

Skills and Strategies
for Health Care
Decision-Making
with Children



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to view this resource online

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Description of Resource

Being a decision-maker for your own healthcare is important. Families and healthcare providers want children to become good decision-makers. For some children this takes more support, practice, and some special tools. Learning this skill should begin in **childhood** and continue into adulthood. This guide and its resources help families and healthcare providers **support children to learn the skills they need.**

Getting ready for a visit to the doctor, dentist, or other medical person is step one. Being at your appointment is step two. Knowing what to do next, after your appointment, is step three. We want to help with all three steps.

We often think about what a child should do at a certain age. But every child is different and learns in different ways. This tool uses *stages* of skill development instead of ages. It includes:

1. Choice-Maker

2. Question-Answerer

3. Decision-Participant

4. Decision-Maker

The resource section has a lot of ideas to help you. There are some **apps** you could use on your tablet or smartphone. There are some other things you can do or read on your **computer**. There are **toys** you can buy at a store or **online**. Some things can be used in the doctor's office. We have tried to make our list so that you can easily see which step our resource might work best with. We also put what stage a tool or strategy might help with. Some ideas are good for more than one stage and more than one step.

Stage Definitions

- 1. Choice-Maker:** A choice-maker child is a beginning communicator. This child has listening skills. They have preferences, and are beginning to communicate them.

Your child may be a choice-maker if they...

- Can communicate "yes" or "no" with accuracy
- Respond to "Want up?"
- Recognize themselves in the mirror
- Point to named body parts
- Prefer one toy over another

To build upon the choice-maker's strengths, a caregiver may ask what toy or food their child wants: "This, or that?" Practicing small decisions can help a child to begin choice-making.

- 2. Question-Answerer:** A question-answerer is an individual who has growing communication skills. The strengths of a question-answerer are curiosity and observation.

Your child may be a question-answerer if they...

- Copy others
- Can follow directions such as, "Please stand up and come here."
- Show self-initiative by choosing when to follow directions
- Answer "wh" questions: what, where, why, when
- Ask simple questions
- Match a picture of a body part to their own body part

A caregiver can ask a question-answerer child their preferences. Caregivers can also answer questions that their child asks and ask follow-up questions. These talks can lead to a child growing their communication skills.

3. Decision-Participant: A decision-participant can tell others about their preferences. They can easily take part in making decisions. Building confidence and independence are important for this child. They can set personal goals and participate in problem-solving. They also may be able to help in planning.

Your child may be a decision-participant if they...

- Can identify more than 4 body parts
- Can identify what key body parts do: for example, that the heart pumps blood, or that the lungs help you breathe
- Pick an option from a list: "Would you like to go to the park, draw a picture, or help me make lunch?"
- Choose an option without a list: "Please pick out what you'd like to wear today."
- Begin to talk about future activities

One important part of decision-making is understanding the future. The future gives information about the consequences of a choice. A caregiver can help their child by pausing in reading a story, and asking what their child thinks will happen next.

4. Decision-Maker: A decision-maker has advanced skills of communication. They understand the future, and think about others and themselves.

Your child may be a decision-maker if they...

- Answer questions about themselves or their surroundings
- Ask questions when confused
- Think about consequences for themselves and others
- Almost always follow a daily task, such as taking a pill
- Enjoy acting independently

Decision-makers are able to make choices for themselves. They can still build skills and confidence. Caregivers can think out loud when making decisions for themselves. This can help grow their child's decision-making skills even more.

1. Choice-Maker

Preparing for Appointments	At the Appointment	Appointment Follow-up
<ul style="list-style-type: none"> - Role play with your child, such as using a toy stethoscope on a stuffed bear. If you have access to a real stethoscope use it with the child so they can be prepared for how it feels (cold, hard). - Read children's stories or look at pictures in books about children going to the doctor. - Read a social story every day for a week before your doctor visit. Try to have pictures of the doctor, nurse, office waiting area, exam room, etc. This will help your child to know exactly what to expect. - Practice labeling body parts on a picture. 	<ul style="list-style-type: none"> - Bring your social story to the appointment so that your child can look at it in the car and/or while they are in the waiting room. - For children with ASD or anxiety, bringing a bag of sensory items the child finds calming can help them with waiting. - Have a picture(s) of the body that your child is familiar with so that they can show the doctor where they hurt, or the doctor can show the child where they will be touched. 	<ul style="list-style-type: none"> - Talk about your appointment with your child and praise them for what went well. Assure them that if there were moments of struggle, that you will try to find a way to make it better next time. - If there are follow-up appointments, prepare ahead using the strategies that worked well for the previous appointment. - Create a visual schedule that goes along with instructions or new medications from your appointment (e.g. "First take pill. Then brush teeth.")

2. Question-Answerer

Preparing for Appointments	At the Appointment	Appointment Follow-up
<ul style="list-style-type: none"> - Read a social story every day for a week before your doctor visit. Try to have pictures of the doctor, nurse, office waiting area, exam room, etc. This will help your child to know exactly what to expect. - Prepare and recite questions to ask the doctor. - If possible, bring your child to siblings' or parents' medical appointments so they can become comfortable in medical settings when the focus is not on them. - Practice labeling and naming body parts. If possible, play games like "Simon Says" and "Head, Shoulders, Knees, and Toes." 	<ul style="list-style-type: none"> - Orient the doctor to your child's preferred method of communication. - Encourage the doctor to communicate directly to your child. - Encourage your child to ask the prepared questions at the appropriate times. If necessary, facilitate use of communication devices or interpretation to allow for direct communication between the doctor and child. - Have a picture(s) of the body, or use an app, that your child is familiar with so that they can show the doctor where they hurt, or the doctor can show the child where they will be touched. 	<ul style="list-style-type: none"> - Ask your child to recall details about the appointment such as "What was the doctor's name?" or "Why did we go to the doctor?" - Ask your child to explain aspects of their medical care, and rehearse simple answers with them. For example, "When do you take your medicine?" - Create a visual schedule that goes along with instructions or new medications from your appointment (e.g. "First take pill. Then brush teeth.") - If there are follow-up appointments, prepare ahead using the strategies that worked well for the previous appointment.

3. Decision-Participant

Preparing for Appointments	At the Appointment	Appointment Follow-up
<ul style="list-style-type: none"> - Look at picture of body and discuss what is going to happen at appointment - Prepare and recite questions to ask the doctor. - Have child pick a few questions they feel comfortable answering and discuss/ role play what they will say. - Practice/ Learn what information is needed to check in to doctor's office and role play checking in. 	<ul style="list-style-type: none"> - Have child check in to their appointment by giving name to receptionist and stating Doctor's name. - Orient the doctor to your child's preferred method of communication. - Encourage the doctor to communicate directly to your child. - Encourage your child to ask the prepared questions at the appropriate times. If necessary, facilitate use of communication devices or interpretation to allow for direct communication between the doctor and child. - Have a picture(s) of the body, or use an app, that your child is familiar with so that they can show the doctor where they hurt, or the doctor can show the child where they will be touched. - Before leaving, ask your child if they understood what was discussed and see if they have any questions. 	<ul style="list-style-type: none"> - If there are follow-up appointments, prepare ahead using the strategies that worked well for the previous appointment - Ask your child to recall details about the appointment such as "What was the doctor's name?" or "Why did we go to the doctor?" - Ask your child to explain aspects of their medical care, and rehearse simple answers with them. For example, "When do you take your medicine?" - Create a visual/visual schedule that goes along with instructions or new medications from your appointment (e.g. "First take pill, Then brush teeth.") - Talk to your child about any new medical decisions that were made to make sure they understand and see if they have any questions or concerns (e.g. new medications or upcoming medical procedures.)

4. Decision-Maker

Preparing for Appointments	At the Appointment	Appointment Follow-up
<ul style="list-style-type: none"> - Prepare and recite questions to ask the doctor. - Gather documentation that is needed for appointments (insurance cards, intake paperwork, etc.) - Bring a calendar to help with dates and timelines. - Make sure to have medication list (if medications will be changing or a new provider). - Bring updated information (new address, new phone number, etc.) - Bring desired communication device; pre-program with questions, concerns, pictures, etc. if needed. 	<ul style="list-style-type: none"> - Ask questions that you have; child may refer to visual support or communication device for prompt or to have script available in order to ask their own questions. - Have provider explain side effects of medications (eg. tired, weight gain, nausea, etc.) and how the child can handle this (eg. eat before taking medications.) - If medical procedures are pending, have the provider explain directly to the child what will/could happen and allow them to express thoughts, fears, etc. - Ask for handouts and notes that were discussed during appointments. - Have doctor complete transition readiness quiz with child and/or parent. 	<ul style="list-style-type: none"> - Encourage child to follow up with the doctor if questions were not answered (phone, call, through chart access). - Make sure the date of next appointment fits in your schedule. - Update medication list and instructions, if necessary. - Involve child in tracking medication side effects and effectiveness. - Have child habit tracker for future appointments such as exercise, self-regulation strategies, food intake, prescription refills, etc. - Think about next level of care (transitions.)

Resources by Stage

Resource	Cost	Link/ Location	Prep for appt	During appt	Follow -Up	Stage	Notes
Melissa and Doug pretend play sets for doctor/dentist	\$24.99-\$29.99	Amazon, Target	☑			1 2	
Book: All Better! By Henning Lohlein	\$15-\$20	Amazon	☑			1 2	
Model Me Kids: Videos for modeling social skills	\$24.95-\$214.95	modelmekids.com/	☑	☑	☑	1 2 3	Each set has a different price or you can bundle buy; Some apps are free
Boxiki Kids Human Body Book (3D, interactive)	\$26.99	Amazon	☑		☑	2 3 4	
This is my body app	\$5.99	Apple store k-5	☑	☑	☑	2 3 4	Designed for iPad
Got Transition: national resource center on health care transition (HCT)	Free	gottransition.org/	☑	☑	☑	3 4	

Essential Anatomy	\$34.99/ year (student)	3d4medical.com	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		4	Available for iOS, macOS, Windows 10 and Android
Essential Anatomy 5	\$14.99	Available on Apple and Android products	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		4	

Resources for All Stages

Resource	Cost	Link/ Location	Prep for appt	During appt	Follow -Up	Stage	Notes				
Medications worksheet (NIH)	Free	nia.nih.gov/sites/default/files/2018-05/medication-worksheet-contrast.pdf	✓	✓	✓	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="background-color: #FFD700; text-align: center;">1</td> <td style="background-color: #ADD8E6; text-align: center;">2</td> </tr> <tr> <td style="background-color: #90EE90; text-align: center;">3</td> <td style="background-color: #8A2BE2; text-align: center;">4</td> </tr> </table>	1	2	3	4	
1	2										
3	4										
Teacher's Pay Teachers	Free to join Lessons usually under \$5	teacherspayteachers.com/	✓	✓	✓	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="background-color: #FFD700; text-align: center;">1</td> <td style="background-color: #ADD8E6; text-align: center;">2</td> </tr> <tr> <td style="background-color: #90EE90; text-align: center;">3</td> <td style="background-color: #8A2BE2; text-align: center;">4</td> </tr> </table>	1	2	3	4	
1	2										
3	4										
"I am going to the doctor" Social Story	Free	educationandbehavior.com/story-about-going-to-the-doctor/	✓		✓	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="background-color: #FFD700; text-align: center;">1</td> <td style="background-color: #ADD8E6; text-align: center;">2</td> </tr> <tr> <td style="background-color: #90EE90; text-align: center;">3</td> <td style="background-color: #8A2BE2; text-align: center;">4</td> </tr> </table>	1	2	3	4	Wise Education and Behavior Copyright 2014
1	2										
3	4										
ABA resources - social stories	Free	abaresources.com/social-stories/	✓		✓	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="background-color: #FFD700; text-align: center;">1</td> <td style="background-color: #ADD8E6; text-align: center;">2</td> </tr> <tr> <td style="background-color: #90EE90; text-align: center;">3</td> <td style="background-color: #8A2BE2; text-align: center;">4</td> </tr> </table>	1	2	3	4	
1	2										
3	4										
do 2 learn social scripts and pictures	Free	do2learn.com	✓		✓	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="background-color: #FFD700; text-align: center;">1</td> <td style="background-color: #ADD8E6; text-align: center;">2</td> </tr> <tr> <td style="background-color: #90EE90; text-align: center;">3</td> <td style="background-color: #8A2BE2; text-align: center;">4</td> </tr> </table>	1	2	3	4	There are many resources available for different ages and stages
1	2										
3	4										
Body Parts for Kids	Free	Google play store and Apple store	✓	✓	✓	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="background-color: #FFD700; text-align: center;">1</td> <td style="background-color: #ADD8E6; text-align: center;">2</td> </tr> <tr> <td style="background-color: #90EE90; text-align: center;">3</td> <td style="background-color: #8A2BE2; text-align: center;">4</td> </tr> </table>	1	2	3	4	Great reviews
1	2										
3	4										
Good Habits for Kids	Free	Google play store			✓	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="background-color: #FFD700; text-align: center;">1</td> <td style="background-color: #ADD8E6; text-align: center;">2</td> </tr> <tr> <td style="background-color: #90EE90; text-align: center;">3</td> <td style="background-color: #8A2BE2; text-align: center;">4</td> </tr> </table>	1	2	3	4	
1	2										
3	4										

Tinybop, Human Anatomy	Cost varies by device	Apple and Google Play store	✓	✓		1 2 3 4	Great reviews Designed for iPad
Texas Children's Autism Center preparing for a visit Social Story	Free	texaschildrens.org/departments/autism/preparing-for-visit	✓			1 2 3 4	
Pictello: app to create and share social stories and visual schedules	\$18.99	Apple and Google Play store	✓	✓	✓	1 2 3 4	
Book Creator: create and share stories; upload pictures and videos; speech to text and text to speech capability	Free and paid versions	Version available on Chrome browsers that work on Android, Windows, Apple devices, etc. Stories can be shared via pdf	✓	✓	✓	1 2 3 4	
Boom Cards	Cost varies	wow.boomlearning.com	✓	✓		1 2 3 4	



MEDICAL VISIT CHECKLIST

Visit: _____

Date & Time: _____

WHAT TO BRING TO ALL APPOINTMENTS

- Blank sheets of note paper _____
- Calendar to schedule next visit _____
- Medication list _____
- Supplement list (e.g. vitamins, essential oils, etc.) _____
- Questions for medical provider _____
- List of all providers _____
- _____

SUPPORTS TO BRING

- Social Story _____
- Electronic device with questions, pictures, calendar, music, etc. _____
- Fidget/sensory/comfort items, books, coloring supplies, etc. _____
- Noise-cancelling headphones _____
- Ear-buds _____
- Laptop or tablet with speech-to-text/text to speech options _____
- _____

OPTIONAL ITEMS

- Pain Scale _____
- Picture of body or body parts _____
- App for parts of body or body systems _____
- _____

EXTRAS

- _____
- _____
- _____
- _____

APPOINTMENT WORKSHEET



Date: _____ Next Appointment: _____

Doctor or Provider's Name: _____

Reason for Visit: _____



MY QUESTIONS

1) _____

2) _____

3) _____



DOCTOR OR PROVIDER'S ANSWERS

1) _____

2) _____

3) _____



MEDICATIONS:

Name of Drug	What It's For	Color/ Shape	How to Take	Refills Left	Other Information



TO DO:

1. _____
2. _____
3. _____



NOTES:

Month: _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
<input type="checkbox"/>						
<input type="checkbox"/>						
<input type="checkbox"/>						
<input type="checkbox"/>						
<input type="checkbox"/>						

Preparing for Your Doctor's Appointment

Here is a list of questions your doctor may ask and a list of questions that you might want to ask them. Before your appointment review the questions and prepare your answers.

Before Appointment

- Write down any symptoms you have been having.
 - What are my symptoms?
 - Are the symptoms constant? If not, when do I experience them?
 - Does anything I do make the symptoms better or worse?
 - Do the symptoms affect my daily activities? Which ones?, How?
- Make a list and prioritize your concerns.
- Make a list of current medications and supplements.
- Write down the questions you want to ask the doctor.
- Send medical records or tests before your appointment.

Questions Your Doctor Might Ask You

- Ask the doctor's office for a list of possible questions to help you prepare. Some Examples of Questions include:
 - What are your concerns?
 - When did you first notice the problem?
 - Where does it hurt?
 - What does it feel like? Sharp, dull, stabbing, itching etc.
 - Does anything make it feel better or worse?
 - What prescription and non-prescription medications do you currently take?
 - What allergies do you have?

At the Appointment

- What do you think is causing my problem?
- Is there more than one condition (disease) that could be causing my problem?
- What tests will you do to diagnose the problems/conditions?
- How good are the tests for diagnosing the problems/conditions?
- How safe are the tests?
- What is the likely course of this condition? What is the long-term outlook with and without treatment?

- What are my treatment options? How effective is each treatment option? What are the benefits versus risks of each treatment option?
- If my symptoms worsen, what should I do on my own? When should I contact you?
- Are you aware of each of the medications that I am taking? Can they adversely interact with the medications you are prescribing for me?
- Should we monitor for side effects of the medications that you are prescribing or for their interactions with other medications I am taking?
- What will this medicine do? What will happen if I don't take it?

Questions to Ask Your Doctor Before a Medical Test

- Why is the test being done?
- What steps does the test involve? How should I get ready?
- Are there any dangers or side effects?
- How will I find out the results? How long will it take to get the results?
- What will we know after the test?
- What is the cost of this test? How will I be billed?

Questions to Ask Your Doctor About Your Diagnosis

- What may have caused this condition? Will it be permanent?
- How is this condition treated or managed? What will be the long-term effects on my life?
- How can I learn more about my condition?

After Appointment

- What are the next steps?
- If I have a question, how can I contact you?

Doctor's Appointment Question and Answer Worksheet

Pick 1-2 questions that you would like to answer during your doctor's apt. Write your question down and then write what your answer can be. Have your answer ready on paper or the communication device of your choice.

 If the Doctor asks this:

 I can answer:

 If the Doctor asks this:

 I can answer:

ABOUT ME



Personal Information

My Name: _____ My Birthday: _____

My Address: _____

My Email Address: _____

My Phone Number: _____

Emergency Contact (Name and Relation): _____

Emergency Contact Phone Number: _____



Health Information

My primary care provider is: _____.

My dentist is: _____.

My other providers are:

_____ for _____.

_____ for _____.

_____ for _____.

_____ for _____.



I take these medications:

_____ for _____.

_____ for _____.

_____ for _____.

_____ for _____.



I am allergic to:

_____, _____, _____.

_____, _____, _____.



Insurance and Pharmacy Information

My insurance company is _____.

The policy holder is _____.

The pharmacy I go to is: _____.

And it is located at: _____.



Transportation

_____ usually takes me to my appointments. You
can contact them at _____.



Some other things you might want to know about me are:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

PAIN SCALE

