MY Health, MY Life

A Toolkit for Individuals with Intellectual and Developmental Disabilities; their Family Members, Friends, or Guardians; and their Provider Support Team

Acknowledgements

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INTRODUCTION

The My Health, My Life Toolkit is designed to help individuals with intellectual and developmental disabilities (I/DD) transition between care settings. You may choose to include family members or friends in discussions about the information contained in this Toolkit. You may also ask family members or friends for help in completing and maintaining this Toolkit. For some conversations, you can also include your provider support team. If you have a guardian, the guardian should also be included in support conversations with family members or friends and the provider support team.

The purpose of the Toolkit is to:

❑ Improve communication in care settings, such as hospitals, nursing facilities, or other long-term care facilities;

❑ Ensure important information is available to your provider support team during changes in care settings; and

❑ Strengthen relationships between you and your providers as well as family members, friends, or guardians.

This Toolkit contains four tools that allow you to keep track of your personal health information, to engage in the planning process, and to communicate with your provider support team so that they understand your preferences and medical history. Using all four tools together supports active **person-centered planning**, a process that focuses on the person as the locus of control and supports the person in making their own choices and having control over their daily lives."[1]

Personal Health Record

Review and update your Personal Health Record regularly and bring it with you to all appointments and care settings. This tool includes important personal information, additional needs and instructions, emergency contact information, provider contact information, health history, an appointment planner, and medication records. Keeping information such as your medical history is important. Regular updates to information are critical to effective management of your health.

Hospital Companion Guide

The Hospital Companion Guide helps prepare you and your support team for the transition home from the hospital or other care settings. The guide includes valuable checklists to make sure you understand the services you will receive after leaving the hospital or care setting.

Discharge Planning Tool for Individuals with I/DD

Work with the provider support team (e.g., doctors, nurses, care managers, discharge planners, social workers or other providers) to use the Discharge Planning Tool to help support your transition home from the hospital.

Self-Advocacy Empowerment Tool

Use the Self-Advocacy Empowerment Tool to help plan for services and supports as your needs, preferences, and interests evolve over time.

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[1] Centers for Medicare and Medicaid Services (2017). Centers for Medicare and Medicaid 42 CFR 483.5 - Definitions. Available at https://www.law.cornell.edu/cfr/text/42/483.5.

MY Health, MY Life

HOW TO USE THIS TOOLKIT

Each tool includes a brief summary of:

- ❑ Who could help you complete this tool;
- ❑ The purpose of the tool; and
- ❑ How to use the tool.

To improve the transition home from the hospital or care setting (also referred to as care transitions), you should actively take part in your care planning. Consistent with person-centered planning principles, this Toolkit:

- ❑ Places you, the person transitioning, at the center of the planning process;
- ❑ Engages you in health care decision-making; and
- ❑ Empowers you to ask questions.

Important members you choose for your support team, such as friends, family members, guardians, and providers (e.g., doctors, nurses, care managers, discharge planners, social workers and other health care workers), can support you in completing this Toolkit and managing your care. You can use this Toolkit to coordinate and track care transition needs and you can choose to involve family members or friends during decision-making. Printing the tools and completing them by hand or downloading for electronic completion are both options; do what works best for you.

To get the most out of this Toolkit:

- ❑ **You are encouraged to complete the tools yourself if possible.** This Toolkit focuses on your preferences and needs. It works best if you complete the tools yourself, but people in your support team can also help.

- ❑ **Complete the tools with as much detail as possible.** The tools are helpful in highlighting your preferences and needs as you transition home. The instructions on how to use the tools and how to use the tools together will be helpful in describing your preferences and needs.

- ❑ **Use all the tools together.** Each tool provides useful checklists and forms to help you navigate the health care system. The tools help improve communication between you, your family members or friends and the provider support team during the care planning process.

A Message for People Transitioning from Care Settings

Staying at the hospital or other care setting can be stressful and confusing. However, your provider support team is there to help you while you are in the hospital and when you go home. Your provider support team includes doctors, nurses, care managers, and other health care workers who help you get and stay healthy. It is important that you understand what is happening and that your provider support team understands your needs so you can get the health care that is right for you.

This Toolkit was designed to help ensure good communication between you and your care team. By completing the tools in this Toolkit and sharing it with your care team, everyone will understand what is important to you about your health and health care.

This Toolkit includes tools to help you live your life the way you want and focus on what you can do. The tools help your family and your provider support team work with you as you come home. The tools help keep your health information in one place so when you change your care setting you can share your health care preferences, needs and medical history. The tools can improve communication and coordination throughout your stay and your transition home.

DESCRIPTION OF YOUR TOOLS

The **Personal Health Record** helps you keep all your health information in one place. It provides a space for you to fill in your personal information, emergency contact information, provider contact information, health conditions, appointments, and medication records. You can use your *Personal Health Record* at the doctor's office, in care settings, and at home. You should update and review your *Personal Health Record* regularly. If you need more space to update your health information, look in the *Personal Health Record Appendix* for blank forms.

The **Hospital Companion Guide** helps prepare you for the transition home from the hospital or other care setting. The *Hospital Companion Guide* provides a helpful checklist to make sure you have the information you need before transition and understand the changes in services and supports you will receive after you go home.

The **Discharge Planning Tool for Individuals with I/DD** helps you work with your provider support team to prepare for a successful transition home from the care setting. You and your provider support team can use the tool to ensure you and your family and friends understand the next steps in your care.

The **Self-Advocacy Empowerment Tool** gives you tips on how to ask questions, find resources and take action to meet your needs, preferences and rights. You can refer to the tips when planning for services and supports.

Note: The My Health, My Life Toolkit was developed by adapting the following resources: Dr. Eric Coleman's Individual Discharge Checklist, Robert Wood Johnson Foundation, Care About Your Care Discharge Checklist & Care Transition Plan, Centers for Medicare and Medicaid Services 2012 publication, Your Discharge Checklist, The United Hospital Fund's Discharge List for Caregivers, and the American Health Information Management Association's (AHIMA) Health Information Form for Adults.
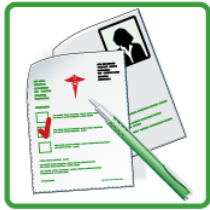
Personal Health Record

Who Could Help You Complete This Tool

❑ You can ask family members, friends or guardians who you choose to support you to complete this tool.

How to Use This Tool

Your **Personal Health Record** includes information about you and your health. It helps you manage your health care and improve communication between you and your health care providers.

Use this tool as a central place to record all of your contact and health information, including:

❑ Personal information

❑ Additional needs and instructions

❑ Contact information for people who help me

❑ Contact information for providers

❑ Health conditions

❑ Appointment details

❑ Medication records

You may find it helpful to bring your **Personal Health Record** with you to all health appointments. You regularly review and update information, such as current medications, recent care visits, and contact information, so that all providers involved in your care have consistent and up-to-date information. If you need more space, look in the *Personal Health Record Appendix* for blank forms.

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Personal Health Record

MY PERSONAL HEALTH RECORD

MY PERSONAL INFORMATION

First Name	Last Name

Address

Home Phone Number			Cell Phone Number		

Birthdate				Gender
Month	Day	Year		☐ **Male**
				☐ **Female**

Height	Weight		Preferred Language(s)

Private Health Insurance Company	Private Health Insurance Number
Medicaid Insurance Number	**Medicare Insurance Number**

MY ADDITIONAL NEEDS AND INSTRUCTIONS

Communication Needs

Transportation Needs

Advanced Directive/DNR Order

Other Requests

MY HELPERS

HELLO my name is John Doe	Helper Name #1		Phone Number		
	Relationship to me		Other Phone Number		

HELLO my name is John Doe	Helper Name #2		Phone Number		
	Relationship to me		Other Phone Number		

HELLO my name is John Doe	Helper Name #3		Phone Number		
	Relationship to me		Other Phone Number		

Note: IF YOU HAVE A GUARDIAN, YOU SHOULD INCLUDE THEIR INFORMATION.

MY EMERGENCY CONTACTS

REMEMBER: IF YOU HAVE AN EMERGENCY AND NEED HELP RIGHT NOW, CALL 911.

	Emergency Contact's Name #1		Phone Number		
	Relationship to me		Other Phone Number		

	Emergency Contact's Name #2		Phone Number		
	Relationship to me		Other Phone Number		

Personal Health Record

MY PRIMARY CARE DOCTOR AND OTHER HEALTH PROVIDERS

HELLO my name is John Doe	**Primary Care Doctor's Name**		**Phone Number**		
🏠	**Primary Care Doctor's Address**				

HELLO my name is John Doe	**Provider's Name #1**		**Phone Number**		
	Provider Type		**Provider's Address**		

HELLO my name is John Doe	**Provider's Name #2**		**Phone Number**		
	Provider Type		**Provider's Address**		

HELLO my name is John Doe	**Provider's Name #3**		**Phone Number**		
	Provider Type		**Provider's Address**		

HELLO my name is John Doe	**Pharmacist's Name**		**Phone Number**		
HELLO my name is John Doe	**Pharmacy's Name**		**Pharmacy's Address**		

MY HOSPITAL AND HOME CARE AGENCY

H	**Hospital's Name**		**Hospital's Address**
	Home Care Agency's Name		**Home Care Agency's Phone #**

MY MEDICAL HISTORY

MY ALLERGIES (E.G., FOOD, MEDICATIONS, ENVIRONMENT)

	Allergy		Reaction and Treatment		Date Last Reaction
	Allergy		Reaction and Treatment		Date Last Reaction
	Allergy		Reaction and Treatment		Date Last Reaction
	Allergy		Reaction and Treatment		Date Last Reaction
	Allergy		Reaction and Treatment		Date Last Reaction

MY HEALTH CONDITIONS

	Date Diagnosed		Health Condition	Doctor	Condition Status
	Date Diagnosed		Health Condition	Doctor	Condition Status
	Date Diagnosed		Health Condition	Doctor	Condition Status
	Date Diagnosed		Health Condition	Doctor	Condition Status
	Date Diagnosed		Health Condition	Doctor	Condition Status
	Date Diagnosed		Health Condition	Doctor	Condition Status
	Date Diagnosed		Health Condition	Doctor	Condition Status

Personal Health Record

MY IMPORTANT HEALTH EVENTS (E.G., SEIZURES, FALLS)

Date	Health Event
Date	Health Event
Date	Health Event
Date	Health Event
Date	Health Event
Date	Health Event

MY IMMUNIZATION HISTORY

Immunization	Date	Booster Date 1	Booster Date 2	Booster Date 3	Provider's Name
Diphtheria					
Hepatitis B					
Hepatitis A					
Measles					
Mumps					
Pertussis/Whooping					
Polio					
Rubella					
Smallpox					
Tetanus					
Tuberculosis					
Typhoid					
Influenza					
Rotavirus					
Acellular Pertussis					
Varicella					
Meningococcal					
Human Papillomavirus					
Other					

MY HOSPITAL VISITS

	Admission Date		Reason for Visit	Hospital
	Discharge Date		Diagnosis and Outcomes	
	Admission Date		Reason for Visit	Hospital
	Discharge Date		Diagnosis and Outcomes	
	Admission Date		Reason for Visit	Hospital
	Discharge Date		Diagnosis and Outcomes	

MY FAMILY MEDICAL HISTORY

	Mother's Health Conditions or Illnesses	Age	If deceased, age and cause of death
	Father's Health Conditions or Illnesses	Age	If deceased, age and cause of death
	Sibling(s)'s Health Conditions or Illnesses	Age	If deceased, age and cause of death
	Grandparent(s)'s Health Conditions or Illnesses	Age	If deceased, age and cause of death

NOTES

MY APPOINTMENT PLANNER

Appointment Date				**Provider's Name**	**Phone Number**	
Month	**Day**	**Year**		**Provider's Address**	**Provider Type**	

Reason for Appointment

Questions I Want to Ask My Provider

Appointment Outcome
What did you hear at this appointment? Do you need to make a new appointment?

Appointment Date				**Provider's Name**	**Phone Number**	
Month	**Day**	**Year**		**Provider's Address**	**Provider Type**	

Reason for Appointment

Questions I Want to Ask My Provider

Appointment Outcome
What did you hear at your doctor's appointment? Do you need to make a new appointment?

Note: If you need more space, look in the *Personal Health Record Appendix* for blank forms.

MY APPOINTMENT LIST

This list should highlight all appointments from the last 12 months as well as previous appointments that are relevant to your current health status. You can remove general appointments that are from long ago to make this appointment list easier to manage.

Appointment Date			Provider's Name	Reason for Appointment	Diagnosis
Month	Day	Year			

Appointment Date			Provider's Name	Reason for Appointment	Diagnosis
Month	Day	Year			

Appointment Date			Provider's Name	Reason for Appointment	Diagnosis
Month	Day	Year			

Appointment Date			Provider's Name	Reason for Appointment	Diagnosis
Month	Day	Year			

Appointment Date			Provider's Name	Reason for Appointment	Diagnosis
Month	Day	Year			

Appointment Date			Provider's Name	Reason for Appointment	Diagnosis
Month	Day	Year			

Appointment Date			Provider's Name	Reason for Appointment	Diagnosis
Month	Day	Year			

Appointment Date			Provider's Name	Reason for Appointment	Diagnosis
Month	Day	Year			

Appointment Date			Provider's Name	Reason for Appointment	Diagnosis
Month	Day	Year			

Appointment Date			Provider's Name	Reason for Appointment	Diagnosis
Month	Day	Year			

Note: If you need more space, look in the *Personal Health Record Appendix* for blank forms.

MY MEDICATION RECORD

Keep track of your prescription and over-the-counter medicines here. Use this list to track your medications and to confirm that you are taking them correctly.

☑ Place a check mark in the box if you have the information you need to take your medications. If you cannot check a box, ask your doctor or nurse to explain the information you need.

☐ Use the Notes section to record what you discussed with your doctor.

Make sure to ask your doctor for written instructions if something is not clear.

Medication Instructions

☐ I know why I need to take my medications.

☐ I can describe what my medications look like.

☐ I know how often and at what time I take my medications each day.

☐ I know what to do if I miss a medication dose. For example, the next time I take my medications I know if I am supposed to double the dose or take the usual dose.

☐ I know what happens if I take more than or less than the usual dose of my medications.

☐ I know when to stop taking my medication.

☐ I know who to call if I have questions about my medications. If I have any questions about how to take my medications, or if I make a mistake with my medications, I will call:

Name	
Phone Number			

☐ I know who to call if I need help taking my medications. If I cannot take my medications by myself, I will call:

Name	
Phone Number			

Medication Side Effects

REMEMBER: IF YOU HAVE AN EMERGENCY AND NEED HELP RIGHT NOW, CALL 911.

☐ I know the side effects of my medications and if they will make me feel different.

☐ I know if this medication will interact with other prescription and over-the-counter medications I am currently taking.

☐ I know if I am allergic to a medication.

☐ I know what signs or symptoms to watch for if something is wrong.

☐ I know when I should report these signs or symptoms. If I have any signs or symptoms, I will call:

Name		
Phone Number		

☐ I know the number for my local poison control center. If I need to call the local poison control center, I will call:

Name		
Phone Number		

In the following table, please indicate side effects of medications that you have experienced.

Side Effects of Medication

☐ Headache	☐ Diarrhea	☐ Vomiting	☐ Sleep Problems	☐ Weight Loss
☐ Dizziness	☐ Constipation	☐ Loss of Appetite	☐ Confusion	☐ Cough
☐ Drowsiness	☐ Upset Stomach	☐ Anxiety	☐ Skin Rash	☐ Increased Risk of Infection
☐ Other:_____		☐ Other: _____		

MY MEDICATION (ONE FORM PER MEDICATION)

Drug Name	What Does this Medication Look Like?
Dosage	**What Health Condition Does this Medication Treat?**
Provider's Name	**Provider's Phone Number**
Pharmacy's Name	**Pharmacy's Phone Number**

Schedule

Time	Dosage

Date Started Taking Medication

Month	Day	Year

Date Ended Taking Medication

Month	Day	Year

I take this Medication when... (e.g. my blood pressure is too high) ?

Reaction to Medication and Side Effects Experienced

Notes

Note: If you need more space, look in the *Personal Health Record Appendix* for blank forms. Additionally, in the Appendix, you can find forms to fill out your Medication List in its entirety and a form to summarize all Personal Health Record information onto one sheet.

NOTES

DATE LAST UPDATED

Month	Date	Year

Note: If you need more space, look in the *Personal Health Record Appendix* for blank forms.

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Hospital Companion Guide

Who Could Help You Complete This Tool

❏ You can ask family members, friends or guardians who you choose to support you to complete this tool.

❏ You can ask your provider support team: all providers who support you in the hospital or community.

How to Use This Tool

The **Hospital Companion Guide** helps you prepare for your return home or to your next care setting. Before you leave the hospital, your provider support team can help you complete this tool. Completing this tool will help ensure you have the support and information you need to go home or to your next care setting.

❏ Use this checklist during each hospital stay.

❏ Talk with doctors and nurses about items on this checklist and any questions that are important to you.

❏ After talking with your doctors and nurses, check each box if you have the information you need. If you cannot check a box, ask your doctor or nurse to explain the information you need.

❏ Hospital staff can use the tool to prepare you and your family members or friends for the next steps in your care.

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HOSPITAL COMPANION GUIDE CHECKLISTS

The checklists can help you prepare for your transition home or to your next care setting. Before you leave the hospital, make sure you have the information you need. If you do not have the information, please ask your provider support team to explain it to you further.

☑ Place a check mark in each box if you have the information you need.

☐ If you cannot check a box, ask your doctor or nurse to explain the information you need.

Preparing to Leave the Hospital

☐ I understand why I am in the

hospital.

☐ I know what I can do to feel better.

☐ I know how to keep myself healthy.

☐ I know what I need to do so I can leave the hospital.

☐ I know where I will get services and supports after I leave the hospital.

☐ I know when to call my doctor after I leave. After I leave the hospital, I

will call:

Doctor's Name			
Phone Number			

Discussing the Discharge Plan

☐ I discussed my discharge plan with my discharge coordinator.

A discharge plan includes information that you need to know when you leave the hospital. Your discharge coordinator is the person who will explain the information to you and your family.

☐ I understand the discharge plan.

☐ If I have someone else with me, they understand the discharge plan.

☐ If I do not understand the discharge plan, I will get help

from: Name			
Phone Number			

Returning Home

☐ Family members, friends, or neighbors know I am coming home and will help me if I need help.

☐ These individuals know what type of help I need when I go

home:

_____

_____

_____

_____

☐ I have home health care when I leave the hospital.

Agency Name			
Phone Number			

Going to a Facility

Instead of going home after the hospital, I am

going to:

Name of Facility			
Phone Number			

Understanding My Medications

☐ I know what my medications are, where to get them, and how to take them.

☐ I know my medication side effects and will report any side effects to my doctor.

☐ I updated My Medication Record in my *Personal Health Record.*

Special Instructions and Home Preparation

☐ I need a home care referral and physical therapy assessment.

☐ When I go home, I will need help with (*place a check mark in each box that your doctor or nurse discusses with you*):

- ☐ Walking
- ☐ Medications or managing pain or nausea
- ☐ Transferring (moving from bed to chair)
- ☐ Bathing or personal hygiene
- ☐ Using the toilet
- ☐ Meals (e.g., diet restrictions, only eat soft foods, foods not allowed)
- ☐ Transportation
- ☐ Dressing
- ☐ Making appointments
- ☐ Physical therapy exercises
- ☐ Special equipment
- ☐ Household
- ☐ Taking care of finances
- ☐ Other _____

☐ I need to remove things from my home that may cause me to trip or fall.

☐ I need to hire additional personnel to help with care.

☐ I need to buy extra supplies (e.g., nutritional supplements) to use at home.

☐ I need medical equipment after I leave the hospital. If I need equipment, I will call:

Name		
Phone Number		

Training for My Family Members, Friends, or Guardians

☐ I know what help I need in the next few months.

☐ I know who will be helping me and that they know how to help me.

☐ My support team understands my discharge plan and related instructions.

☐ I talked to my discharge coordinator about training my family members, friends, or guardian to support me.

    ☐ I asked where they can get trained.

    ☐ I asked who will train them.

    ☐ I asked when they can get trained.

    ☐ I asked if training can begin in the hospital.

☐ My support team is trained to help with my care.

    ☐ They are trained in transfer skills and preventing falls.

    ☐ They know how to turn me in bed so I do not get bedsores.

    ☐ Other

☐ My support team can complete all the care tasks I checked that I need help with.

    ☐ My support team cannot complete the care tasks I checked and needs to learn how to:

        ☐ Change dressings

        ☐ Give injections

        ☐ Use special equipment

        ☐ Other

    ☐ If my support team cannot complete the care tasks I checked, I talked to my discharge coordinator about getting help with these activities.

    To get the help I need, I can contact my local agency for additional training or temporary assistance.

Agency Name	
Phone Number	

    ☐ If I had any questions on how someone can help me with these tasks, I discussed these questions with my discharge coordinator.

Follow-Up Appointments

Before leaving the hospital

☐ Make a list of the doctors or other health care providers I need to make an appointment with.

HELLO my name is John Doe	Provider's Name #1		Provider Type	Appointment timeframe
				Schedule within ____ months
	Their Phone Number		Reason for Appointment	
HELLO my name is John Doe	Provider's Name #2		Provider Type	Appointment timeframe
				Schedule within ____ months
	Their Phone Number		Reason for Appointment	
HELLO my name is John Doe	Provider's Name #3		Provider Type	Appointment timeframe
				Schedule within ____ months
	Their Phone Number		Reason for Appointment	

Once I get home, I will:

☐ Call my primary care doctor to let them know what happened in the hospital.

☐ Call my doctors to make follow-up appointments.

☐ Record my follow-up appointments in my *Personal Health Record.*

☐ Make transportation arrangements to get to my appointments.

Follow-Up Appointments

Preparing for each appointment

- ☐ Talk with someone I trust about what I need to do before the appointment.
    - ☐ Discuss what will happen during each visit.
    - ☐ Review questions I recorded in my *Personal Health Record* for my doctor.
- ☐ Bring these items to each follow-up appointment.
    - ☐ My insurance card (and payment if a co-pay is required).
    - ☐ My *Personal Health Record*.

Keeping track of all appointments

- ☐ Complete and revise my *Personal Health Record* after each appointment.

Follow-Up Appointments

Checklist when discharge is to a facility (e.g., rehabilitation)

- ☐ I know who will help me select the facility. I know I have a choice.
- ☐ I have checked online resources such as *www.Medicare.gov* for ratings.
- ☐ My loved ones know how long I am expected to remain in the facility.
- ☐ The facility is clean, well-kept, quiet, and kept at a comfortable temperature.
- ☐ There are special facilities or programs to meet my needs.
- ☐ The residents have safe access to the outdoors.
- ☐ My family and friends will be able to visit me in the facility.
- ☐ The location is convenient and I have transportation to get there.
- ☐ The staff members are welcoming to my family and friends.
- ☐ There are ways for family and friends to interact with staff that are sufficient for my wants.
- ☐ I know how many staff are on duty at any given time.
- ☐ I know the staff turnover rate.
- ☐ I can talk to staff about support groups and other resources if I am concerned about my loved one being sick.
- ☐ I can talk to the hospital social worker and care manager if I am concerned about how to pay for help and equipment.
- ☐ If there is a social worker, I can call:

Name	
Phone Number	

Questions to better prepare for conversations about returning home or to your next care setting

Question 1:

Question 2:

Question 3:

Question 4:

Question 5:

Question 6:

Question 7:

Question 8:

Question 9:

Question 10:

Hospital Companion Guide

Hospital Companion Guide Summary

For your complete medical history, refer to your *Personal Health Record* and Discharge Plan.

Hospital Visit Summary		
Admission Date	Discharge Date	
Hospital Name		
Hospital Address		
City	State	Zip Code

I was in the hospital because:

Signs and symptoms to watch for when I leave (If they are present, I should call my doctor):

Diagnosis or outcome of my visit:

Information About My Provider Support Team	
My Primary Doctor	
Name	Phone Number
My Hospital Doctor	
Name	Phone Number
My Hospital Nurse	
Name	Phone Number
My Care Manager or Care Coordinator	
Name	Phone Number
My Home Health Care Provider	
Name	Phone Number
My Pharmacy	
Pharmacy Name	Phone Number
Pharmacy Address	

Prescriptions or Special Equipment

My Prescriptions to Fill After Leaving the Hospital

Drug Name	Dose	Pharmacy Name

My Special Equipment to Order

Equipment Name	Person to Contact

Appointments After Leaving the Hospital

My Next Appointments

Date	Provider Name	Provider Type
Address		Phone Number
Date	Provider Name	Provider Type
Address		Phone Number
Date	Provider Name	Provider Type
Address		Phone Number

Appointments I Need to Make

Provider Name	
Provider Type	Phone Number
Provider Name	
Provider Type	Phone Number
Provider Name	
Provider Type	Phone Number

Things to talk to my provider about at appointments:

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Discharge Planning Tool for Individuals with I/DD

- ❑ You can ask family members, friends or guardians who you choose to support you to complete this tool.
- ❑ You can ask your provider support team: all providers who support you in the hospital or community.

How to Use This Tool

During your stay, it is important that you develop and understand your comprehensive plan for leaving the care setting. To develop this plan, it is best to work with your provider support team and care manager to ensure you understand all of the needed elements for your discharge. Below is a checklist of important things that you may find helpful to know to prepare for a successful transition to the next step in recovery. You can use this checklist over the course of your stay. This checklist ensures that you understand the next steps in care.

Instructions:

Keep this checklist where you and all members of the provider support team can easily access it. This checklist ensures you have and understand all the information needed during discharge. It is important to ask for support to complete the *Discharge Planning Tool,* as needed.

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Discharge Planning Tool for Individuals with I/DD

DISCHARGE PLANNING CHECKLIST

Use the checklist items to guide discussion with the provider support team and prepare for discharge. Place a check in the box as you discuss each item with the provider support team. Skip any items that do not apply to your situation.

✓ Place a check mark in each box if you discussed the information with the provider support team.

My Health

☐ Review the reasons for hospitalization with the provider support team.

☐ Ask for education materials about self-management techniques for your health condition.

☐ Ask for written and verbal information about symptoms to watch for after leaving the hospital.

☐ Ask for the hospital or doctor's number to call if you have any problems or questions.

My Medications

☐ Review medications with the provider support team.

☐ Make sure you have access to a pharmacy and new prescriptions. If you cannot get medications:

    ☐ Ask the doctor who is prescribing the medication to prescribe generic or alternative medications that cost less.

    ☐ Ask for a referral to prescription assistance programs.

Planning for Discharge

☐ Home care referral made.

Name	
Agency Name	
Phone Number	

Recovery and Support

☐ Review medical equipment you may need after hospitalization.

☐ Review daily activities that you may need help with after hospitalization.

☐ Seek guidance on any special assistance you may need after hospitalization.

    ☐ Learn how to complete these tasks.

    ☐ Ask for a name and number to call if you need assistance or have questions.

Discharge

☐ Ask for clear, written instructions that are easy to understand.

☐ Ask for a summary of your current health status.

Self-Advocacy Empowerment Tool
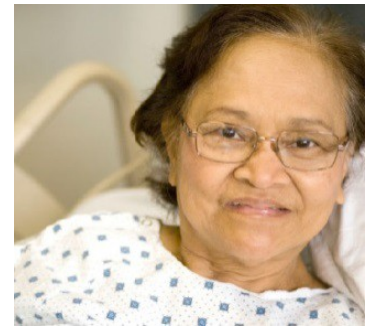
Who Could Help You Use This Tool

❑ You can ask family members, friends or guardians who you choose to support you to complete this tool.

How to Use This Tool

This tool provides strategies for asking questions, finding resources, and taking action to address your needs, preferences, and rights. You can use the different tips to stay motivated and engaged in the delivery of your services and supports. If you have a friend, family member, guardian, or care manager who helps you manage your health care, they can review this tool with you.

Read about the following tips:

❑ Tip 1: Do the planning yourself. You are in charge.

❑ Tip 2: Don't be afraid to ask for help.

❑ Tip 3: Slow down.

❑ Tip 4: You have rights!

❑ Tip 5: Get involved.

❑ Tip 6: Advocate for yourself always!

MY Health, **MY** Life

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Self-Advocacy Empowerment Tool

Standing Up for Yourself or Other People

There may come a time when you feel like you are not getting the support you need or deserve. This may require that you say something and stand up for yourself. Speaking up lets others know what you want and need. There are many different ways to stand up or advocate for yourself or other people. Some ways may feel more comfortable to you than others. This tool provides some helpful tips and ideas.

Tips for Advocating or Standing Up for Yourself

- ❑ **Tip 1: Understand the basics of advocating for yourself!**
  Here are some advocacy basics to consider:

    - ▶ *This process begins with you*—Speak up!

    - ▶ *Take a team approach*—Work with others to maximize available resources.

    - ▶ *Pick an issue to champion*—Advocacy begins by choosing an issue or challenge that is important to you.

    - ▶ *Break the issue down into chunks and manageable steps*—As you gain confidence, you can build to bigger and bigger challenges.

    - ▶ *Locate supports and better understand critics*—Know the people that impact the issue or challenge you want to address. Tackle issues with support, and be prepared by understanding the thoughts of critics. Keep a list of names, addresses, phone numbers, and a description of the role of persons needed to address the challenge.

    - ▶ *Be factual*—Advocacy is best served through a combination of real life experience and facts! Staying informed is critical to successful advocacy.

    - ▶ *Know your rights*—Advocate for yourself and others! Don't give up!

- ❑ **Tip 2: You are in charge. Do the planning yourself.**
  When you feel like you need to stand up for yourself, take the lead by bringing together the people who support you and your interests to start planning and making decisions. If you already have a person-centered plan, make sure to use it! Talk to people you trust about your preferences for when you go home, the services and supports you need, and who you want involved in changes to your health care plan.

- ❑ **Tip 3: Don't be afraid to ask for help.**
  There are many places that can offer services to help you and your family members, friends, or guardians. For example, there are organizations that can

help you with transportation, meals, support groups, or counseling services. The hospital discharge planner and your community-based care manager (for example, your care manager or social worker from an agency) can help you find the support you need. More information is found under the *National Resources* section of this tool.

❑ **Tip 4: Start early.**

It is important to start researching and asking about your options for care once you are discharged from the hospital. You may want to begin this early by seeking help from your discharge planner while in the hospital and seeking out support from your care manager for services in the community.

❑ **Tip 5: You have rights!**

If you feel it is too soon to leave the hospital or you feel that the process is moving too fast, *you have the right to say so.* You have a right to be heard! Your first step is to talk with your doctor and discharge planner and voice your concerns. If you think you are being discharged too soon, the hospital is required to tell you what you need to do to appeal the discharge decision.

❑ **Tip 6: Get involved.**

If you have time and interest, you can get involved in improving the discharge planning process. Sometimes, it is unclear who is doing what, why, and when. Improvements may be needed in education and training, preventive care, and care planning. You can help by offering feedback to your hospital and health care providers. You can also offer feedback on educational materials and engage in policies that impact public programs.

National Resources

The Administration for Community Living's No Wrong Door (NWD) System

NWD systems are single points of entry into the long-term services and supports system for older adults and people with disabilities. They address many of the frustrations individuals and their families experience when trying to find needed information, services, and supports. Through integration or coordination of existing aging and disability service systems, NWD systems raise visibility about the full range of options that are available; provide objective information, advice, counseling and assistance; empower people to make informed decisions about their long-term supports; and help people access public and private long-term services and supports programs more easily.

Website: *www.nwd.acl.gov*

The Arc

The Arc is the nation's leading advocate for all people with I/DD and their families, and a leading provider of the supports and services people want and need. Supports and services offered by The Arc chapters include: information and referral services; individual advocacy for education, employment, health care and other concerns; self-advocacy initiatives; residential and family support; employment programs; and leisure and recreational programs.

Phone: 1-800-433-5255
Website: *www.thearc.org*

Eldercare Locator

The Eldercare Locator, a public service of the Administration on Aging, U.S. Department of Health and Human Services, is a nationwide service that connects older adults and people with disabilities, and their families, with information on various services available in their area.

Phone: 1-800-677-1116
Website: *www.eldercare.gov*

Medicare

Get answers to Medicare billing questions, claims questions, medical records issues, and expense questions.

Phone: 1-800-MEDICARE (1-800-633-4227)
Website: *www.medicare.gov*

Medicare: Planning for Your Discharge (Publication 11376)

This document from the Centers for Medicare and Medicaid Services (CMS) is a discharge planning checklist for patients preparing to leave a hospital, nursing home, or other care setting and their family members or guardians.

Website: *www.medicare.gov/Publications/Pubs/pdf/11376.pdf*

Medicare's Nursing Home Compare

Nursing Home Compare has detailed information about every Medicare- and Medicaid- certified nursing home in the country.

Website: *www.medicare.gov/nhcompare/*

Medicare Rights Center

The Medicare Rights Center is a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives.

Website: *www.medicarerights.org*

Quality Improvement Organization (QIO)

QIOs are private, typically not-for-profit organizations, which are staffed by doctors and other health care professionals. The health care professionals are trained to review medical care and help beneficiaries with complaints about the quality of care, and to implement improvements in the quality of care available throughout the spectrum of care.

Website: *http://www.ahqa.org*

United Hospital Fund

United Hospital Fund's Next Step in Care: Family Caregivers and Health Care Professionals Working Together is a multi-year, multi-dimensional campaign that is designed to change health care practice by routinely recognizing, training, and supporting family caregivers, especially at times of transitions in care. The campaign is part of a broader movement in health care to improve quality and safety. While New York is the focus of United Hospital Fund's work, the impact and relevance are national.

Website: *www.nextstepincare.org*

Personal Health Record Appendix

❑ You can ask family members, friends or guardians who you choose to support you to complete this tool.

How to Use This Tool

Your **Personal Health Record Appendix** includes additional pages to update your *Personal Health Record* as needed. This Appendix includes the following:

❑ My Appointment Planner

❑ My Appointment List

❑ My Medication

❑ My Personal Health Record Summary

❑ Notes

MY Health, **MY** Life

MY APPOINTMENT PLANNER

Appointment Date			HELLO my name is John Doe	Provider's Name	Phone Number		
Month	Day	Year	🏠	Provider's Address	Provider Type		

Reason for Appointment

Questions I Want to Ask My Provider

Appointment Outcome
What did you hear at this appointment? Do you need to make a new appointment?

Appointment Date			HELLO my name is John Doe	Provider's Name	Phone Number		
Month	Day	Year	🏠	Provider's Address	Provider Type		

Reason for Appointment

Questions I Want to Ask My Provider

Appointment Outcome
What did you hear at your doctor's appointment? Do you need to make a new appointment?

Personal Health Record Appendix

MY APPOINTMENT LIST

Appointment Date			Provider's Name	Reason for Appointment	Diagnosis
Month	Day	Year			
Appointment Date			**Provider's Name**	**Reason for Appointment**	**Diagnosis**
Month	Day	Year			
Appointment Date			**Provider's Name**	**Reason for Appointment**	**Diagnosis**
Month	Day	Year			
Appointment Date			**Provider's Name**	**Reason for Appointment**	**Diagnosis**
Month	Day	Year			
Appointment Date			**Provider's Name**	**Reason for Appointment**	**Diagnosis**
Month	Day	Year			
Appointment Date			**Provider's Name**	**Reason for Appointment**	**Diagnosis**
Month	Day	Year			
Appointment Date			**Provider's Name**	**Reason for Appointment**	**Diagnosis**
Month	Day	Year			
Appointment Date			**Provider's Name**	**Reason for Appointment**	**Diagnosis**
Month	Day	Year			
Appointment Date			**Provider's Name**	**Reason for Appointment**	**Diagnosis**
Month	Day	Year			
Appointment Date			**Provider's Name**	**Reason for Appointment**	**Diagnosis**
Month	Day	Year			
Appointment Date			**Provider's Name**	**Reason for Appointment**	**Diagnosis**
Month	Day	Year			

MY MEDICATION (ONE FORM PER MEDICATION)

Drug Name	What Does this Medication Look Like?
Dosage	**What Health Condition Does this Medication**
Provider's Name	**Provider's Phone Number**
Pharmacy's Name	**Pharmacy's Phone Number**

Schedule		Date Started Taking Medication		
Time	**Dosage**	Month	Day	Year
		Date Ended Taking Medication		
		Month	Day	Year

I take this Medication when... (e.g. my blood pressure is too high) ?

Reaction to Medication and Side Effects Experienced

Notes

MY PERSONAL HEALTH RECORD SUMMARY

Information About Me

First Name	Last Name

Address

City	State	Zip Code

Home Phone	Cell Phone

Date of Birth	☐ Male	☐ Female

My Health Insurance Information

Private Health Insurance Company

Private Health Insurance Number

Medicaid Insurance Number

Medicare Insurance Number

My Additional Needs and Instructions

Communication Needs

Transportation Needs

Other Requests

My Medical History

My Allergies

Allergy	Date Last Reaction

My Health Conditions

Health Condition	Doctor

My Important Health Events

Health Event	Date

Information About People Who Help Me

My Helper or Guardian

First Name	Last Name

Phone Number	Relationship to me

In Case of Emergency, Contact:

First Name	Last Name

Phone Number	Relationship to me

My Primary Care Doctor

First Name	Last Name
Phone Number	Address

My Provider #1

First Name	Last Name

Phone Number	Address

My Provider #2

First Name	Last Name

Phone Number	Address

My Pharmacy

Pharmacy Name	Phone Number

Pharmacy Address

My Hospital

Hospital Name	Address

My Home Care Agency

Agency Name	Phone Number

My Medication Record

My Medication List

Drug Name	Dose	Time of Day

NOTES

DATE LAST UPDATED

Month	Date	Year

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