice."

"It's important to me to challenge myself today."

Write your own:

"I want to do this on my own. If you think I am failing, please wait until I ask you for help."

Friends

Friends can be some of the most important people in your life. Some friends have grown up with you for a long time, but other friends are new.

You Change, And Your Friendships Will, Too

As you become older, you change. What you like might change and what your friend likes might change, too. You can still stay friends, but it's also natural if you grow apart. You don't have to like or do everything your friend likes, especially if it's not something you want to do.

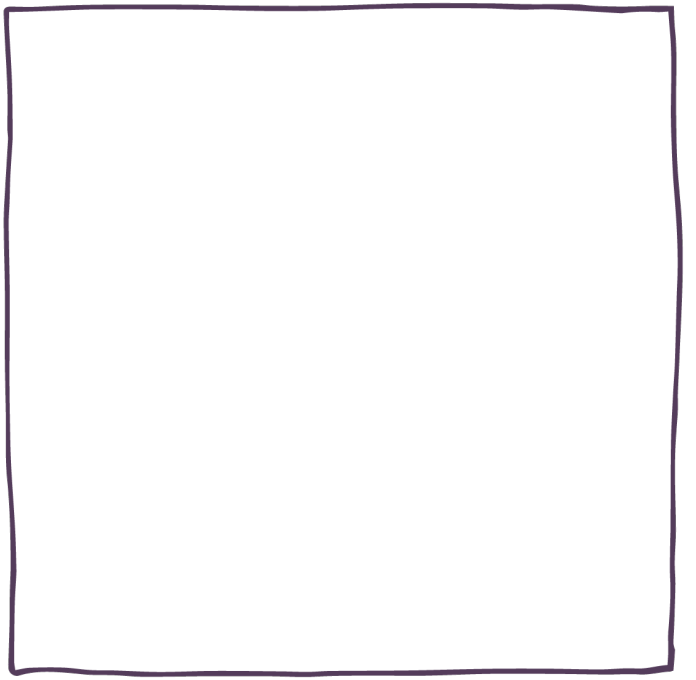
Peer Pressure

As you get older, some of your friends might get more curious about things that are dangerous. They might try things like drugs or alcohol that your parents or teachers won't approve of. They can say or do mean things to others to exclude people or put people down.

If you see this happen, or if someone invites you to do it, stop and think about it. Remember who you are, and stay true to that. A good friend will understand even if they disagree or act differently.

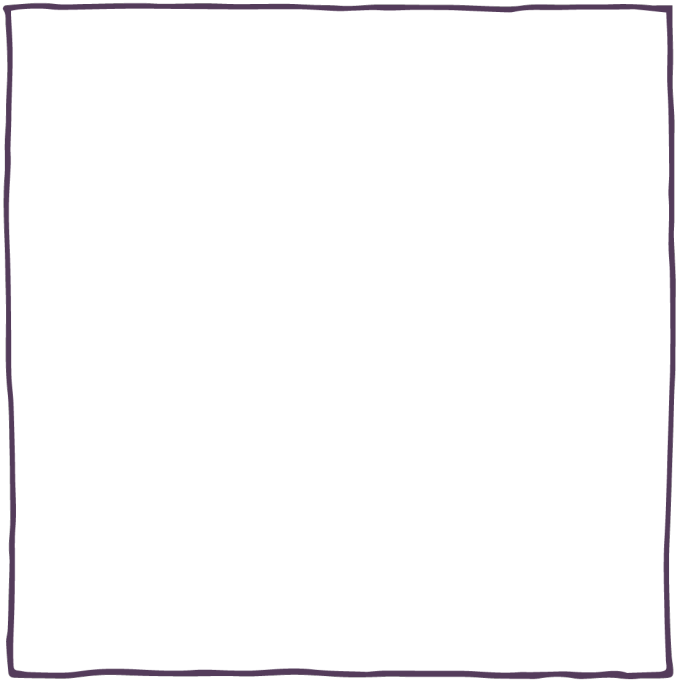
Think of a time that you were the happiest with your friends.

In the space, write and draw how that felt.



Has a friend ever done something you didn't want to do?

In the space, write and draw what happened.



Dating & Relationships

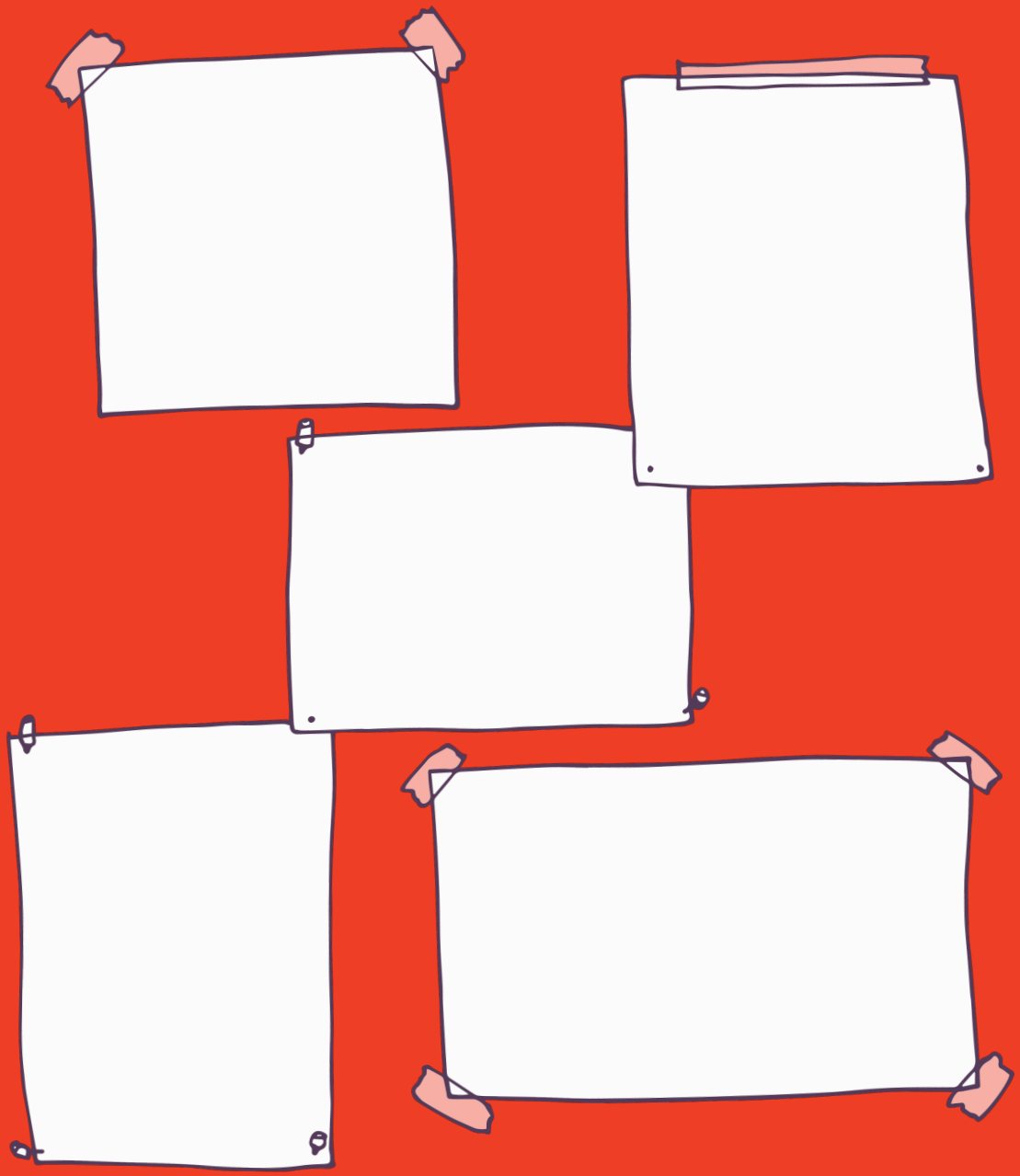
As you grow up, you might start wishing that you could go on a date or have a boyfriend/girlfriend. Crushes and relationships are a part of what happens when you become an adult, but everyone starts having relationships at different ages. No matter what medical or health conditions you have, wanting relationships is a very natural part of becoming an adult.

Don't worry if you feel like you're "late" to having a relationship. These things happen at different times for everyone.

A big part about being attractive and having a successful relationship is loving yourself. If you love yourself, it makes it easier for others to love you too.

Write 5 things you love about yourself.

Make sure it's a mix of things about your personality and your body!



Sex

As you grow closer to being an adult, you might have the urge to touch others in private places or to have sex. Or, maybe your boyfriend or girlfriend will suggest that they want to have sex with you.

It's Okay to Say No

Even if it seems like the other person really wants to, remember that it's your body and your right to say "no." Sex can be very painful if you don't actually want it. You might say "no" because you're not interested, you're not ready, it's not the right time, or you simply just don't want to. Any reason you might have to say "no" is okay.

Can You Get Pregnant?

If you have any questions about whether you can have sex or get pregnant because of a physical condition, your doctor is the best person to ask. As you start to get older, your doctor will start setting aside some time during appointments to talk alone. That's a perfect opportunity for you to ask!

Communication is Everything!

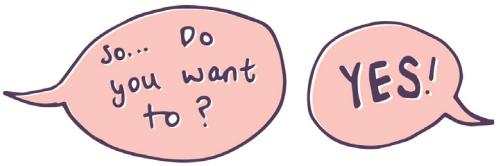
Good sex requires good communication. Be honest and speak your mind, it will bring you closer together.

Ready to say "Yes" ?

Here are three important things to keep in mind:

1. Consent

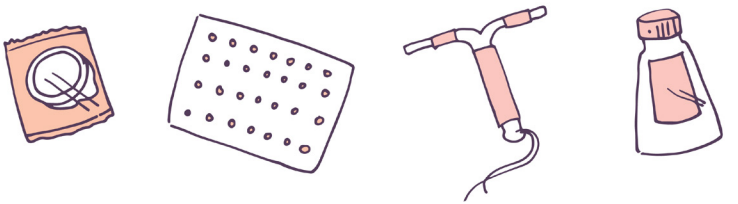
This means you ask each other if you want to be touched and you both clearly say "yes"–every time. If you don't want to have sex right now, it is 100% OK to say "no." In a good relationship, your partner will understand and respect your decisions.



Only say "yes" if you really mean it!

2. Safety and protection

This means using safe practices to protect you from unwanted pregnancy and diseases that only get passed on through sex. If you have questions about what that means or what you can use to stay safe, ask a parent or adult. Online information can help, but it's best to talk to your doctor or nurse who you can trust.



3. Trust and emotional health

Sex and touching is a very intimate, personal activity. You should only do it with a person you know you can trust, who you are close to and treats you right, both physically and emotionally.

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How to Talk to Your Doctor

Here are the three most important things you might want to talk with your doctor about before your appointment is over. Remember, your doctor only has 5 minutes, so try to practice!

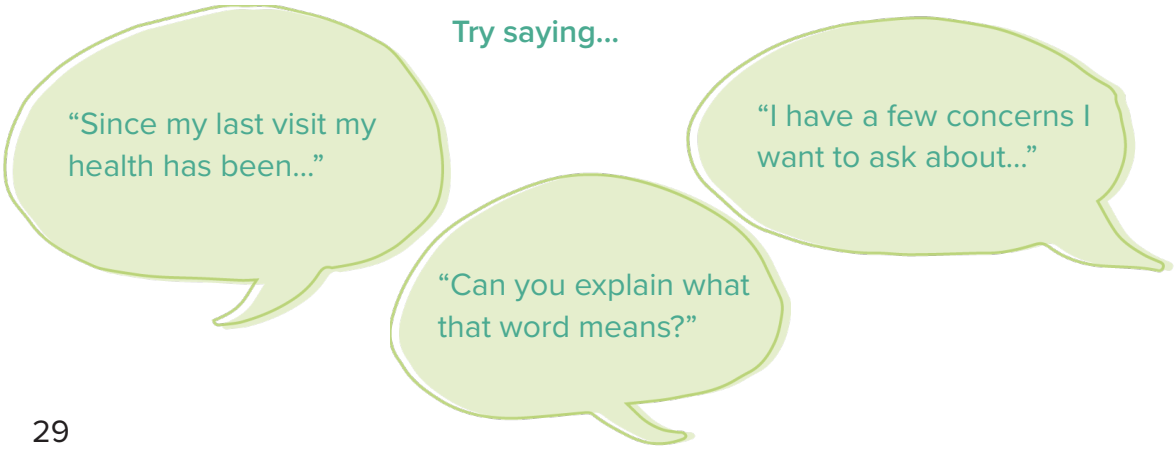
Know your rights!
Once you turn 16 you can request for your parents to leave the room so you can talk to your doctor alone.

1. Tell your doctor if your health has changed or stayed the same since your last visit
   For example, are you coughing more?
   Do you have a sore that has not been healing?
   Are you feeling more tired during the day?

2. It's okay to ask questions if you don't understand something. If your doctor uses a new word you don't understand, you can ask them to explain what they mean. They are here for your care.

3. Don't be afraid to tell your doctor what is going on with your body, and be honest with them.

Try saying...



Prepare for an Appointment

You can make the most of your routine appointments by preparing and gathering everything you will need the night before.

Prepare

1. Know what you want to ask your doctor about. It helps to write a list of questions down.

2. Bring a list or the bottles of the current prescription medications you are taking.

3. Bring something that will help you relax in the waiting room, such as a book to read, a game to play, or music to listen to.

What to Bring: Routine Appointment

- ☐ A list of health concerns and questions
- ☐ Insurance card
- ☐ A list of current medications or all your medication bottles
- ☐ Something to help you relax

Make an Appointment

With your parent, use this script to rehearse the phone conversation to practice setting up a doctor's appointment.

Gather the information you need to make an appointment.

Telephone number
Provider's name
Your insurance name
Your availability

Secretary: Hi, Dr. _____'s office, this is _____ speaking. How may I help you?

Patient: Hello, my name is _____ and I'm calling to make an appointment with Dr. _____.

The reason that I am making the appointment is _____.

Will they take my insurance?
If you're setting up an appointment with a new doctor's office for the first time make sure to ask if they take your insurance!

Secretary: Hi _____. Sure thing. Dr. _____ is not available until the week of _____.

Do you prefer mornings or afternoons?

Patient: I prefer an appointment in the _____.
Both the morning and afternoon are fine with me.
That week is very busy for me. Is the doctor available anytime the week after?

Secretary: How about on _____ at _____ am/pm?

Patient: Yes, that works for me!
I can't make that.

Secretary: Great. Your appointment is confirmed. Please give me your contact information.

Patient: If the office needs to contact me back, they should contact _____.

This person is my _____ *(ex. parent / caretaker)* and their phone number is _____.

Secretary: Okay thank you _____. Do you have any questions?

Patient: How long will the appointment take?
Where is the office located?

Secretary: The appointment will take approximately ___ hour(s).

The office is located at _____.

Patient: Is there anything special I need to do to prepare, or anything special I should bring with me?

Secretary: Yes, you will need to _____
(ex. Make sure to not eat anything for 3 hours before / bring your medical history)
No, you do not need to do or bring anything.

Patient: Thank you! Bye!

Keep Track of your Appointments!

It can be a lot to keep track of all your upcoming doctor's appointments. Find a system that works for you to keep track of all your appointments. Here are some organization tips that you can try, or come up with your own!

1

If your doctor's office gives you an appointment card, put it in a pocket in the back of this book on the **Appointment Cards page (pg. 50)**.

2

Put it on your **phone's calendar**, or any scheduling app that you like.

3 Do you have another way to keep organized?
Write down your plan here!

Insurance

Doctor's appointments and health care costs can be really expensive. You may not have to worry about that yet, but it's good to get started on learning for the future.

Health insurance helps manage the costs. When you turn into an adult you will "age out" of being on your parent's insurance. You'll need to make sure your doctors accept your new insurance plan!

There are many "brands" of insurance companies with different kinds of plans that cover different medical needs. Most people with disabilities will have either Medicaid or Medicare, but there are many other options out there.

What does insurance cover?
Doctor's appointments, medication, and even transportation sometimes! Ask your insurance company about some of these benefits.

You can have more than one insurance!
Even if you're still on your parents insurance, you can sign up for your own and use both. Your parents insurance will be listed as secondary insurance.

Ask your parents or other adults to answer the following questions.

Insurance is a very complex topic -
don't be surprised if your parent or adult has to look it up!

When do I "age out" of my parent's insurance?

How will I know if a doctor will be covered by my insurance?

What "brand" of health insurance do we have right now?

How do I know if I can get Medicare?

How do I know if I can get Medicaid? What about a Medicaid Waiver?

Will my health insurance cover all of my healthcare needs? (for example: supplies, home aide, therapy, etc.)

Finding a New Doctor

If you currently see a pediatrician, you will have to switch to an adult doctor eventually. Ask your doctor at your next appointment when you "age out" of their care.

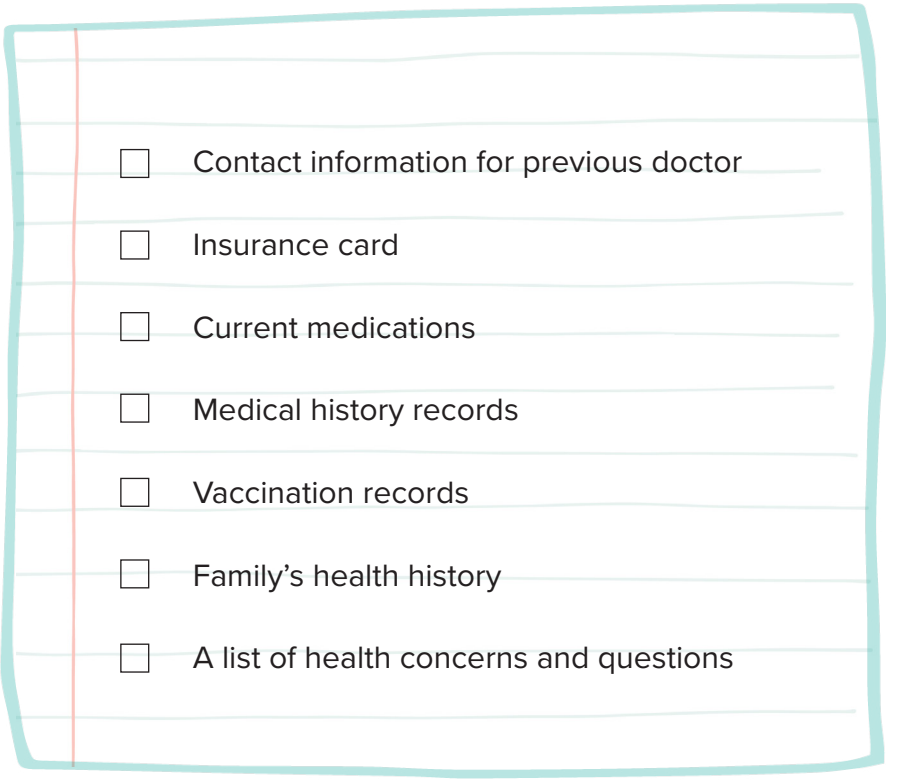
If you also go to a clinic for your specific medical condition, you should ask them if you can continue seeing them when you are an adult, and if not, if there is an adult clinic for your condition.

How do you know who is a good adult doctor?

You can try asking your current doctor for recommendations or see if any of your family or friends have recommendations. It is a good idea to try having the same family doctor as your parent.

Try interviewing an adult about what makes a "good" doctor for them.

What to Bring: New Appointment

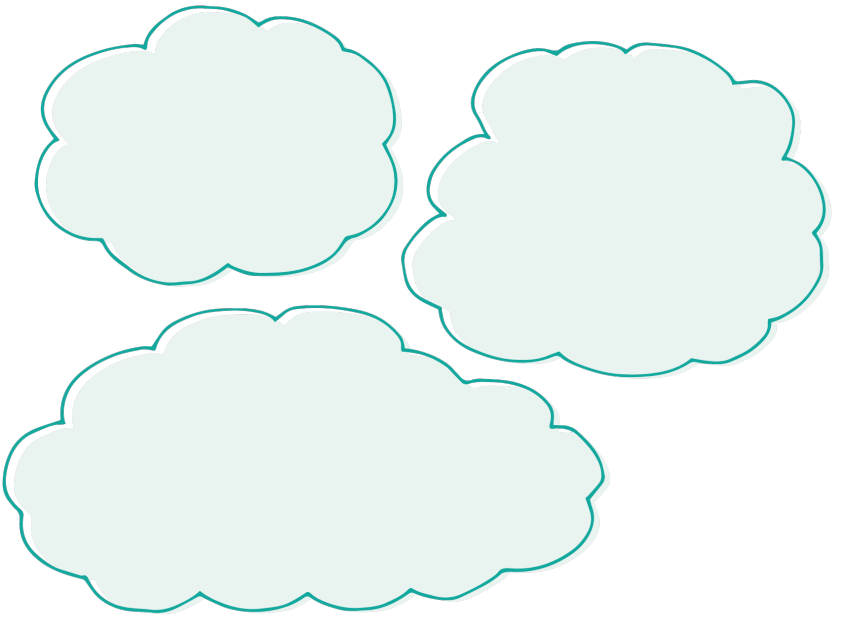


- [ ] Contact information for previous doctor
- [ ] Insurance card
- [ ] Current medications
- [ ] Medical history records
- [ ] Vaccination records
- [ ] Family's health history
- [ ] A list of health concerns and questions

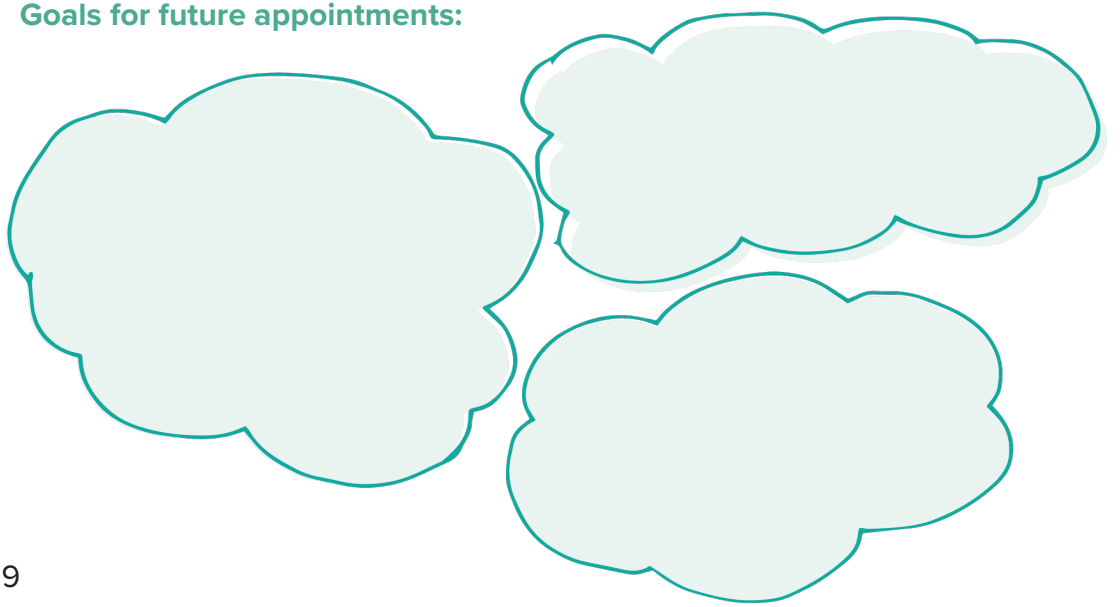
New Appointment Goals

Set some goals for yourself before your first appointment. *This could include things like talking to your doctor yourself, taking notes during the appointment or following up on any referrals or presciptions your doctor gives you.*

Goals for your first appointment:



Goals for future appointments:



After Appointment Checklist

- [ ] Do I know when the next appointment with this doctor will be?
- [ ] Do I need to fill a new prescription?
  - [ ] Do I know where to get the prescription?
  - [ ] Do I know when to take the medicine?
  - [ ] Do I know when to stop taking the medicine?
- [ ] Do I need to see a specialist?
  - [ ] Do I know who to call?
- [ ] Do I need to get any tests done (ex.: bloodwork)?
  - [ ] Do I know who to call?

Referrals

Did your doctor refer you to another doctor?

Go through this list of questions and think about what you know and what you still need to ask to be prepared to see a specialist.

Speak up!
Doctors might forget to tell you some of these details—but you can use your voice to advocate for yourself.

Additional Tests

If your doctor has ordered tests that have to go to a lab, such as X-rays or bloodwork, these questions can help you think through all the steps to getting those tests done.

Getting the test

- What is the name of the test or procedure?
- Are there special instructions? (Ex.: Fast for 12 hours before the test)
- How will I learn the results of the test?
- What will I need to do after learning the results?
- What will the test or procedure be like? (Ex.: Will there be strange sounds or sensations?)

Scheduling

- When will the test or procedure be done?
- Where do I go to have the test or procedure done?
- Who do I schedule the appointment with?
- Do I just show up or do I schedule an appointment?

Prescriptions

Got a new prescription from your doctor, or changed the dose of the one you were taking?

Make sure you know what the medicine is before you agree to take it. Sometimes a medicine can cause problems with medicine you are already taking, or the medicine could give you side effects.

If you are concerned about a medicine's side effects, speak up and ask your doctor if there are other medication options.

Use these questions on the right to check what you know and to ask what you still need to know.

Taking my Medicine

How and when will I know if it is working?

Do I need any accessible supports to take my medication? (Ex.: Talking prescription bottles, brailled prescriptions, medicine organizers?)

What is the name of the medication?

How many pills or how much liquid do I take?

When do I take the medicine?

When do I stop taking it?

Side Effects of my Medicine

Will it be okay to take this with my current medicine?

Would smoking and drinking affect my medication?

What side effects could happen?

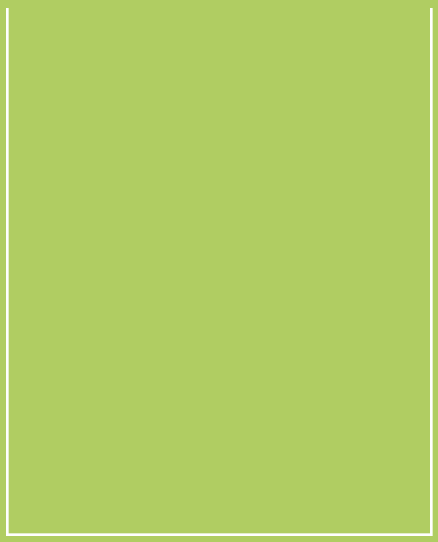
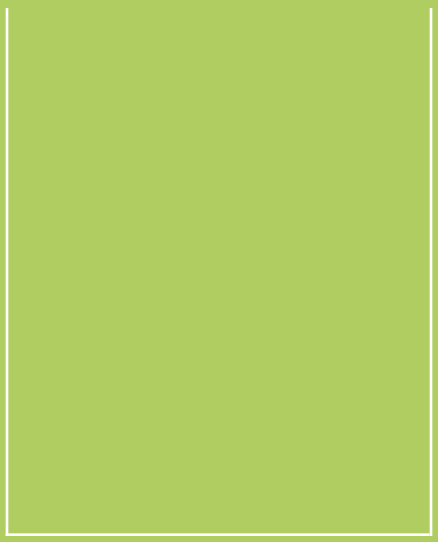
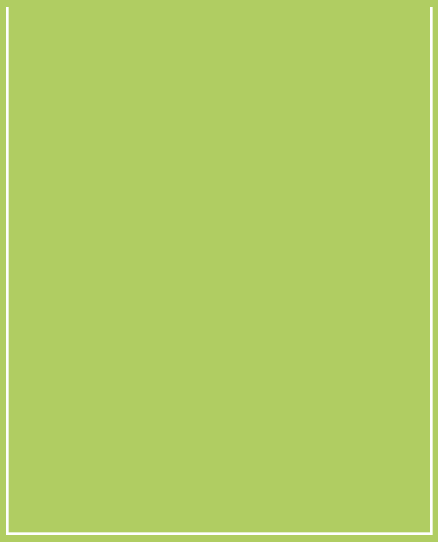
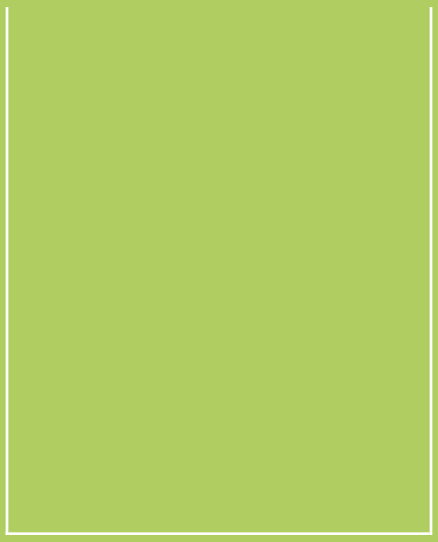
Do I need to store the medication in a special way?

Take Notes

Write down what you've learned that might help in the future. It might be about yourself, other people, or your health.

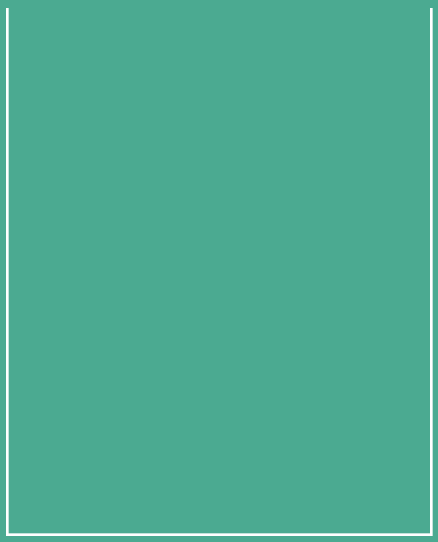
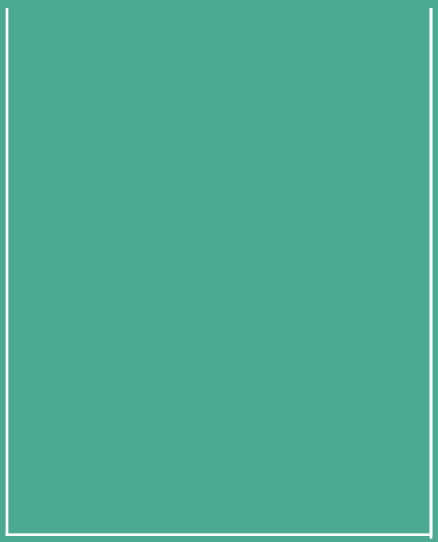
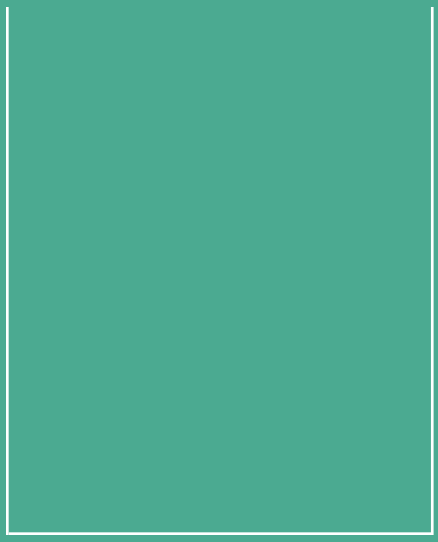
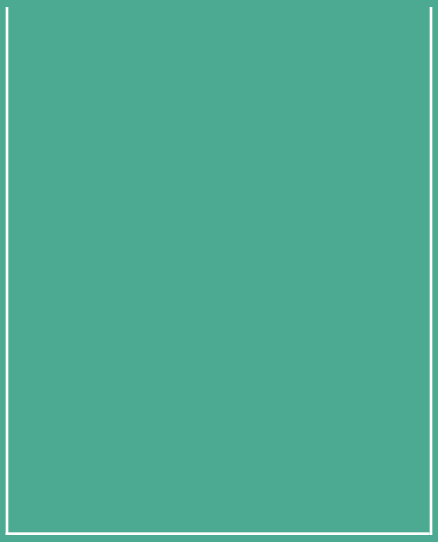
Business Card Gallery

It can be a lot to remember all of your doctors' contact information. Store their business cards in these pockets for future reference!

Appointment Cards

Don’t know where to put those handy appointment cards doctors give you to help remember when your next appointment is? Store them here!

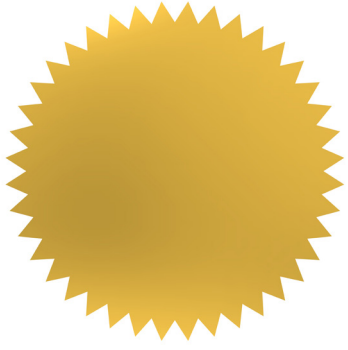





Certificate of Completion

To recognize that

_____

has completed their transition guidebook and learned what steps they need to take for a successful transition!



Doctor

Parent

RHLC
Regional Health Literacy Coalition

The Regional Health Literacy Coalition works with communities, health care providers, universities, and you to make health care in Western Pennyslvania person-centered and easy to use.

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Learn more at www.ahealthyunderstanding.org

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A Teen's Guide to Medical Transition was developed with the oversight of the Regional Health Literacy Coalition and is intended for the use of teens and health advocates everywhere.

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