



Transition Care Plans

TRANSITION ACTION CARE PLAN

Child's/Youth's Name: _____ D.O.B. _____ Patient # _____ Parents/Guardians: _____

Primary Diagnosis: _____ Secondary Diagnosis: _____ Phone # _____

Main Concerns	Related Current Information	Current Plans/Interventions	Person(s) Responsible	Date - Initials	Review Date
Topics to Review Health promotion Health Condition Management Health Insurance Functional Independence		High School Goals/Plans Post secondary plans Work Plans Independent Living Issues Community Inclusion			

Building Your Own Care Notebook

Below is a list of downloadable forms that can be used to build your own **Care Notebook**. You may download a complete section's documents by clicking on the section's ZIP link, or select specific documents by clicking on the sub-category links below. All Care Notebook forms are made available in both **Microsoft Word** and **Adobe PDF** versions for your convenience.

Complete List of Forms Available:
www.medicalhomeinfo.org/CareNoteBook

Care Notebook Cover Page

Personal Information

- Care Providers
- Insurance Information
- Family Information
- Family Support Resources
- Funding Resources

Pages to Keep Track of Appointments and Care

- Appointment Log
- Diet Tracking Form
- Equipment-Supplies
- Growth Tracking Form
- Hospital Stay Tracking Form
- Immunizations
- Information Needed by Emergency Care Providers
- Lab Work-Tests-Procedures
- Make-a-Calendar

- Medical Bill Tracking Form
- Medical-Surgical Appointments
- Medications
- Family and Child Medical History

Personal Notes

- Parent and Child Questions for Doctor
- Parent and Child Questions for Setting up Home Care

Care Needs of My Child's Abilities and Special Needs

- Activities of Daily Living
- Care Schedule
- Child's Page – Now and Later
- Communication
- Coping-Stress Tolerance
- Mobility
- Nutrition
- Respiratory
- Rest-Sleep
- Social-Play
- Emergency Plan
- Baby-sitters Guide
- Information for Caregivers-Instructions for Care

Community Health Care-Service Providers

- Medical/Dental
- Public Health

- Home Care
- Therapists
- Early Intervention Services
- Child Care
- Respite Care
- Pharmacy
- Special Transportation

School Issues

- School: Making it work
- Home-School Worksheet
- School Communication Sheet
- Permission for Procedures-Medications at School
- Physical Education Activity Guide
- Insert your Individual Education Plan or 504 Plan
- Transitions-Looking Ahead



Self-Management



Getting What You Need at Your Doctor Visit

When you make an appointment to see your doctor, whether if it's for a routine check-up or for a new health issue, there is more to do than just call the office to schedule the appointment. Planning ahead and being prepared can help lower your stress and make your visit more productive, both for you and your doctor.

BASIC IDENTIFICATION (ID) – ALWAYS CARRY WITH YOU

- State issued identification card
- Health Insurance Card(s) – private and Medicaid/Medicare
- Updated portable medical summary/emergency information sheet (1 page)
- Signature stamp (if you have trouble writing your name)

Before Your Appointment – Medical Information and Health Insurance

MEDICAL INFORMATION FOLDER/BAG – TAKE TO THE DOCTOR

Sometimes it's easier to have things organized ahead of time. Some folks have a plastic folder or canvas bag already packed with items they will need for their appointments.

- Copies of items listed in "Basic ID"
- Any new test results you have received, list of questions
- Money for co-pay, parking, taxi and phone calls

PREPARE A HEALTH FILE – KEEP AT HOME IN A SAFE PLACE

While your doctor and hospital will create and keep a file on you that has your medical information, immunization records and hospitalizations, what happens when YOU need information from these files when the office is closed or when you are out of state? It's a good idea for YOU to have a duplicate file at home. Here's what you need to file in a safe place. If you do not have these items ask your doctor for help in getting copies.

FILE 1 – PERSONAL HEALTH INFORMATION

- Copy of your health insurance card(s) front and back
- Copy of State issued identification card (Drivers' License or state ID card)
- Portable medical summary/emergency medical information sheet (1 page)

FILE 2 – RECORDS AND TEST RESULTS

- Immunization records
- Copies of medical tests, blood work, height/weight chart and other test results

FILE 3 - RECEIPTS

- Receipts from insurance company of bills they have paid or reimbursed you
- Receipts from out-of pocket medical expenses: co-pays for office visits, prescriptions, equipment and other related items (may be tax-deductible)

FILE 4 – MEDICAL HISTORY & NOTES

- Copies of hospitalization discharge summaries
- Copies of discharge summaries from any specialists

FILE 5 – NOTES FROM YOUR DOCTOR

- Copies of progress notes from your doctor
- Copies of letters that your doctor writes to other doctors about your health
- Ask your doctor to cc you on these letters

FILE 6 – CORRESPONDENCE

- Copies of letters you have written: medical justification documentation, appeals to insurance companies, requests for services and other medically related correspondence
- Replies to your letters paper clipped or stapled to your letter

GETTING THE APPOINTMENT THAT WORKS FOR YOU

PLAN TO MAKE AN APPOINTMENT	<p>Before calling for an appointment, look at your schedule to see what dates/times work best for you – think about not missing school, work and arranging transportation. Write down dates/times that are good and ones that would not work due to something else being scheduled.</p> <p>Tell the scheduler your preferred dates/times.</p>
CALL & GET THAT APPOINTMENT	<p>When you talk to the person who schedules the appointment, tell him/her dates and times that work best for you and request an appointment time that you know you can be there.</p>
MEDICAL TESTS	<p>Sometimes during routine visits your doctor will want to order some tests. When you make this appointment ask if you will be having blood work or a urine specimen and, if so, should you eat or not before the visit. Some tests can't be done if you have eaten.</p>
URGENT VISITS	<p>While you may have routine appointments for "well visits," there may come a time when you are not feeling well and need to be seen the same day or as soon as possible. When you get connected to the person in charge of scheduling appointments you will need to identify that you have an urgent medical issue that requires you to be seen by the doctor today or as soon as possible. The office receptionist may ask you what the problem is – sometimes the doctor or nurse will call and talk to you and then decide if you need to come into the office or if a prescription can be called in to your pharmacy.</p> <p>** If you have an emergency that is life threatening, go to the emergency room immediately. If you have time <i>en route</i> call your doctor's office and let them know you are going to the ER and why.</p>
TRANSPORTATION	<p>How are you getting to the doctor's office? Are you driving, or is someone else? Are you taking public transportation (cab, bus, subway)? Figure out how much time it will take to get to the office, then add 30 minutes – to make sure you won't be late. Bring along money for parking or transportation fares. Remember it is better to arrive early than be late. (Some people call the office ahead of time to see if the Doctor's appointments are running behind and then adjust when they will arrive.</p>

DAY OF YOUR APPOINTMENT

BE ON TIME	<p>Figure out how you will get to/from your doctor's visit, then allow some extra time (for example 30-60 minutes) for travel. Remember that your appointment time is when you need to actually be in the doctor's waiting area, already signed in – not the time that you arrive at the front door of the building or medical center.</p> <p>YOU ARE LATE - Always call ahead if you are unexpectedly running late (for example, due to transportation problems).</p> <p>DOCTOR IS LATE – It's okay to call the office and see if the appointments are running on time or if there has been a major delay due to an unexpected emergency. You can decide whether to reschedule or adjust your arrival time. Some people use this time to do homework, write letters or read.</p>
HEALTH INFO	<p>Bring your health insurance card, state-issued identification, updated portable medical summary, and signature stamp if you need one. See sample HRTW Portable Medical Summary –1 page. www.hrtw.org</p>
PAPERWORK	<p>If this visit was a referral from your primary doctor, make sure to bring copy of the referral (insurance companies require this).</p>
MONEY / CHECK	<p>Bring money or check to pay for transportation, phone calls, office co-pays that are not covered by your insurance.</p>
PERSONAL CALENDAR	<p>If you need to make another appointment, it is helpful to know the dates/times that are good for you. Dates can be written or logged in paper calendars, appointment books or PDAs.</p>
MEDICAL UPDATE & QUESTIONS	<p>Your updated portable medical summary will list any new medications or herbs, names of doctors you are seeing and other important medical information. Prepare a list of questions and concerns you would like to discuss with your doctor. It's easy to forget things once you are in the examining room. Write down, tape record or program your questions onto your communication device or ask someone to help you do this.</p>
WHAT TO WEAR	<p>Wear clothes and shoes that will make it as easy as possible for you to get undressed for your examination and dressed afterwards.</p>

YOUR APPOINTMENT

- **ON YOUR OWN or NOT?** Decide ahead of time if your parent and/or guardian will come into the room with you, and let the office staff know this when you arrive for your appointment.
- **WHAT DO YOU NEED?** Speak up for the accommodations that you need, if they are not offered to you. For example, if you cannot get onto the examining table by yourself, there should be an adjustable height table in the room or staff to assist you. Your family members should not be expected to do this. If you cannot stand on the scale, there should be an alternate type of scale available. Not getting weighed is not an option and could possibly be bad for your health. If you are incontinent, be sure that appropriate bathroom facilities are available- lying on the floor is not an option! If you have requested an interpreter, always call a day or two beforehand to confirm that the interpreter will be present. Do not agree to let family members or friends interpret for you.
- **QUESTIONS NEEDING ANSWERS** - Let your doctor know that you have some questions to ask during your visit. Make sure your doctor communicates with you in a way that you can understand. Tell the doctor if he or she is using medical jargon or vocabulary that is hard for you to understand.
- **WHAT'S HAPPENING?** Keep asking questions – what are you doing to me? What is the name of that instrument? What test have you ordered and the reason for it? When will you have the results? Are there risks? What are my options? What are the side effects of the medicine you want me to take? When do I need to see you again and why? How can I reach you if I have questions or problems?

Web Sites

Tips for Taking Charge of Your Health

INSTITUTE FOR COMMUNITY INCLUSION www.communityinclusion.org

Offers transition manual for free download, includes section on health transitions, with fact sheets for families and YSCHN. "Taking Charge of Your Health Care" and "Communicating with Doctors and Other Health Care Providers".

KIDS AS SELF ADVOCATES (KASA) www.fvkasa.org/health.asp

Written by and for teens and young adults with special health care needs, includes helpful articles such as "Communicating with Your Doctor", "Keeping a Health Diary", and "Transition to Adulthood". Lots of helpful resources, links, listserv and opportunities to get involved.

HEALTH CARING CARDS www.savethepatient.org

Offers "Health Caring Cards" in five languages, available for free download. Designed to be printed out, filled in and folded down to pocket size. Includes rights of patients, getting ready for doctor visits, questions to ask at your appointment, questions about medicines for your doctor and pharmacist, and emergency information card.

VIRTUAL HOSPITAL www.vh.org/adult/patient/familymedicine/prose

Information site for providers and patients offers "Communicating with Doctors: It's Their Job to Listen" as part of "Health Prose – One Minute Update for Your Health" feature. Many resources and links related to all aspects of health care.

Tip sheet developed by Patti Hackett, Glen Gallivan, KASA and Faye Manaster, 2003, revised 2007..

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Finding and Using Adult Health Care

As young people grow from childhood into adulthood, many will move from care by pediatricians into adult medicine. Moving to a different town due to school or a change of employment will also create a need to find a new doctor, especially if you happened to grow up with chronic health issues. So, how do you find a doctor who will meet your medical needs, that will be covered by your health plan, and who will give you the care you are looking for?

- Before you start looking for a new doctor, think about what do you want:
 - Is where the office located important? Will you need help with transportation? Do you need an office that is wheelchair accessible or do you need other special assistance in the doctor's office? Are office hours convenient? How do you contact the doctor at other times? What hospital do you want to use, and is this doctor on the staff there?
 - Do you want someone who will take time with you during an office visit or are you comfortable being seen by someone who is "good" in his or her field but perhaps does not have the best bedside manner?
 - Is it important that this new doctor is knowledgeable about your special health care needs or do you think you can provide that information or connect the new doctor with those who could provide medical insight?

- Ways to look for a new doctor include:
 - Ask your current doctor
 - Check out the doctor your parents or other family members see
 - Call a family support group or adult disability agency and check around
 - Ask adults who have health needs similar to yours for recommendations
 - Refer to your health insurance company booklet of approved providers
 - Ask a Vocational Rehabilitation or Independent Living Center counselor
 - Find a university health center (sometimes there are research studies going on which offer free care)
 - Contact your local Medical Society, American Academy of Family Practitioners, or Internal Medicine Society either through the Yellow Pages or on their national websites

Since your wellness depends on the medical services you receive, it is important that you are comfortable talking with your new doctor and feel that he or she understands your concerns. Consider scheduling a "get-acquainted" interview before you make a final choice of a new doctor. You will have to pay for this visit, as it is NOT covered by insurance benefits. An ideal interview time is about 15 to 30 minutes and should not waste your time or the doctor's. The best time to see a new physician is when your health condition is stable so you aren't asking for crisis care while seeing if you can develop a working relationship.

Think about (and write down) questions that are important to you:

- Is the doctor knowledgeable about your health issues and/or willing to learn from you and from previous doctors?
- Do you like the communication style with the doctor and in the office?

- Are you satisfied with office practices and access during an emergency or in urgent situations?
- Do you have access to hospitals and specialists if you need them?

Doctors who like to care for children are different from doctors who like to care for adults. For this reason, young adults seeking health care need certain skills:

- Ability and willingness to tell the doctor about your history, current symptoms, lifestyle, and self-care in just a few minutes (including carrying your own records and a summary of your medical history).
- Ability to ask questions about your condition and how it will affect your school, work, recreation, and social life.
- Ability to tell the doctor about your needs for education, technology, and accommodations and how your condition affects or might be affected by these.
- Willingness to follow medical recommendations that have been mutually developed by you and your doctor.
- More independence in following up with referrals and keeping all agencies informed.
- More involvement in keeping yourself well with diet and weight control, exercise and recreation, following medication, treatment and hygiene regimens, limiting risk-taking behaviors (such as drinking alcohol, smoking, taking non-prescription drugs, or unsafe sexual practices), and getting help when you feel angry, lonely, or sad for long periods.
- Being more aware of your physical and mental symptoms and health needs before you have a serious medical crisis and knowing when to inform your doctor.
- Developing a plan for action for when you need emergency care: when to consult with the doctor, what hospital to report to, what care you want and do not want, and naming someone who can let your wishes be known if you cannot (health care surrogate).
- Understanding how the health care benefits/insurance plan you have works for you: when to call for pre-approval, how to get reimbursements, what services are not covered, and how to file an appeal if you do not agree with decisions from the plan.
- Recognizing that as you become more capable in directing your care that you, not your parents, should make medical appointments, be the most knowledgeable about your health needs, know when to seek guidance in solving problems, and demonstrate that you are capable and competent and ready for adulthood!

9/6/01



KY Commission for Children with
Special Health Care Needs
KY TEACH Project



MCHB Healthy and Ready To Work Projects

Shriners Hospitals for Children

When you call to make a medical appointment, you need to have some information ready. Fill out this form before making an appointment. This will help you have all the information you need in front of you. You should also have your calendar available when you call.

Important Information for your Records

Doctor/medical provider you are calling: _____

Type of doctor: _____

Address: _____ City/State/Zip: _____

Phone number: _____

Sample Call Script

Step 1

Introduce yourself and reason for your visit

Hello, my name is _____.

I need to make an appointment with _____ for a _____
(Doctor's name) (Reason for visit)

Routine health wellness visit

Illness (don't feel well)

Lab work/tests

Consultation

Immunization

Medical Exam

Step 2

Ask about health insurance and other charges

Does the doctor accept my health insurance? _____
(List the name(s) of your health insurance provider)

If yes – check your insurance plan to see how much to pay for your visit.

If no, or you do not have health insurance, ask them how much do they charge for this type of visit?

Approximate cost of visit: \$ _____

If the cost of the visit is more than you are able to pay, you might want to check with other providers on options for such services.

Step 3 | **Schedule the appointment**

How soon can I get an appointment? Date: _____ Time: _____: _____ (am/pm)
(Write the date and time you are told here)

Note: *If the time/date given does not fit your schedule ask for another time and write it on the line above.*

How long is the appointment? _____
Write the amount of time here (min/hours)

Note: *Be sure to let them know if you will need more time and how much time.*

Step 4 | **Request special accommodations**

I will need accommodation(s) such as: _____
(Accommodations needed)

Types of accommodations (sample list)

- Accessible entrance to building
- Communication equipment
- Mobility/Positioning support
- Large Print/Braille documents
- Assistance with filling out medical forms
- Interpreter/Translator
- Special medical supplies
- Clipboard for completing forms
- Assistive Listening Device

Does the doctor's office provide these accommodations? YES NO

Step 5 | **Confirm your appointment**

Ok, my appointment is with _____ on _____ at _____
(Date) (Time)

for _____

Thank you.

Be sure to confirm all the appointment information before you hang up!





Knowing what medicines you are taking and how frequently you need to order these medicines is a major part of knowing how to manage your own health care. Once you reach adulthood, you will be responsible for making sure you have the right medication and when to order these medicines before you run out!

Medication Information

What to Know about Your Medicine

- * **Name of each medicine**
What is the name of this medicine?
- * **Dosage**
How much are you supposed to take?
- * **Frequency**
How often are you supposed to take it?
 - **Monthly?**
 - **Weekly?**
 - **Daily?**
 - **How many times per day?**
- * **Condition Treated**
What condition is this medicine supposed to treat?
- * **Side Effects**
What other effects does the medicine have on your body?
- * **Medicine Interactions**
Will this medicine create a problem if taken with other medicines?

Tips on Medications

- * Establish a set schedule for taking your medication(s) if needed.
- * Know what each medication does and possible side effects.
- * Let your doctor know if you are having serious side effects.
- * Keep track of your daily medicine intake by using a pill box, calendar or your preferred method.
- * Let your doctor, nurse, and pharmacist know of any over the counter (OTC) medicine(s) you are taking.
- * Carry an updated list of all of the medications you are taking at all times in case of an emergency.
- * Do not share prescribed medication(s) with anyone.
- * Do not allow a doctor or nurse to prescribe medication(s) you do not think you need. If you are not sure what the medications prescribed do, ask your doctor for more information.

Making the Call

When you call the pharmacy, a person may answer and take your information. Sometimes you may get an answering system that tells you how to give the information the pharmacy needs by pushing certain numbers on the phone. If this is too hard or too confusing, you can usually stay on the phone or push a number given to get help from a person who will take the information from you directly.

Prescription Ordering Information

Some pharmacies offer the option to order refills online or by mail order. Some pharmacies also offer delivery services (usually they charge a delivery fee). Check with your pharmacist to find out if these choices are available. Also be sure to tell the pharmacist how many prescriptions need to be refilled.

**** new/changed prescriptions**** the doctor will call your pharmacist with your prescription or give you the prescription to take to your pharmacist. Generally with new prescriptions you need to go to the pharmacy to request the medication rather than calling.

Check the Number of refills

The number of refills is usually on the lower left part of the label on the medication bottle. If you don't have any more refills left, but still need the medication, the pharmacy may call your doctor to get a new prescription, or you may need to schedule an appointment with your doctor.

Call Ahead of Time

Call to order refills on your medications when you have one week of medicine left, so you don't run out on a weekend, holiday or while on a trip. Mark your calendar to remind yourself when to re-order.

Picking up the Medications

Some pharmacies will give you the option of having the medicines delivered to you in the mail, or you can go directly to the pharmacy. If you cannot pick up your medicines you may need to authorize someone else to do this for you. If someone else agrees to pick up your prescriptions, you may need to fill out a form to let the pharmacist know someone else is authorized to pick up the medicine in your absence. A sample of this form is included.

Ask Questions

Make sure you understand how to take your medication and any side effects that might happen. You will get written information when you pick up your medication, but ask the pharmacist any questions you may want answered.

If you get home and have a question or concern, call and ask the pharmacist for information over the phone. You can also call your doctor's office and ask to speak to your doctor's nurse. Nurses can also answer a lot of your questions and can check with your doctor, if needed.

This form is designed to help you remember the information you need to have when ordering your prescription refills. Use the information on your medication bottle and write the information in the blanks on this form before you make your phone call.

Remember:

- ✚ When calling for a refill you can only order medicine you are already taking
- ✚ Check the back of this form to find out how to read the prescription label of your medicine
- ✚ Write down the name, address and phone number of your pharmacy in the box below

Keep This Information for your records

Pharmacy Name: _____

Pharmacy Address: _____

Pharmacy Phone Number: _____

Pharmacy Days: _____ Hours: _____:_____ (am/pm) to _____:_____ (am/pm)
(Days of the week – Pharmacy Open) Time Open Time Closed

Sample Call Script

Hello, my name is _____ and I need a refill on a prescription.

My prescription number is _____
(The number is usually on the upper right or left of the label on the bottle)

and the name of the medication is _____.

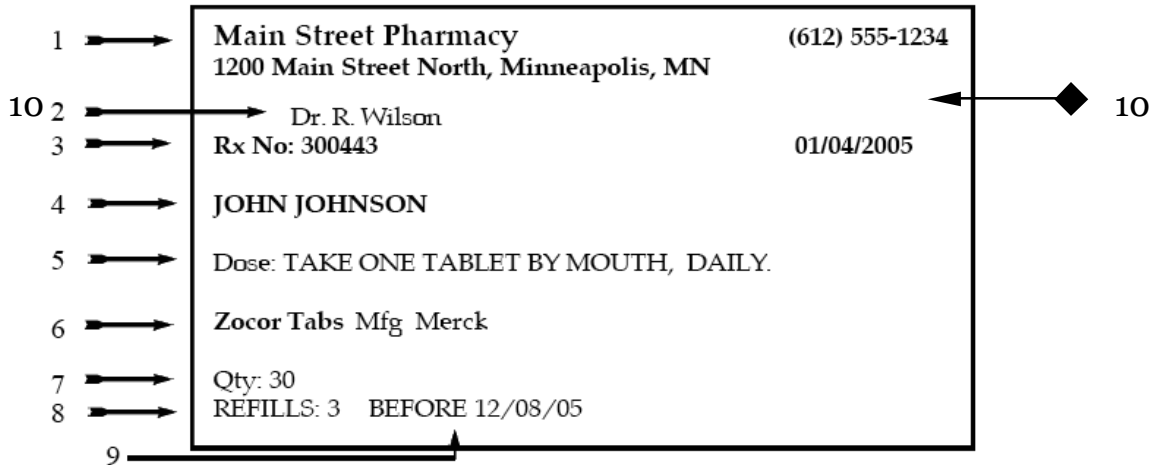
I, or _____ (authorized person) will pick it up on _____ (day) around _____:_____ (time am/pm).

Is there a **co-pay**? Yes No How much will it cost? _____

****Note**** Repeat the script above for each prescription that needs to be refilled.

Remember to take your insurance card every time you go to the pharmacy!

The label on your prescription has important information. Some labels may have a different order.¹



	Description		Description
1	The name, address and phone number of the pharmacy that filled the prescription. <i>This is from "main street pharmacy".</i>	6	The name of medicine, and the name of the company that manufactured it. <i>This medicine is called "Zocor", and Merck makes it.</i>
2	The name of the doctor. <i>Doctor R. Wilson prescribed this medicine.</i>	7	The number of tablets. This may be written after the abbreviation "Qty" or the word "Quantity". <i>This prescription is for 30 pills</i>
3	The prescription number, which begins with the abbreviation "Rx" or "No". <i>This prescription number is 300443.</i>	8	The number of refills available. When no refills are available the number will be "0". <i>There are 3 refills left for this prescription</i>
4	The name of the patient. This medicine is for John Johnson. <i>No one else should take this medicine.</i>	9	The expiration date of the prescription. This may be written after "refill before" or the abbreviation "Exp". This is the last date the pharmacy can refill the prescription. <i>This prescription expires on 12/08/2005</i>
5	Tells how much medicine to take and when to take it. This may be written after the word "dose". <i>John should take 1 tablet once a day.</i>	10	The date the prescription was filled in the pharmacy. It may be different than the date that you pick it up. <i>The pharmacist filled the prescription on 01/04/2005</i>

¹ The LaRue Medical Literacy Exercises were created by Charles LaRue through a grant from the Minnesota Department of Education under the supervision of the Minnesota Literacy Council. ©2005 MN Dept of Education

**All About Your Medications
Authorization for Medication Pickup**

Form 3 (2009)

This form gives permission to a trusted support person (e.g. family member or friend) to pick up your medications for you. Give this signed form to your pharmacist so he/she has it on file. This form is only needed if you chose to have someone pick up your medication. There is space at the bottom of the form to provide your phone number in case your pharmacist has a question and needs to contact you.

I, _____ hereby,
(Name of person authorizing pickup)

approve _____
(Authorized person's name)

to pickup my medication(s) at _____.
(Pharmacy)

One time only _____
(Date)

Multiple times from _____ to _____
(Start date) (End date)

Authorizing Person's Signature

Date

Authorizing Person's Phone number

Fill this form out and take it with you when you go to a new doctor. This is information you will receive when you call to make your appointment.

Date of Appointment _____ Time: _____

Doctor's Name _____

Nurse's Name _____

Office's Name _____

Office's Address _____

Phone Number _____ Fax: _____

Reason(s) for my visit: 1. _____

2. _____

Take pertinent information with you

1. Your insurance card
2. List of current medications and medication history
3. Health Record and information
4. Information from the referral to the doctor
5. Forms for the doctor to complete
6. Directions to appointment
7. Agency on-call information
8. Family/guardian information
9. Name, location and phone of pharmacy
10. Date, time, location of appointment

Remember to call your last doctor and make sure you give them approval to send your medical files to your new doctor.

Questions you may be asked on your first visit

1. What is your medical history? (including major surgeries and hospital visits)
2. What is your medical condition(s)/disability?
3. Are you on any medications (prescribed or Over the Counter (OTC))?
4. Are you allergic to any medications?
5. Do you have any other allergies?
6. What other doctors have you seen?
7. How do you communicate best?

Other things doctors should know about me.

This form includes questions a new doctor may ask you before or during your first appointment. Look over the questions and fill in your answers if you would like so that you can become aware of the questions you may be asked and you can become better prepared to answer them.

For each question, please circle the choice that best fits you according to the key below.

NA= Does not apply to me
 WA= With Assistance
 DK= Don't Know

Topic	<i>Know your health condition and how to take care of yourself</i>
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1. Do you understand what caused your medical condition/disability?
 Yes No NA WA DK
2. Do you understand how your medical condition/disability affects you in your day to day life?
 Yes No NA WA DK
3. Do you manage your everyday treatment needs?
 Yes No NA WA DK
4. Do you have any problems with your everyday treatment needs?
 Yes No NA WA DK

5. Do you understand why you take the medications your prescribed?

Yes No NA WA DK

6. Do you usually understand the reason for the medical tests given by your doctor?

Yes No NA WA DK

Topic	<i>Keeping Healthy</i>
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1. Do you have a primary care provider (PCP) that you see regularly?

Yes No

2. Are you up-to-date with immunizations (shots) and health care screenings?

Yes No DK

3. If not, do you know how to access the information?

Yes No NA WA

4. Do you ever use alcohol, cigarettes or illegal drugs? Yes No

If so, which one(s) _____

5. If so, do you feel like you use them too much? Yes No DK

6. Do you ever engage in unprotected sex? Yes No
(unprotected sex is sex without a condom or other form of birth control)

7. Do you take only your prescribed medications as prescribed?

Yes No NA WA

8. Do you drink caffeine? Yes No
If so, how much per day? _____

9. Do you exercise regularly?
Yes No NA WA DK
If so, how often per week? _____
What type of exercise do you do? _____

10. Do you see a dentist every 6 months?
Yes No NA WA DK

Topic	<i>What to do in case of emergency</i>
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1. Do you have access to a phone in case of an emergency?
Yes No NA WA DK
2. Are your family/friend's numbers easy to access in case of an emergency?
Yes No NA WA DK
3. Do you have essential numbers (911, poison control, your doctor's number) in an easily accessible location?
Yes No NA WA

4. Do you know where the emergency room and/or hospital closest to you house is located?

Yes No NA WA

Topic	<i>Finding and Using Community Resources</i>
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1. Do you need assistance with transportation to appointments?

Yes No

2. Do you have a driver's license? Yes No

If not, what form of transportation do you use?

3. Do you know how to get the services you need in your area?

Yes No NA WA

4. Are you able to use community transportation when you need it?

Yes No NA WA DK

Topic	<i>Talking to your doctor and asking questions</i>
--------------	---

1. Do you know how to seek answers to health related concerns?

Yes No NA WA DK

2. Are you able to get the help you need to communicate with your doctor and nurses?

Yes No NA WA DK

Topic	<i>Responsible sexual activity</i>
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1. Are you able to identify sexually situations that may make you feel unsafe or uncomfortable?

Yes No NA WA DK

2. Are you able to provide a true sexual history to your doctor?

Yes No NA WA DK

3. Do you know what a sexually transmitted disease (STD) is and how it can affect you?

Yes No NA WA DK

4. Do you have enough information about ways to prevent STDs?

Yes No NA WA DK

5. Do you understand some of the possible risks related to teen/unplanned pregnancy?

Yes No NA WA DK

Topic	<i>Keeping track of health records</i>
--------------	---

1. *Do you have a copy of your health records from major medical events?*

Yes No NA WA DK

2. Do you have a calendar or another way of keeping track of health care appointments?

Yes No NA WA DK

Topic	<i>Health Insurance</i>
--------------	--------------------------------

1. Do you have an up to date insurance card or a copy of it?

Yes No NA WA DK

2. Do you know what number to contact if you have concerns about your health insurance?

Yes No NA WA

3. Have you applied for income assistance programs such as Social Security Income (SSI)?

Yes No NA WA DK



Portable Medical Summaries

New York State Institute for Health Transition Training
Developmental Disabilities Planning Council

TRANSITION INFORMATION FORM

Adapted from the Emergency Information Form for Children with Special Needs
American College of Emergency Physicians – American Academy of Pediatrics

Date Form Completed Revised Initials:
By Whom Revised Initials:

Name: Jane Doe	Date of Birth: 1/25/87
Home Address: 123 Maple Lane Anytown, USA 12345	Home Phone: 123-456-7890 Work Phone: 234-567-8901
Health Care Guardian: <u>X</u> (N/A)	Health Care Guardian Phone:
Signature/consent:	Emergency Contact Names and Relationship Jane Doe
Communication barriers: Non verbal learning disability: Provide written Instructions	Phone Number(s): 234-567-8902

Current insurance provider	Anticipated adult insurance provider
Primary: BCBC Account Number: XZ-2345-6789-20 Case manager: none	Primary: BCBS student rider Account Number: XZ-2345-6789-20 Case manager:
Secondary: Medicaid Account number: AB-123-456789- Case manager:	Secondary: Account Number: Case Manager:
ICD-9 codes: 741.03 (Spina Bifida with shunted hydrocephalus) 344.61 (neurogenic bladder)	

Current pediatric healthcare providers	Anticipated adult healthcare providers
Primary Care:	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Neurosurgery	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Urology	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Orthopedics	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Mental Health	
Current Provider: Social Worker: Spina Bifida Center Address: Phone/fax:	Adult Provider: College Town Counselor Address: Phone/fax:
Specialty:	
Current Provider: Address: Phone/fax:	Adult Provider: Address: Phone/fax:
Emergency Department:	
Current: Hometown ED	Anticipated: College Town/State Hospital
Tertiary Care Hospital:	
Current: Home Town Medical Center 123-456-6789	Anticipated: College Town/State Hospital 987-654-3210

New York State Institute for Health Transition Training
Developmental Disabilities Planning Council

Current ancillary service providers	Anticipated ancillary service providers
Pharmacy:	
Current: Hometown Pharmacy Address: Phone/fax:	Anticipated: College Town Pharmacy Address: Phone/fax:
Durable Medical Equipment Vendor:	
Current: Hometown Vendor Company Address: Phone/fax:	Anticipated: College Town Vendor Company Address: Phone/fax:
Medical Service Coordinator:	
Current: Address: Phone/fax:	Adult: Address: Phone/fax:
Home Health Agency:	
Current: Address: Phone/fax:	Adult: Address: Phone/fax:

Diagnosis/Past Procedures	Physical Exam
<p>Problem List:</p> <ol style="list-style-type: none"> 1. Lumbar myelomeningocele s/p closure at birth. S/P detethering 1/1999 and 2/2004 2. Ventriculo-atrial shunted hydrocephalus, s/p V-P shunt placement at birth with revision x2 in first year of life. VP was changed to VA shunt when there was shunt malfunction after ACE/Mitrofanoff 3. Chiari malformation, has problems swallowing pills and has mild dysarthria, otherwise asymptomatic. Is known to have C6-T4 syrinx, stable~ Does have weakness in hand intrinsic on left, but otherwise no symptoms 4. Neurogenic bladder: S/p augmentation cystoplasty and Mitrofanoff in 2/2002. Catheterizes via umbilical stoma q. 4 hours. Normal renal function. 5. Neurogenic bowel s/p Chaitt tube placement in 2/2004. Flushes with 800 cc's tap water nightly. Occasionally uses immodium. 6. Motor impairment: L2 paraplegia-primarily uses wheelchair for mobility. Has left dislocated hip. 7. Scoliosis s/p Harrington rod placement in 2000. 8. Osteoporosis s/p pathologic fracture left femur in 1996. DEXA scan in 2004, on fosomax 700 mg weekly. 9. Insensate in saddle distribution and below knees bilaterally. Coccygeal decubitus x 2, with hospitalization for osteomyelitis in 2/1999. 10. Depression, in remission. No longer on medications. <p>Synopsis: Dusty is a 17 year old with mild lumbar level paraplegia who had Chaitt ACE/Mitrofanoff procedures when he was 14. The Mitrofanoff stoma has been problematic and if he is not able to cath easily he needs to be seen promptly. He has short term memory problems.</p>	<p>Baseline physical findings: Venous stasis resolves when legs elevated (not lymphedema) See neuro exam below for pertinent positives</p> <p>Baseline vital signs: Normal</p> <p>Baseline neurologic status: Mild dysarthria (Chiari-related) Tongue deviates slightly to left Left exotropia End point horizontal nystagmus with leftward gaze L2 level paraplegia</p>

**New York State Institute for Health Transition Training
Developmental Disabilities Planning Council**

Medication List Bicitra 10 MEq BID 16 French catheters Water soluble lubricant Prostheses/Appliances/Implantable Devices: Quicki manual wheelchair with ROHO cushion	Significant baseline ancillary findings (lab, x-ray, ECG) CT Head (2004, when asymptomatic): Mild Ventriculomegaly of lateral ventricles. Thickened calvarium
---	---

Management Data	
Allergies: Medications/Food to be avoided Latex	And why: Latex sensitive (hives)
Procedures to be avoided MRI studies Prolonged immobilization without pressure relief surface	And why: Harrington rods Insensate L2: Prone to pressure sores

Immunizations (mm/yy)			
Dates			

Common Presenting Problems/Findings with Specific Suggested Managements		
Problem 1. Unable to catheterize 2. Odiferous urine, no fever	Suggested Workup Cystogram No urine culture is needed. Please follow guidelines for management of asymptomatic bacterium	Treatment considerations This is potentially a surgical emergency. Call urologist immediately for inability to catheterize. At high risk for bladder rupture Increase fluid intake. Re-evaluate in 24 hours if symptoms persist or if symptoms worsens or if febrile

Condition-specific health maintenance recommendations: Augmentation cystoplasty: 1) Beginning 10 years after surgery, annual cystoscopy 2) Urinary alkalization to prevent osteoporosis, 3) Annual B12 level. SBAA Guidelines for Health Maintenance in Adulthood: http://www/sbaa.org/site/PageServer?pagename=about_livingadults

Additional comments: Jane has impairment of short term memory and non-verbal learning disability. Please provide written healthcare instructions. Thorough skin examination is recommended. He has recently has several decubitus ulcers.

Physician/providers signature:	Print Name:	Date:
---------------------------------------	--------------------	--------------

Emergency Information Form for Children With Special Needs

Last name:



American Academy of Pediatrics



Date form completed
By Whom

Revised
Revised

Initials
Initials

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
Physicians:			
Primary care physician:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Anticipated Primary ED:		Pharmacy:	
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1 . _____	Baseline physical findings:
_____	_____
2. _____	_____
_____	_____
3. _____	Baseline vital signs:
_____	_____
4. _____	_____
_____	_____
Synopsis:	_____
_____	Baseline neurological status:
_____	_____
_____	_____

*Consent for release of this form to health care providers

Diagnoses/Past Procedures/Physical Exam continued:

Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1.	
2.	
3.	
4.	Prostheses/Appliances/Advanced Technology Devices:
5.	
6.	

Management Data:

Allergies: Medications/Foods to be avoided	and why:
1.	
2.	
3.	
Procedures to be avoided	and why:
1.	
2.	
3.	

Immunizations

Dates						Dates					
DPT						Hep B					
OPV						Varicella					
MMR						TB status					
HIB						Other					

Antibiotic prophylaxis:

Indication:

Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: _____ **Print Name:** _____

NAME

Address, Home Phone, Cell Phone, Email

DOB 5/24/73 SS# 289-XX-XXXX

ALLERGY: Sulfa Drugs, Adhesive Tape

- High intelligence (130 IQ), compliant patient, high tolerance to pain
- Incomplete Quad (has sensation), only movement left index finger 10 cm
- Need to explain EVERY procedure, when possible, ask for consent prior to doing
- If unable to talk => one blink = yes / two blinks = no - Read his lips - OR - letter/word board to direct his care.

PRIMARY DIAGNOSIS AGE: 30 HEIGHT 4'3" (51inches) WEIGHT 80lbs approx

1. **NEURO/MUSCULAR** Spinal Muscular Atrophy Type 2 (Severe Anterior Horn Cell disease, dx 3/74)
359 Muscular Dyst/335.1 SMA incomplete quad (has full sensation), no functional movement
2. **RESPIRATORY** Respiratory failure - trach and vent (9/01), Chronic RLL Atelectasis, Recurrent pneumonia
V44 Trach, 518.81 Resp Failure Respiratory insufficiency, poor residual functions/reserved capacities
486, Pneumo Org NOS
3. **GASTRO** Decreased esophageal motility, s/p feeding gastrostomy tube (7/83)
V44.1 Gastro Status
4. **ORTHOPEDIC** Severe deformities: thoracic, pelvic obliquity, bilateral dislocated hips, flexion contractures
737.4, 754.89, 754.81 spinal fusion (3/82 Lueke Rod), pectus excavatum
5. **UROLOGICAL** Undescended L testicle (since birth), intermittent cath (10/01), cath: 10 Fr,
752.51 Cystoscopy/left ureteral stent (10/01), IVP (6/90)
6. **BLOOD TYPE** A + (positive)
7. **SPECIAL NOTES** IV: Porta Cath (10/24/01) RIS right clavicle (PC 0603880 - lot 36HI124)

MEDICAL

ACUPUNCTURE PHYSICIAN
Barbara XXXXX RN, AP, Ocala, FL
O: 352- xxx -xxxx

HOSPITAL North FL Regional Medical Center, Gainesville, FL
4/95, 1/97, 5/01, 9-10/01

INTENSIVIST: Melvin XXXX, MD, Ocala, FL
O: 352-622-xxxx

IMMUNIZATIONS Flu 02 Pneumo 79, 01 Tetanus 85
DPT 73, 79 Measles 74 Mumps 74
TB 78, 87

PULMONOLOGIST: Robert xxx MD, Gainesville, FL
O: 352- xxx -xxxx Bpr: 352- xxx -xxxx

ENTERAL Pulmocare 237ml x 2 cans, nocturnal, 70 ml/hr

MEDICATIONS

- Rx DAILY
1. Alprazolam (xanax) 0.5 mg QID anxiety
 2. Aspirin-Child 81 mg 1 x prevent clots
 3. Temazepam 15 mg H S sleeping pill
 4. DuoNeb 1 vial QID nebulizer
(Ipratropium, Bromide & Albuterol)

HERBS / DROPS

1. Lymphatic 5 x2
2. Flu Balancing 10 x2
3. Respiratory 7 x2
4. Allertox -airborne 5 x2
5. " " Aleer-Total 3 x3
6. " " Allerdrain 10 x4
7. Immune 6 x2
8. Acute Rescue 5 x2
9. Urinary 8 x2
10. Digestive 3 x2
11. Mucous 5 x2
12. Cell 7 x2
13. Muscular 4 x2
14. Integumentary 8 x2
15. Er Cheng Tang 1 tsp x2

VENT / TRACH / O2

VENT - Pulmonetic LTV 900
Breaths 05
Tidal Volume 310 Inspiration 1.1
Pressure Support 13
Sensitivity 02
High 40
Low 02
TRACH: Shiley 6 cuffed (deflated)
SPEAKING VALVE: Passy-Muir PMV007
OXYGEN 1.5 liters

- Rx MONTHLY
1. Thiamine 100 mg monthly vitamin
 2. Cyanocobalamin 1000 mcg/ml monthly (B12)

- Rx PRN
1. Darvocet-N pain
 2. Zithromax SUS PFIZ 200/5ml 45ml antibiotic
 3. Diphnoxyllate/atropine 1-2 tablets diarrhea

INSURANCE

BlueCross BlueShield of Massachusetts
Primary Subscriber: xxxxx xxxxx
BC/BS PPO Plan Code 200
Customer service: 800-296-xxxx
XXP XXXXXXXX 10 PPO

BlueCross BlueShield of Massachusetts
Secondary Subscriber: xxxxx xxxxx
BC/BS Blue Choice Plan 2, POS Code 200
Customer service: 800-222-xxxx
XX XXXXXXXX 10

HEALTH SURROGATE Pxxxx Hxxxxx (mother) c 352-xxx-xxxx h 352-xxx-xxxx

BC/BS Case Manager	Debra XXXXXXXX	800-392-xxxx	ext. xx	
Health Vendor	Option Care	800-825-xxxx	352-373-xxxx	acc't. # xxxxx
Home Nursing Agency	House Calls	352- xxx-xxxx		acc't. # xxxxx
Pharmacy	Bitting's	352-732-xxxx		



Health Insurance

Mock Insurance Card (Sample)

The Right Stuff	Your choice to better healthcare	PPO
Subscriber # AQKR83240918		
NC GoodDecision Premium		
Group # M36100		
	Member Effective	
01, Tom Hamerick	05-20-06	
02, Mary Hamerick	05-20-06	
03, Sarah Hamerick	05-20-06	
www.rightstuffhealthcare.com		

*This is an example of what a **group insurance** card would look like.
This is not a real insurance company.

Here is what we know:

- **NO HEALTH INSURANCE** - Two out of five college graduates and one-half of high school graduates who do not go on to college will experience a time without health insurance in the first year after graduation. (*Commonwealth Fund 2003*)
- **DROPPED FROM HEALTH INSURANCE** - Young adults are often dropped from their parents policies or public insurance programs at age 19, or when they graduate from college and struggle to find jobs with health benefits. Young adults are far more likely to be uninsured than older adults: four of 10 young adults between the ages of 19 and 29 can expect to be uninsured at sometime during the year--twice the rate of adults ages 30 to 64. (*Commonwealth Fund 2003*)
- **BARRIERS TO GETTING AND KEEPING HEALTH INSURANCE** - "Americans with disabilities face a number of distinct barriers in obtaining, maintaining, and using health insurance and in accessing and using health care services. At the same time, Americans with disabilities also confront the barriers, problems, and frustrations with which most Americans routinely struggle in the insurance and health care systems."
(*National Council on Disability 2002 annual National Disability Policy: A Progress Report*)

PUBLIC HEALTH INSURANCE: Changes after reaching majority age

MAINTAIN MEDICAID

- Passed SSI Redetermination - continue benefits
- Emancipated Minor - by marriage or court decision may qualify or continue Medicaid due to income or disability status.

DROP FROM MEDICAID

- Former childhood SSI recipient at age 18 did not qualify under SSI redetermination and loses benefits (income too high or does not meet disability criteria.)

NOT APPROVED - SECTION 301: PROVISION TO CONTINUE RECEIVING SSI BENEFITS

- Individuals found ineligible during SSI redetermination may continue to receive SSI benefits *IF* they began receiving state vocational rehabilitation agency services before their 18th birthday.
- Section 301 allows the young adult to retain benefits (SSI & Medicaid) while he/she participates in approved vocational rehabilitation program.
[Http://policy.ssa.gov/poms.nsf/lnx/0412515001](http://policy.ssa.gov/poms.nsf/lnx/0412515001)

NEW to MEDICAID

- Child did not qualify for SSI under 18 due to family income.
- At age 18 may qualify for SSI and Medicaid as an adult single head of household.

NOTE: "209B States," require separate application to Medicaid, not linked to SSI.

11 States have elected to have at least one more stringent requirement than the SSI rules for Medicaid eligibility: CT, HI, IN, IL, MN, MO, ND, NH, OK, OH, and VA.

PUBLIC HEALTH INSURANCE: Continued Medicaid Eligibility

MEDICAID BUY-IN WHILE WORKING: Section 1619(b)

- Still meets SSI criteria,
- Needs Medicaid in order to work; and
- Gross earned income is insufficient to pay for other supports

TICKET TO WORK

- Worker could opt to buy-in and receive Medicaid benefits
- Program is too new to assess if states are providing full benefit packages and at what level of sliding fee

Creative – MaineCare for Childless Adults

- Meets low income eligibility
- Plan pays insurance premiums for those who meet certain criteria
- Plan uses employer-sponsored insurance for the expansion

PRIVATE HEALTH INSURANCE: Continued Benefits via Family Plan

ADULT DISABLED DEPENDENT CHILD

- Youth over 18 may continue on family plan if dependent for life.
- Must be on the family plan prior to turning 18. (Legal Statute: 40 states)
- No substantial gainful employment
- Annual re-certification - disability & dependent

STUDENT STATUS

- Proof of college class load each semester (often requires full-time status)
- Ages 18-22, sometimes older
- Annual re-certification

PRIVATE HEALTH INSURANCE: Young Adult Pays Premium

OPTIONS to buy private insurance health care benefits:

- College - student plan
- Employed - group plan
- Self-pay: single plan
- Ticket to Work (Medicaid Buy-in)
- COBRA
- State High Risk Pools

Concern: What happens if health status changes and affects continuous employment or attending school? There is no safety-net or easy on/off for health care benefits.

Tip Sheet Developed by: Patti Hackett & Glen Gallivan, Ocala, FL



The HRTW National Center www.hrtw.org enjoys a working partnership with the Shriners Hospitals for Children and KASA. The National Center is funded through a cooperative agreement (U93MC00047) from the Integrated Services Branch, Division of Services for Children with Special Health Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS).
HRSA/MCHB Project Officer: Monique Fountain, MD.

HRTW Phase II Projects are currently active in Arizona, Iowa, Maine, Mississippi, and Wisconsin.

The opinions expressed herein do not necessarily reflect the policy or position nor imply official endorsement of the funding agency or working partnerships.



Good Questions for Your Good Health

Every time you talk with a doctor, nurse, or pharmacist, use the **Ask Me 3** questions to better understand your health.

①

What is my main problem?

②

What do I need to do?

③

Why is it important for me to do this?

When to Ask Questions

You can ask questions when:

- You see your doctor, nurse, or pharmacist.
- You prepare for a medical test or procedure.
- You get your medicine.

What If I Ask and Still Don't Understand?

- Let your doctor, nurse, or pharmacist know if you still don't understand what you need to do.
- You might say, "This is new to me. Will you please explain that to me one more time?"

Who Needs to Ask 3?

Everyone wants help with health information. You are not alone if you find things confusing at times. Asking questions helps you understand how to stay well or to get better.

The **Ask Me 3** questions are designed to help you take better care of your health.

To learn more, visit www.npsf.org/askme3

Your Doctor, Nurse, and Pharmacist Want to Answer 3

Are you nervous to ask your health provider questions? Don't be. You may be surprised to learn that your medical team wants you to let them know that you need help.

Like all of us, doctors have busy schedules. Yet your doctor wants you to know:

- All you can about your condition.
- Why this is important for your health.
- Steps to take to keep your condition under control.

Asking these questions can help me:

- Take care of my health
- Prepare for medical tests
- Take my medicines the right way
- I don't need to feel rushed or embarrassed if I don't understand something. I can ask my doctor again.
- When I **Ask 3**, I am prepared. I know what to do for my health.

Bring your medicines with you the next time you visit your doctor or pharmacist. Or, write the names of the medicines you take on the lines below.

Like many people, you may see more than one doctor. It is important that your doctors know all the medicines you are taking so that you can stay healthy.

Write Your Doctor's Answers to the 3 Questions Here:

1 What is my main problem?

2 What do I need to do?

3 Why is it important for me to do this?

Ask Me 3™ is an educational program provided by the **Partnership for Clear Health Communication at the National Patient Safety Foundation™** – a coalition of national organizations that are working together to promote awareness and solutions around the issue of low health literacy and its effect on safe care and health outcomes.

 **Partnership for
Clear Health Communication**
at the National Patient Safety Foundation™

www.npsf.org/askme3