



DMD PATHWAYS



Care Binder

Helping you keep the information
you use most often in one place.

One place.

Your family.

Your journey.

This Binder Belongs To



Child's Name _____

Preferred Name (optional) _____

Date of Birth _____

Diagnosis Date _____

Primary Diagnosis _____

Primary Neuromuscular Clinic _____

Quick Reference

Quick facts at your fingertips.



Child's Photo
(optional)

Child's Name: _____

Preferred Name (optional): _____

Date of Birth: _____

Diagnosis Date: _____

Primary Diagnosis: _____



Genetic Results

Gene: _____

Variant: _____

Exon(s): _____

Zygosity: _____



Emergency Contacts

Contact	Relationship	Phone
Emergency Contact 1		() -
Emergency Contact 2		() -
Other Emergency Contact		() -



Medical Alerts



Allergies: _____



Medical Alerts: _____



Assistive Devices: _____



Communication Needs: _____



Current Medications

Medication	Dose	Schedule / Frequency

☐ Additional medication list attached



Primary Care Team

Specialty	Provider	Phone
Neuromuscular		() -
Primary Care		() -
Cardiology		() -
Pulmonology		() -
Physical Therapy		() -
Other		() -



Insurance Information

Primary Insurance: _____

Member ID / Policy #: _____

Group #: _____

Case Manager: _____

Case Manager Phone: () -

Secondary Insurance: _____

Member ID / Policy #: _____



Emergency Care Information

Preferred Hospital: _____

Emergency Care Considerations:

Examples: Steroid dependent, uses BiPAP at night,
wheelchair-accessible transport needed, difficult airway history, etc.



Remember to update this page whenever important information changes.



Continuation of the Quick Reference Guide

Date Updated: _____

[illegible]☐ Additional medication page attached



Additional Notes for Emergencies

Additional information for emergency providers

Child's Name: _____

Date of Birth: _____

Date Updated: _____



Important Medical Considerations



Respiratory / Cardiac Considerations



Mobility / Equipment



Communication / Behavioral Considerations



Other Information We Want Providers to Know



Remember to update this page whenever important information changes.



..... Table of Contents



The first three pages behind the cover make up the Quick Reference Guide. During an emergency, hospital visit, or first appointment with a new provider, begin there.



QUICK REFERENCE GUIDE

LOCATED IMMEDIATELY BEHIND THE COVER

1



MEDICAL HISTORY & CARE

Medical records organized by specialty so providers can quickly review the information most relevant to their care.

2



MEDICATIONS

Current medications, medication history, infusion records, pharmacy information, and medication-related documents.

3



APPOINTMENT TRACKER

Keep track of upcoming appointments, questions, referrals, recommendations, and follow-up tasks.

4



INSURANCE & BILLING

Insurance information, authorizations, billing records, financial assistance, and related documents.

5



SCHOOL

Educational records, school accommodations, therapy services, and communication with your child's school.

6



CAREGIVERS

Information to help family members, respite providers, nurses, and caregivers safely care for your child.

7



FUNDING & FAMILY RESOURCES

Grants, financial assistance, wish organizations, community resources, legal documents, and other programs that support your family.

8



OPTIONAL TRACKING & NOTES

A flexible place for personal notes, symptom tracking, health logs, goals, and other information you'd like to record over time.



TIP: File new records at the front of each section so the most current information is always found first.



SECTION 1

MEDICAL HISTORY & CARE



This section contains your child's medical history organized by specialty.

Keeping records together by provider makes it easier to prepare for appointments, share information with new care teams, and quickly locate important documents when they're needed most.



*Within each specialty, file the newest records at the front
so the most current information is always easy to find.*





NEUROMUSCULAR CLINIC



PROVIDER INFORMATION

Primary Neuromuscular Physician _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

- ☒ Clinic notes
- ☒ Genetic testing reports
- ☒ Neurological exams
- ☒ Pulmonary Function Tests
- ☒ Sleep study results
- ☒ EMG / Nerve Conduction
- ☒ Laboratory tests
- ☒ Medication Changes
- ☒ Care Recommendations
- ☒ Other Neuromuscular Records

☐ _____

☐ _____



Keep the newest records at the front of this section.



NEUROMUSCULAR CLINIC

Specialty Profile

This page provides an enduring overview of your child's neuromuscular care.
Update only when information changes significantly.



CARE TEAM

Primary Neuromuscular Physician _____
Clinic / Hospital _____
Phone _____
Care Coordinator _____
Phone _____
Clinic Website _____



2 DIAGNOSIS INFORMATION

Primary Diagnosis _____
Genetic Variant _____
Date Diagnosed _____
Age at Diagnosis _____ Current Age _____
Ambulatory Status (check one)
☐ Ambulatory ☐ Non-Ambulatory ☐ Power Wheelchair
Gene Therapy Received
☐ Yes ☐ No If yes, date _____
Current Steroid Therapy
☐ Yes ☐ No If yes, which _____



LONG-TERM CARE SERVICES

Services currently part of ongoing care:

- | | |
|---|--|
| ☐ Cardiac Surveillance | ☐ Nutrition / Dietetics |
| ☐ Pulmonary Surveillance | ☐ Mental Health Support |
| ☐ Physical Therapy | ☐ Palliative Care |
| ☐ Occupational Therapy | ☐ Other _____ |
| ☐ Speech Therapy | ☐ Other _____ |



DURABLE MEDICAL EQUIPMENT

Equipment currently used:

- | | |
|---|---|
| ☐ Manual Wheelchair | ☐ Lift / Hoyer Lift |
| ☐ Power Wheelchair | ☐ Shower Chair / Commode |
| ☐ Standing Device | ☐ Orthotics / Bracing |
| ☐ Cough Assist | ☐ Communication Device |
| ☐ BiPAP / Ventilator | ☐ Other _____ |



BASELINE FUNCTIONAL STATUS

Current baseline (check all that apply):

- | | |
|---|--|
| ☐ Walks independently | ☐ Independent in daily activities |
| ☐ Requires assistance to walk | ☐ Requires assistance for ADLs |
| ☐ Uses wheelchair | ☐ Speech is understandable |
| ☐ Transfers independently | ☐ Uses communication support |
| ☐ Requires assistance with transfers | ☐ Feeds independently |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives any provider a quick understanding of your child's neuromuscular care at a glance, no matter when or where care is provided.



TIP:

Review this page at least once a year or when major changes occur.



NEUROMUSCULAR CLINIC

Visit Summary

Use this page to capture key information from each visit.

Place this summary at the front of the visit records in this section.



Keep your most recent visit summaries at the front of this section.



Visit Date _____



Provider _____



Clinic / Location _____

Reason for Visit _____



TESTS & EVALUATIONS PERFORMED

(Check all that apply)

- | | |
|--|---|
| ☐ Physical Exam | ☐ Genetic Testing |
| ☐ Pulmonary Function Test (PFT) | ☐ EMG / Nerve Conduction |
| ☐ Sleep Study | ☐ Swallow Study |
| ☐ Strength Assessment | ☐ Mobility / Functional Assessment |
| ☐ Labs | ☐ Other _____ |
| ☐ Imaging (MRI / Other) | ☐ Other _____ |

See Test Tracker for details and results.



KEY FINDINGS

Summary of important findings from this visit.



CHANGES OR UPDATES



MEDICATION CHANGES

- ☐ New Medication
☐ Dose Change
☐ Discontinued

Details: _____



THERAPY / TREATMENT CHANGES

- ☐ New Therapy
☐ Change in Frequency
☐ Discontinued

Details: _____



EQUIPMENT / SUPPLY CHANGES

- ☐ New Equipment
☐ Equipment Adjustment
☐ Repairs / Replacement

Details: _____



OTHER CHANGES

- ☐ Care Plan Update
☐ Activity / Restrictions
☐ Other _____

Details: _____



FOLLOW-UP PLAN

Next Appointment Date _____

With _____

Recommended Tests / Referrals _____

Other Instructions / Recommendations _____



QUESTIONS

Questions Answered

- ☐ _____
☐ _____
☐ _____
☐ _____

Questions I Still Have

- ☐ _____
☐ _____
☐ _____
☐ _____



ADDITIONAL NOTES



INFORMATION SOURCE

This summary was completed by:

- ☐ Parent / Caregiver
☐ Patient
☐ Other _____

Date Completed _____



TIP: Complete this summary during or right after the visit while information is fresh.
Then place the clinic note, test results, and other documents behind this page.

LAST REVISION DATE

____ / ____ / ____



CARDIOLOGY



PROVIDER INFORMATION

Primary Cardiologist _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

- ☒ Clinic notes
- ☒ Echocardiograms
- ☒ ECGs
- ☒ Holter Monitor Reports
- ☒ Cardiac MRI
- ☒ Medication Changes
- ☒ Care Recommendations
- ☒ Other Cardiology Records







Keep the newest records at the front of this section.



CARDIOLOGY

Specialty Profile

This page provides an enduring overview of your child's cardiology care.
Update only when information changes significantly.



CARE TEAM

Primary Cardiologist _____
Clinic / Hospital _____
Care Coordinator _____
Phone _____
Clinic Website _____



2 DIAGNOSIS INFORMATION

Primary Cardiac Diagnosis _____
Cardiac Findings / Concerns _____
Date Diagnosed _____
Age at Diagnosis _____ Current Age _____
Cardiac Medications (check one)
☐ Yes ☐ No If yes, which _____
Arrhythmia Monitoring (check one)
☐ Yes ☐ No If yes, type _____
Other Cardiac Conditions _____



LONG-TERM CARE SERVICES

Services currently part of ongoing care:

- | | |
|--|--|
| ☐ Cardiac Surveillance | ☐ Mental Health Support |
| ☐ Medication Management | ☐ Palliative Care |
| ☐ Nutrition / Dietetics | ☐ Social Work Support |
| ☐ Physical Therapy | ☐ Home Nursing |
| ☐ Occupational Therapy | ☐ Other _____ |
| ☐ Speech Therapy | ☐ Other _____ |



DURABLE MEDICAL EQUIPMENT

Equipment currently used:

- | | |
|---|---|
| ☐ Blood Pressure Monitor | ☐ Automated External Defibrillator (AED) |
| ☐ Pulse Oximeter | ☐ Medication Organizer |
| ☐ Heart Rate Monitor | ☐ Stethoscope |
| ☐ ECG / Holter Monitor | ☐ Other _____ |
| ☐ Scale | |
| ☐ Other _____ | |



BASELINE FUNCTIONAL STATUS

Current baseline (check all that apply):

- | | |
|---|--|
| ☐ Walks independently | ☐ Independent in daily activities |
| ☐ Requires assistance to walk | ☐ Requires assistance for ADLs |
| ☐ Uses wheelchair | ☐ Speech is understandable |
| ☐ Transfers independently | ☐ Uses communication support |
| ☐ Requires assistance with transfers | ☐ Feeds independently |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives providers a quick understanding of your child's cardiology care at a glance.



TIP:

Review this page at least once a year or when major changes occur.





CARDIOLOGY

Visit Summary

Use this page to capture key information from each visit.
Place this summary at the front of the visit records in this section.



Keep your most recent
visit summaries at the
front of this section.

 Visit Date _____

 Provider _____

 Clinic / Location _____

Reason for Visit _____



TESTS & EVALUATIONS PERFORMED

(Check all that apply)

- | | |
|--|--|
| ☐ Physical Exam | ☐ Labs (Blood Work) |
| ☐ Echocardiogram | ☐ Medication Review |
| ☐ ECG (Electrocardiogram) | ☐ Stress Test |
| ☐ Holter Monitor | ☐ Other _____ |
| ☐ Cardiac MRI | ☐ Other _____ |

See Test Tracker for details and results.



KEY FINDINGS

Summary of important findings from this visit.



CHANGES OR UPDATES



MEDICATION CHANGES

- ☐ New Medication
- ☐ Dose Change
- ☐ Discontinued

Details: _____



THERAPY / TREATMENT CHANGES

- ☐ New Therapy
- ☐ Change in Frequency
- ☐ Discontinued

Details: _____



EQUIPMENT / SUPPLY CHANGES

- ☐ New Equipment
- ☐ Equipment Adjustment
- ☐ Repairs / Replacement

Details: _____



OTHER CHANGES

- ☐ Care Plan Update
- ☐ Activity / Restrictions
- ☐ Other _____

Details: _____



FOLLOW-UP PLAN

Next Appointment Date _____

With _____

Recommended Tests / Referrals _____

Other Instructions / Recommendations _____



QUESTIONS

Questions Answered

☐ _____

☐ _____

☐ _____

☐ _____

Questions I Still Have

☐ _____

☐ _____

☐ _____

☐ _____



ADDITIONAL NOTES



INFORMATION SOURCE

This summary was completed by:

- ☐ Parent / Caregiver
- ☐ Patient
- ☐ Other _____

Date Completed _____



TIP: Complete this summary during or right after the visit while information is fresh.
Then place the clinic note, test results, and other documents behind this page.

LAST REVISION DATE

____ / ____ / ____





PULMONOLOGY



PROVIDER INFORMATION

Primary Pulmonologist _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

- ☒ Clinic notes
- ☒ Pulmonary Function Tests
- ☒ Sleep Studies
- ☒ Cough Assist Evaluations
- ☒ Overnight Oximetry
- ☒ Ventilation / BiPAP Reports
- ☒ Medication Changes
- ☒ Care Recommendations
- ☒ Other Pulmonology Records

☐ _____

☐ _____



Keep the newest records at the front of this section.



PULMONOLOGY

Specialty Profile

This page provides an enduring overview of your child's pulmonology care.
Update only when information changes significantly.



CARE TEAM

Primary Pulmonologist _____
Clinic / Hospital _____
Phone _____
Care Coordinator _____
Phone _____
Respiratory Therapist _____
Clinic Website _____



DIAGNOSIS INFORMATION

Primary Pulmonary Diagnosis _____
Respiratory Findings / Concerns _____
Date Diagnosed _____ Age at Diagnosis _____
Current Age _____
Ventilatory Support
☐ None ☐ Nighttime ☐ Daytime ☐ 24 Hour
Cough Assist Used ☐ Yes ☐ No
Supplemental Oxygen ☐ Yes ☐ No If yes, L/min _____
Airway Clearance Needs _____
Other Respiratory Support / Equipment _____



LONG-TERM CARE SERVICES

Services currently part of ongoing care:

- | | |
|---|--|
| ☐ Pulmonary Surveillance | ☐ Physical Therapy |
| ☐ Sleep Medicine | ☐ Nutrition / Dietetics |
| ☐ Respiratory Therapy | ☐ Mental Health Support |
| ☐ Airway Clearance Program | ☐ Palliative Care |
| ☐ Occupational Therapy | ☐ Other _____ |



DURABLE MEDICAL EQUIPMENT

Equipment currently used:

- | | |
|---|--|
| ☐ Cough Assist | ☐ Oxygen Concentrator / Tanks |
| ☐ BiPAP / Ventilator | ☐ Chest Vest |
| ☐ Suction Machine | ☐ Peak Flow Meter |
| ☐ Pulse Oximeter | ☐ Other _____ |
| ☐ Nebulizer | ☐ Other _____ |



BASELINE FUNCTIONAL STATUS

Current baseline (check all that apply):

- | | |
|---|--|
| ☐ Walks independently | ☐ Independent in daily activities |
| ☐ Requires assistance to walk | ☐ Requires assistance for ADLs |
| ☐ Uses wheelchair | ☐ Speech is understandable |
| ☐ Transfers independently | ☐ Uses communication support |
| ☐ Requires assistance with transfers | ☐ Feeds independently |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives providers a quick understanding of your child's pulmonology care at a glance, no matter when or where care is provided.



TIP:

Review this page at least once a year or when major changes occur.





PULMONOLOGY

Visit Summary

 Keep your most recent visit summaries at the front of this section.

Use this page to capture key information from each visit.
Place this summary at the front of the visit records in this section.

 Visit Date _____	Reason for Visit _____
 Provider _____	_____
 Clinic / Location _____	_____

 **TESTS & EVALUATIONS PERFORMED**
(Check all that apply)

☐ Physical Exam	☐ Imaging (X-ray / CT)
☐ Pulmonary Function Test (PFT)	☐ Ventilation / BiPAP Review
☐ Sleep Study	☐ Swallow Study
☐ Cough Assist Evaluation	☐ 6MWT (6-Minute Walk Test)
☐ Overnight Oximetry	☐ Other _____
☐ Labs	☐ Other _____

See Test Tracker for details and results.

 **KEY FINDINGS**
Summary of important findings from this visit.

 **CHANGES OR UPDATES**

 MEDICATION CHANGES ☐ New Medication ☐ Dose Change ☐ Discontinued Details: _____	 THERAPY / TREATMENT CHANGES ☐ New Therapy ☐ Change in Frequency ☐ Discontinued Details: _____	 EQUIPMENT / SUPPLY CHANGES ☐ New Equipment ☐ Equipment Adjustment ☐ Repairs / Replacement Details: _____	 OTHER CHANGES ☐ Care Plan Update ☐ Activity / Restrictions ☐ Other _____ Details: _____
--	---	--	---

 **FOLLOW-UP PLAN**

Next Appointment Date _____
With _____
Recommended Tests / Referrals _____
Other Instructions / Recommendations _____

 **QUESTIONS**

Questions Answered	Questions I Still Have
☐ _____	☐ _____
☐ _____	☐ _____
☐ _____	☐ _____
☐ _____	☐ _____

 **ADDITIONAL NOTES**

 **INFORMATION SOURCE**

This summary was completed by:

☐ Parent / Caregiver	Date Completed _____
☐ Patient	
☐ Other _____	



PRIMARY CARE

PRIMARY CARE



This section includes your child's primary care records and general health information.

Keeping records together by provider makes it easier to prepare for appointments, share information with new care teams, and quickly locate important documents when they're needed most.

Within each specialty, file the newest records at the front so the most current information is always easy to find.



Your child. Your records. Your voice. Always with you.



PRIMARY CARE

Specialty Profile

This page provides an enduring overview of your child's primary care.
Update only when information changes significantly.



CARE TEAM

Primary Care Provider _____

Clinic / Practice _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____



HEALTH INFORMATION

Primary Diagnosis _____

Other Diagnoses _____

Date of Birth _____

Primary Pharmacy _____

Immunizations Current ☐ Yes ☐ No

Preferred Hospital _____



ONGOING CARE & SERVICES

Services currently part of ongoing care:

- | | |
|--|--|
| ☐ Routine Wellness Visits | ☐ Nutrition / Dietetics |
| ☐ Vaccinations | ☐ Mental Health Support |
| ☐ Care Coordination | ☐ Social Work / Case Management |
| ☐ School / Work Forms | ☐ Other |



MEDICAL EQUIPMENT / SUPPORTS

Equipment currently used:

- | | |
|---|---|
| ☐ Power Wheelchair | ☐ Lift / Hoyer Lift |
| ☐ Manual Wheelchair | ☐ Shower Chair / Commode |
| ☐ Cough Assist | ☐ Communication Device |
| ☐ BiPAP / Ventilator | ☐ Other |



BASELINE HEALTH STATUS

Current baseline (check all that apply):

- | | |
|---|---|
| ☐ Stable overall health | ☐ Has respiratory support |
| ☐ Needs help with daily activities | ☐ Has cardiac monitoring |
| ☐ Uses wheelchair | ☐ Has swallowing concerns |
| ☐ Receives home supports | ☐ Has chronic pain / fatigue |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



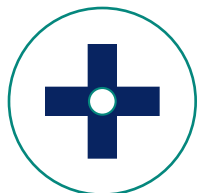
WHY THIS MATTERS

This profile gives any provider a quick understanding of your child's primary care needs at a glance, no matter when or where care is provided.



TIP:

Review this page at least once a year or when major changes occur.



PRIMARY CARE

Visit Summary

Keep a summary of each visit to track care, recommendations, and next steps.
File visit summaries in chronological order with the newest at the front.



VISIT INFORMATION

Visit Date _____

Provider _____

Clinic / Location _____

Visit Type

☐ Routine Follow-Up ☐ New Patient ☐ Annual Wellness

☐ Other _____

Next Visit Date _____



VISIT SUMMARY

Reason for Visit

Summary of Visit / Findings

Recommendations / Plan

Orders / Referrals / Tests

Medications / Treatment Changes



Keep the newest records at the front.



Your child. Your records. Your voice. Always with you.

LAST REVISION DATE

___ / ___ / ___



PHYSICAL THERAPY



PROVIDER INFORMATION

Primary Physical Therapist _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

- ☒ Physical therapy evaluations
- ☒ Range-of-motion assessments
- ☒ Strength / functional assessments
- ☒ Mobility / gait assessments
- ☒ Stretching / exercise plans
- ☒ Transfer training notes
- ☒ Equipment evaluations
- ☒ Home / school recommendations
- ☒ Progress notes
- ☒ Care recommendations
- ☒ Other Physical Therapy Records

☐ _____

☐ _____



Keep the newest records at the front of this section.



PHYSICAL THERAPY

Specialty Profile

This page provides an enduring overview of your child's physical therapy care.
Update only when information changes significantly.



CARE TEAM

Primary Physical Therapist _____

Clinic / Hospital _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____



LONG-TERM CARE SERVICES

Services currently part of ongoing care:

- | | |
|---|--|
| ☐ Physical Therapy | ☐ Neuromuscular Clinic |
| ☐ Occupational Therapy | ☐ School-Based Services |
| ☐ Speech Therapy | ☐ Home Health / Nursing |
| ☐ Orthopedics | ☐ Palliative Care |
| ☐ PM&R | ☐ Other |



BASELINE FUNCTIONAL STATUS

Current baseline (check all that apply):

- | | |
|---|--|
| ☐ Walks independently | ☐ Independent in daily activities |
| ☐ Requires assistance to walk | ☐ Requires assistance for ADLs |
| ☐ Uses wheelchair | ☐ Uses communication support |
| ☐ Transfers independently | ☐ Pain limits function |
| ☐ Requires help with transfers | ☐ Feeds independently |



LONG-TERM CARE GOALS

Our long-term goals for care:



THERAPY INFORMATION

Primary PT Concerns _____

Referring Diagnosis _____

Date Therapy Began _____

Current Therapy Frequency _____

School / Work Setting _____

Home Exercise Program
☐ Yes ☐ No Last updated _____

Primary Functional Goals _____



DURABLE MEDICAL EQUIPMENT

Equipment currently used:

- | | |
|--|---|
| ☐ Manual Wheelchair | ☐ Shower Chair / Commode |
| ☐ Power Wheelchair | ☐ Orthotics / Bracing |
| ☐ Standing Device | ☐ Positioning Supports |
| ☐ Walker / Gait Trainer | ☐ Other |
| ☐ Lift / Transfer Aid | ☐ Other |



ALLERGIES / PRECAUTIONS



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives any provider a quick understanding of your child's physical therapy needs, equipment, functional goals, and precautions.



TIP:

Review this page at least once a year or when major changes occur.





PHYSICAL THERAPY

Visit Summary

Use this page to capture key information from each physical therapy visit.
Place this summary at the front of the visit records in this section.



Keep your most recent
visit summaries at the
front of this section.

 **Visit Date** _____

 **Provider** _____

 **Clinic / Location** _____

Reason for Visit _____

TESTS & EVALUATIONS PERFORMED

(Check all that apply)

- | | |
|---|--|
| ☐ Functional assessment | ☐ Balance assessment |
| ☐ Range of motion | ☐ Equipment evaluation |
| ☐ Strength assessment | ☐ Orthotics / bracing check |
| ☐ Mobility / gait assessment | ☐ Home / school access |
| ☐ Transfer assessment | ☐ Other |

See therapy records for details and results.



KEY FINDINGS

Summary of important findings from this visit.



CHANGES OR UPDATES

THERAPY / TREATMENT CHANGES

- ☐ New therapy goal
- ☐ Change in frequency
- ☐ Home program updated

Details: _____

EQUIPMENT / SUPPLY CHANGES

- ☐ New equipment
- ☐ Adjustment / repair
- ☐ New orthotic / brace

Details: _____

MOBILITY / ACCESS CHANGES

- ☐ Mobility status change
- ☐ Transfer support
- ☐ Accessibility update

Details: _____

OTHER CHANGES

- ☐ Care plan update
- ☐ Activity / restrictions
- ☐ Other

Details: _____



FOLLOW-UP PLAN

Next Appointment Date _____

With _____

Recommended Tests / Referrals _____

Other Instructions / Recommendations _____



QUESTIONS

Questions Answered

☐ _____

☐ _____

☐ _____

☐ _____

Questions I Still Have

☐ _____

☐ _____

☐ _____

☐ _____



ADDITIONAL NOTES



INFORMATION SOURCE

This summary was completed by:

- ☐ Parent / Caregiver
- ☐ Patient
- ☐ Other

Date Completed _____

TIP:

Complete this summary during or right after the visit while information is fresh.
Then place therapy notes, evaluations, and other documents behind this page.

LAST REVISION DATE

____ / ____ / ____





OCCUPATIONAL THERAPY



PROVIDER INFORMATION

Primary Occupational Therapist _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

- ☒ OT evaluations
- ☒ Functional assessments
- ☒ Fine-motor testing
- ☒ Range-of-motion records
- ☒ Splinting / orthotics notes
- ☒ ADL assessments
- ☒ Equipment evaluations
- ☒ Home / school accessibility
- ☒ Therapy plans and goals
- ☒ Progress notes
- ☒ Care recommendations
- ☒ Other Occupational Therapy Records
- ☐ _____
- ☐ _____



Keep the newest records at the front of this section.



OCCUPATIONAL THERAPY

Specialty Profile

This page provides an enduring overview of your child's occupational therapy care.
Update only when information changes significantly.



CARE TEAM

Primary Occupational Therapist _____

Clinic / Hospital _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____



2

DIAGNOSIS INFORMATION

Primary OT Concerns _____

Referring Diagnosis _____

Date Therapy Began _____

Current Therapy Frequency _____

School / Work Setting _____

Current Splints / Orthotics
☐ Yes ☐ No If yes, which _____

Primary Functional Goals _____



LONG-TERM CARE SERVICES

Services currently part of ongoing care: _____

Services currently part of ongoing care:

- | | |
|--|--|
| ☐ Occupational Therapy | ☐ Social Work / Case Management |
| ☐ Physical Therapy | ☐ Mental Health Support |
| ☐ Speech Therapy | ☐ Palliative Care |
| ☐ School-Based Services | ☐ Other |
| ☐ Assistive Technology | ☐ Other |



DURABLE MEDICAL EQUIPMENT

Equipment currently used: _____

Equipment currently used:

- | | |
|---|---|
| ☐ Manual Wheelchair | ☐ Adaptive Utensils |
| ☐ Power Wheelchair | ☐ Positioning Supports |
| ☐ Transfer Equipment | ☐ Communication Device |
| ☐ Shower Chair / Commode | ☐ Other |
| ☐ Splints / Orthotics | ☐ Other |



BASELINE FUNCTIONAL STATUS

Current baseline (check all that apply):

- | | |
|--|--|
| ☐ Walks independently | ☐ Independent in daily activities |
| Current baseline (check all that apply): | |
| ☐ Feeds independently | ☐ Needs help toileting |
| ☐ Needs help dressing | ☐ Needs transfer assistance |
| ☐ Needs help grooming | ☐ Uses upper-extremity support |
| ☐ Needs help bathing | ☐ Uses adaptive equipment |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives any provider a quick understanding of your child's occupational therapy needs, goals, supports, and equipment.



TIP:

Review this page at least once a year or when major changes occur.



OCCUPATIONAL THERAPY

Visit Summary

Use this page to capture key information from each occupational therapy visit.
Place this summary at the front of the visit records in this section.



Keep your most recent
visit summaries at the
front of this section.



Visit Date _____



Provider _____



Clinic / Location _____

Reason for Visit _____



TESTS & EVALUATIONS PERFORMED

TESTS & EVALUATIONS PERFORMED

(Check all that apply)

- | | |
|---|--|
| ☐ Functional assessment | ☐ Seating / positioning |
| ☐ Range of motion | ☐ Splint / orthotic check |
| ☐ Upper-extremity strength | ☐ Equipment assessment |
| ☐ ADL evaluation | ☐ Home / school access |
| ☐ Fine-motor assessment | ☐ Other |

See therapy records for details and results.



KEY FINDINGS

Summary of important findings from this visit.



CHANGES OR UPDATES



MEDICATION CHANGES

THERAPY / TREATMENT CHANGES

- ☐ New therapy goal
☐ Change in frequency
☐ Home program updated

Details: _____



THERAPY / TREATMENT CHANGES

EQUIPMENT / SUPPLY CHANGES

- ☐ New equipment
☐ Adjustment / repair
☐ New splint / orthotic

Details: _____



EQUIPMENT / SUPPLY CHANGES

HOME / SCHOOL MODIFICATIONS

- ☐ Accessibility change
☐ Positioning support
☐ Adaptive strategy

Details: _____



OTHER CHANGES

OTHER CHANGES

- ☐ Care plan update
☐ Activity / restrictions
☐ Other

Details: _____



FOLLOW-UP PLAN

Next Appointment Date _____

With _____

Recommended Tests / Referrals _____

Other Instructions / Recommendations _____



QUESTIONS

Questions Answered

☐ _____
☐ _____
☐ _____
☐ _____

Questions I Still Have

☐ _____
☐ _____
☐ _____
☐ _____



ADDITIONAL NOTES



INFORMATION SOURCE

This summary was completed by:

- ☐ Parent / Caregiver
☐ Patient
☐ Other _____

Date Completed _____



TIP: Complete this summary during or right after the visit while information is fresh.
Then place therapy notes, evaluations, and other documents behind this page.

LAST REVISION DATE

____ / ____ / ____





GASTROENTEROLOGY



PROVIDER INFORMATION

Primary Gastroenterologist _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:



Clinic notes



Endoscopy / colonoscopy reports



Liver function / GI lab results



Swallow study or feeding evaluations



Nutrition / dietitian notes



Imaging reports



Medication Changes



Care Recommendations



Hospital discharge summaries



Other Gastroenterology Records







Keep the newest records at the front of this section.



GASTROENTEROLOGY

Specialty Profile

This page provides an enduring overview of your child's gastroenterology care.
Update only when information changes significantly.

CARE TEAM

Primary Gastroenterologist _____

Clinic / Hospital _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____

DIAGNOSIS INFORMATION

Primary Diagnosis _____

Secondary Diagnosis _____

Date Diagnosed _____

Current Concerns _____

Feeding Tube ☐ Yes ☐ No If yes, type _____

Current GI Medications _____

LONG-TERM CARE SERVICES

- | | |
|--|---|
| ☐ GI / Motility Follow-Up | ☐ Nutrition / Dietetics |
| ☐ Feeding Therapy | ☐ Speech / Swallow Therapy |
| ☐ Mental Health Support | ☐ Palliative Care |
| ☐ Other | ☐ Other |

MEDICAL EQUIPMENT / SUPPORTS

- | | |
|--|--|
| ☐ Feeding Pump | ☐ Feeding Tube Supplies |
| ☐ Suction | ☐ Specialized Formula |
| ☐ Adaptive Seating During Meals | ☐ Other |

BASELINE FUNCTIONAL STATUS

- | | |
|---|---|
| ☐ Eats by mouth independently | ☐ Needs help with meals |
| ☐ Uses modified diet / thickened liquids | ☐ Has swallowing concerns |
| ☐ Uses feeding tube for some nutrition | ☐ Uses feeding tube for full nutrition |
| ☐ Has chronic constipation | ☐ Has reflux / GERD |

ALLERGIES / PRECAUTIONS

LONG-TERM CARE GOALS

WHY THIS MATTERS

This profile gives every provider a quick understanding of your child's gastroenterology care at a glance, no matter when or where care is provided.

TIP: Review yearly or whenever major changes occur.

LAST REVISION DATE



GASTROENTEROLOGY

Visit Summary

Use this page to capture key information from each visit.
Place this summary at the front of the visit records in this section.



Keep your most recent visit summaries at the front of this section.



Visit Date _____

Reason for Visit _____



Provider _____



Clinic / Location _____



TESTS & EVALUATIONS PERFORMED

(Check all that apply)

- | | |
|---|---|
| ☐ Physical Exam | ☐ Swallow / Feeding Assessment |
| ☐ Labs | ☐ Nutrition Assessment |
| ☐ Imaging (X-ray / Ultrasound) | ☐ Stool Testing |
| ☐ Endoscopy | ☐ Other _____ |
| ☐ Colonoscopy | ☐ Other _____ |

See Test Tracker for details and results.



KEY FINDINGS

Summary of important findings from this visit.



CHANGES OR UPDATES



MEDICATION CHANGES

- ☐ New Medication
- ☐ Dose Change
- ☐ Discontinued

Details: _____



DIET / NUTRITION CHANGES

- ☐ New Diet Plan
- ☐ Formula Change
- ☐ Feeding Schedule Change
- ☐ Discontinued

Details: _____



EQUIPMENT / SUPPLY CHANGES

- ☐ New Equipment
- ☐ Supply Adjustment
- ☐ Repairs / Replacement

Details: _____



OTHER CHANGES

- ☐ Care Plan Update
- ☐ Activity / Restrictions
- ☐ Other _____

Details: _____



FOLLOW-UP PLAN

Next Appointment Date _____

With _____

Recommended Tests / Referrals _____

Other Instructions / Recommendations _____



QUESTIONS

Questions Answered

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Questions I Still Have

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____



ADDITIONAL NOTES



INFORMATION SOURCE

This summary was completed by:

- ☐ Parent / Caregiver
- ☐ Patient
- ☐ Other _____

Date Completed _____

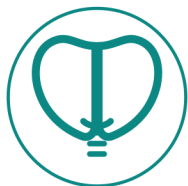


TIP: Complete this summary during or right after the visit while information is fresh.
Then place the clinic note, test results, and other documents behind this page.

LAST REVISION DATE

____ / ____ / ____





ENDOCRINOLOGY

ENDOCRINOLOGY CLINIC



This section includes your child's endocrine care records, including growth, puberty, bone health, steroid-related monitoring, adrenal health, thyroid function, and blood sugar screening.

Keeping these records together makes it easier to prepare for appointments, share current information with new care teams, and quickly locate important results and treatment plans when they are needed most.

Within this specialty, file the newest records at the front so the most current information is always easy to find.



Your child. Your records. Your voice. Always with you.



ENDOCRINOLOGY CLINIC

Specialty Profile

This page provides an enduring overview of your child's endocrine care.
Update only when information changes significantly.

CARE TEAM

Primary Endocrinologist _____

Clinic / Hospital _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____

ENDOCRINE INFORMATION

Primary Endocrine Diagnosis _____

Date Diagnosed _____

Current Steroid Regimen _____

Growth / Puberty Concerns _____

☐ Bone Health Monitoring

☐ Vitamin D / Calcium

☐ Diabetes Screening

☐ Adrenal Plan on File

Last DEXA / Bone Density _____

ONGOING CARE SERVICES

☐ Endocrinology Follow-Up

☐ Social Work / Case Management

☐ Nutrition / Dietetics

☐ Mental Health Support

☐ Bone Health Clinic

☐ Palliative Care

☐ Physical Therapy

☐ Other

MONITORING / SUPPORTS

☐ Growth Tracking

☐ Adrenal Insufficiency Plan

☐ Blood Glucose Monitoring

☐ Emergency Steroid Card

☐ Vitamin D / Calcium

☐ Puberty / Hormone Support

☐ DEXA / Bone Density

☐ Other

BASELINE HEALTH STATUS

☐ Growth within expected range

☐ Low bone density

☐ Weight concerns

☐ Blood sugar concerns

☐ Delayed puberty

☐ Adrenal insufficiency risk

☐ Fracture history

☐ Thyroid concerns

! ALLERGIES / PRECAUTIONS

LONG-TERM CARE GOALS

? IMPORTANT PERMANENT NOTES



WHY THIS MATTERS

This profile gives any provider a quick understanding of your child's endocrine care at a glance, no matter when or where care is provided.

TIP:

Review this page at least once a year or when major changes occur.



ENDOCRINOLOGY CLINIC

Visit Summary

Keep a summary of each visit to track endocrine care, recommendations, and next steps.
File visit summaries in chronological order with the newest at the front.

VISIT INFORMATION

Visit Date _____

Provider _____

Clinic / Location _____

Care Team Present _____

Visit Type

☐ Routine Follow-Up

☐ New Patient

☐ Procedure

☐ Bone Health

☐ Growth / Puberty

☐ Other

Next Visit Date _____

VISIT SUMMARY

Reason for Visit

Summary of Visit / Findings

Recommendations / Plan

Orders / Referrals / Tests

Medications / Treatment Changes

Notes



Keep the newest records at the front.



Your child. Your records. Your voice. Always with you.

LAST REVISION DATE

___ / ___ / ___



ORTHOPEDICS



PROVIDER INFORMATION

Primary Orthopedic Provider _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

- ☒ Orthopedic evaluations
- ☒ X-ray / imaging reports
- ☒ Mobility / gait assessments
- ☒ Casting / splinting records
- ☒ Bracing / orthotics notes
- ☒ Surgical consultations
- ☒ Operative reports
- ☒ Post-op follow-up notes
- ☒ Equipment recommendations
- ☒ Care recommendations
- ☒ Other Orthopedic Records
- ☐ _____
- ☐ _____



Keep the newest records at the front of this section.



ORTHOPEDICS

Specialty Profile

This page provides an enduring overview of your child's orthopedic care.
Update only when information changes significantly.



CARE TEAM

Primary Orthopedic Provider _____

Clinic / Hospital _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____



ORTHOPEDIC INFORMATION

Primary Diagnosis / Concern _____

Affected Area(s) _____

Date Orthopedic Care Began _____

Last Imaging Date _____

Current Weight-Bearing Status _____

Current Braces / Orthotics
☐ Yes ☐ No If yes, which _____

Recent Surgery / Procedure _____

Services currently part of ongoing care:

- | | |
|---|--|
| ☐ Orthopedics | ☐ Cardiac Surveillance |
| ☐ Physical Therapy | ☐ Palliative Care |
| ☐ Occupational Therapy | ☐ Mental Health Support |
| ☐ Neuromuscular Clinic | ☐ Other |
| ☐ Pulmonary Surveillance | ☐ Other |

Equipment currently used:

- | | |
|--|---|
| ☐ Manual Wheelchair | ☐ Braces / Orthotics |
| ☐ Power Wheelchair | ☐ Shower Chair / Commode |
| ☐ Standing Device | ☐ Communication Device |
| ☐ Walker / Gait Trainer | ☐ Other |
| ☐ Lift / Transfer Aid | ☐ Other |

Current baseline (check all that apply):

- | | |
|--|---|
| ☐ Walks independently | ☐ Transfers independently |
| ☐ Uses braces regularly | ☐ Requires help with ADLs |
| ☐ Requires assistance for walking | ☐ Pain affects function |
| ☐ Uses wheelchair | ☐ Recent falls / instability |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives any provider a quick understanding of your child's orthopedic needs, equipment, goals, and precautions.



TIP:

Review this page at least once a year or when major changes occur.



ORTHOPEDICS

Visit Summary

Keep a summary of each visit to track care, recommendations, and next steps.
File visit summaries in chronological order with the newest at the front.



VISIT INFORMATION

Visit Date _____

Provider _____

Clinic / Location _____

Care Team Present _____

Visit Type

☐ Routine Follow-Up ☐ New Patient ☐ Procedure

☐ Other _____

Next Visit Date _____



VISIT SUMMARY

Reason for Visit _____

Summary of Visit / Findings _____

Recommendations / Plan _____

Orders / Referrals / Tests _____

Bracing / Equipment / Treatment Changes _____

Notes _____



TIP: Keep the newest orthopedic records at the front.



Your child. Your records. Your voice. Always with you.

LAST REVISION DATE

____ / ____ / ____



NUTRITION & DIETETICS



PROVIDER INFORMATION

Primary Dietitian / Nutritionist _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

- ☒ Nutrition assessments
- ☒ Growth charts
- ☒ Diet plans
- ☒ Feeding evaluations
- ☒ Laboratory results
- ☒ Formula / supplement orders
- ☒ Swallow study reports
- ☒ Tube-feeding records
- ☒ Medication changes
- ☒ Care recommendations
- ☒ Other Nutrition & Dietetics Records
- ☐ _____
- ☐ _____



Keep the newest records at the front of this section.



NUTRITION & DIETETICS

Specialty Profile

This page provides an enduring overview of your child's nutrition and feeding care.
Update only when information changes significantly.



CARE TEAM

Primary Dietitian / Nutritionist _____

Clinic / Hospital _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____



NUTRITION INFORMATION

Primary Nutrition Concerns _____

Current Diet / Formula _____

Date Nutrition Care Began _____

Current Weight _____

Current Height _____

Feeding Tube
☐ Yes ☐ No If yes, type _____

Food Allergies / Intolerances _____



LONG-TERM CARE SERVICES

Services currently part of ongoing care:

- | | |
|---|--|
| ☐ Nutrition / Dietetics | ☐ Social Work / Case Management |
| ☐ Feeding Therapy | ☐ Mental Health Support |
| ☐ Speech / Swallow Therapy | ☐ Home Health / Nursing |
| ☐ Gastroenterology | ☐ Palliative Care |
| ☐ Endocrinology | ☐ Other |



NUTRITION SUPPORTS & EQUIPMENT

Nutrition supports currently used:

- | | |
|--|---|
| ☐ Feeding Pump | ☐ Positioning Supports |
| ☐ Feeding Tube Supplies | ☐ Thickened Liquids |
| ☐ Specialized Formula | ☐ Suction Equipment |
| ☐ Oral Supplements | ☐ Other |
| ☐ Adaptive Utensils | ☐ Other |



BASELINE NUTRITION STATUS

Current baseline (check all that apply):

- | | |
|--|---|
| ☐ Eats by mouth independently | ☐ Uses feeding tube partly |
| ☐ Needs help with meals | ☐ Uses feeding tube fully |
| ☐ Uses modified diet | ☐ Swallowing concerns |
| ☐ Uses oral supplements | ☐ Constipation / reflux concerns |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives any provider a quick understanding of your child's nutrition needs, feeding supports, goals, and precautions.



TIP:

Review this page at least once a year or when major changes occur.



NUTRITION & DIETETICS

Visit Summary

Keep a summary of each visit to track nutrition status, recommendations, and next steps.
File visit summaries in chronological order with the newest at the front.



VISIT INFORMATION

Visit Date _____

Provider _____

Clinic / Location _____

Care Team Present _____

Visit Type

☐ Routine Follow-Up ☐ New Patient ☐ Feeding Assessment

☐ Other _____

Next Visit Date _____



VISIT SUMMARY

Reason for Visit

Nutrition Status / Findings

Recommendations / Plan

Labs / Tests / Referrals

Diet / Formula / Feeding Changes

Notes



TIP: Keep the newest nutrition records at the front.



Your child. Your records. Your voice. Always with you.

LAST REVISION DATE

____ / ____ / ____



PHYSICAL MEDICINE & REHABILITATION



PROVIDER INFORMATION

Primary PM&R Provider _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

- ☒ PM&R evaluations
- ☒ Functional assessments
- ☒ Mobility / gait assessments
- ☒ Spasticity management notes
- ☒ Bracing / orthotics recommendations
- ☒ Equipment evaluations
- ☒ Rehabilitation therapy plans
- ☒ Pain management notes
- ☒ Procedure notes
- ☒ Care recommendations
- ☒ Other PM&R Records

☐ _____

☐ _____



Keep the newest records at the front of this section.



PHYSICAL MEDICINE & REHABILITATION

Specialty Profile

This page provides an enduring overview of your child's PM&R care.
Update only when information changes significantly.



CARE TEAM

Primary PM&R Provider _____

Clinic / Hospital _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____



REHABILITATION INFORMATION

Primary Diagnosis / Concern _____

Primary Functional Goals _____

Date PM&R Care Began _____

Last PM&R Visit _____

Current Mobility Status _____

Spasticity Management
☐ Yes ☐ No If yes, type _____

Current Braces / Orthotics _____

Services currently part of ongoing care:

- | | |
|---|---|
| ☐ PM&R | ☐ Neuromuscular Clinic |
| ☐ Physical Therapy | ☐ Pulmonary Surveillance |
| ☐ Occupational Therapy | ☐ Palliative Care |
| ☐ Speech Therapy | ☐ Mental Health Support |
| ☐ Orthopedics | ☐ Other |

Equipment currently used:

- | | |
|--|---|
| ☐ Manual Wheelchair | ☐ Shower Chair / Commode |
| ☐ Power Wheelchair | ☐ Orthotics / Bracing |
| ☐ Standing Device | ☐ Communication Device |
| ☐ Walker / Gait Trainer | ☐ Other |
| ☐ Lift / Transfer Aid | ☐ Other |

Current baseline (check all that apply):

- | | |
|---|---|
| ☐ Walks independently | ☐ Independent in daily activities |
| ☐ Requires assistance to walk | ☐ Requires assistance for ADLs |
| ☐ Uses wheelchair | ☐ Uses communication support |
| ☐ Transfers independently | ☐ Pain or spasticity limits function |
| ☐ Requires help with transfers | ☐ Feeds independently |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives any provider a quick understanding of your child's PM&R needs, equipment, functional goals, and precautions.



TIP:

Review this page at least once a year or when major changes occur.





PHYSICAL MEDICINE & REHABILITATION

our most recent
nmaries at the
this section.

Visit Summary

Use this page to capture key information from each visit.
Place this summary at the front of the visit records in this section.

Visit Date _____

Provider _____

Reason for Visit _____

TESTS & EVALUATIONS PERFORMED

(Check all that apply)

- | | |
|---|--|
| ☐ Functional assessment | ☐ Spasticity assessment |
| ☐ Range of motion | ☐ Equipment evaluation |
| ☐ Mobility / gait assessment | ☐ Bracing / orthotics eval |
| ☐ Strength assessment | ☐ Imaging (X-ray / MRI / Other) |
| ☐ Pain assessment | ☐ Other |

See visit records for details and results.



KEY FINDINGS

Summary of important findings from this visit.

CHANGES OR UPDATES

MEDICATION CHANGES

- ☐ New Medication
☐ Dose Change
☐ Discontinued

Details: _____

THERAPY / TREATMENT CHANGES

- ☐ New Therapy
☐ Change in Frequency
☐ Discontinued

Details: _____

EQUIPMENT / SUPPLY CHANGES

- ☐ New Equipment
☐ Equipment Adjustment
☐ Repairs / Replacement

Details: _____

OTHER CHANGES

- ☐ Care Plan Update
☐ Activity / Restrictions
☐ Other

Details: _____

Next Appointment Date _____

With _____

Recommended Tests / Referrals _____

Other Instructions / Recommendations _____

Questions Answered

- ☐ _____
☐ _____
☐ _____
☐ _____

Questions I Still Have

- ☐ _____
☐ _____
☐ _____
☐ _____



ADDITIONAL NOTES



INFORMATION SOURCE

This summary was completed by:

- ☐ Parent / Caregiver
☐ Patient
☐ Other _____

Date Completed _____



TIP: Complete this summary during or right after the visit while information is fresh.
Then place the clinic note, test results, and other documents behind this page.

LAST REVISION DATE

____ / ____ / ____





PAIN MANAGEMENT



PROVIDER INFORMATION

Primary Pain Management Provider _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

- ☒ Pain management evaluations
- ☒ Pain assessments / scales
- ☒ Medication records
- ☒ Procedure notes
- ☒ Imaging reports
- ☒ Therapy recommendations
- ☒ Complementary treatment notes
- ☒ Hospital discharge summaries
- ☒ Progress notes
- ☒ Care recommendations
- ☒ Other Pain Management Records

☐ _____

☐ _____



Keep the newest records at the front of this section.



PAIN MANAGEMENT

Specialty Profile

This page provides an enduring overview of your child's pain management care.
Update only when information changes significantly.



CARE TEAM

Primary Pain Management Provider _____

Clinic / Hospital _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____



PAIN INFORMATION

Primary Pain Diagnosis / Concern _____

Pain Location(s) _____

Date Pain Care Began _____

Typical Pain Level (0-10) _____

Pain Triggers _____

Breakthrough Pain Plan
☐ Yes ☐ No Last updated _____

Current Pain Medications _____

Services currently part of ongoing care:

- | | |
|---|--|
| ☐ Pain Management | ☐ Neuromuscular Clinic |
| ☐ Physical Therapy | ☐ Orthopedics |
| ☐ Occupational Therapy | ☐ Integrative Therapies |
| ☐ Behavioral Health | ☐ Social Work / Case Management |
| ☐ Palliative Care | ☐ Other |

Pain supports currently used:

- | | |
|--|---|
| ☐ Positioning Supports | ☐ Massage / Stretching |
| ☐ Pressure Relief Cushion | ☐ Sleep Positioning |
| ☐ Heat / Cold Therapy | ☐ Mobility Equipment |
| ☐ TENS Unit | ☐ Other |
| ☐ Braces / Orthotics | ☐ Other |

Current baseline (check all that apply):

- | | |
|--|--|
| ☐ Pain absent at rest | ☐ Pain limits mobility |
| ☐ Pain with activity | ☐ Needs help with transfers |
| ☐ Pain affects sleep | ☐ Uses positioning support |
| ☐ Pain affects mood | ☐ Uses rescue medication |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives any provider a quick understanding of your child's pain patterns, treatments, goals, and safety considerations.



TIP:

Review this page at least once a year or when major changes occur.



PAIN MANAGEMENT

Visit Summary

Use this page to capture key information from each pain management visit.
Place this summary at the front of the visit records in this section.



Keep your most recent
visit summaries at the
front of this section.



Visit Date _____



Provider _____



Clinic / Location _____

Reason for Visit _____



TESTS & EVALUATIONS PERFORMED

ASSESSMENTS & EVALUATIONS

(Check all that apply)

- | | |
|---|---|
| ☐ Pain scale assessment | ☐ Medication review |
| ☐ Physical exam | ☐ Imaging review |
| ☐ Functional assessment | ☐ Procedure evaluation |
| ☐ Sleep assessment | ☐ Caregiver interview |
| ☐ Mood / coping assessment | ☐ Other |

See pain management records for details and results.



KEY FINDINGS

Summary of important findings from this visit.



CHANGES OR UPDATES



MEDICATION CHANGES

MEDICATION CHANGES

- ☐ New Medication
- ☐ Dose Change
- ☐ Discontinued

Details: _____



THERAPY / TREATMENT CHANGES

PROCEDURE / TREATMENT CHANGES

- ☐ New Procedure
- ☐ Therapy Change
- ☐ Home Plan Updated

Details: _____



EQUIPMENT / SUPPLY CHANGES

EQUIPMENT / SUPPORT CHANGES

- ☐ New Equipment
- ☐ Positioning Change
- ☐ Supply Adjustment

Details: _____



OTHER CHANGES

OTHER CHANGES

- ☐ Care Plan Update
- ☐ Activity / Restrictions
- ☐ Other

Details: _____



FOLLOW-UP PLAN

Next Appointment Date _____

With _____

Recommended Tests / Referrals _____

Other Instructions / Recommendations _____



QUESTIONS

Questions Answered

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Questions I Still Have

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____



ADDITIONAL NOTES



INFORMATION SOURCE

This summary was completed by:

- ☐ Parent / Caregiver
- ☐ Patient
- ☐ Other _____

Date Completed _____



TIP: Complete this summary during or right after the visit while information is fresh.
Then place clinic notes, test results, and other documents behind this page.

LAST REVISION DATE

____ / ____ / ____





BEHAVIORAL HEALTH



PROVIDER INFORMATION

Primary Behavioral Health Provider _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

- ☒ Therapy / counseling notes
- ☒ Psychiatric evaluations
- ☒ Psychological testing
- ☒ Treatment plans
- ☒ Medication records
- ☒ Crisis / safety plans
- ☒ School / behavior plans
- ☒ Hospital discharge summaries
- ☒ Progress notes
- ☒ Care recommendations
- ☒ Other Behavioral Health Records

☐ _____

☐ _____



Keep the newest records at the front of this section.



BEHAVIORAL HEALTH

Specialty Profile

This page provides an enduring overview of your child's behavioral health care.
Update only when information changes significantly.



CARE TEAM

Primary Behavioral Health Provider _____

Clinic / Hospital _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____



2

DIAGNOSIS INFORMATION

Primary Diagnosis / Concern _____

Co-occurring Diagnoses _____

Date Care Began _____

Current Therapy Frequency _____

School / Work Setting _____

Crisis / Safety Plan
☐ Yes ☐ No Last updated _____

Current Medications _____

Services currently part of ongoing care:

- | | |
|---|--|
| ☐ Individual Counseling | ☐ Social Work / Case Management |
| ☐ Family Therapy | ☐ Peer Support |
| ☐ Psychiatry | ☐ Crisis Services |
| ☐ Psychology / Neuropsychology | ☐ Palliative Care |
| ☐ School Counseling | ☐ Other |

Supports currently used:

- | | |
|---|--|
| ☐ School / Work Plan | ☐ Crisis Contacts |
| ☐ Behavior Support Plan | ☐ Safety Plan |
| ☐ Sensory Supports | ☐ Caregiver Support |
| ☐ Communication Supports | ☐ Other |
| ☐ Sleep Routine Plan | ☐ Other |

Current baseline (check all that apply):

- | | |
|--|--|
| ☐ Mood generally stable | ☐ Needs help with transitions |
| ☐ Manages anxiety with support | ☐ Sleep concerns |
| ☐ Communicates emotions | ☐ Behavioral outbursts |
| ☐ Participates in school / work | ☐ Safety concerns |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives any provider a quick understanding of your child's behavioral health needs, supports, goals, and safety considerations.



TIP:

Review this page at least once a year or when major changes occur.



BEHAVIORAL HEALTH

Visit Summary

Use this page to capture key information from each behavioral health visit.
Place this summary at the front of the visit records in this section.



Keep your most recent
visit summaries at the
front of this section.



Visit Date _____



Provider _____



Clinic / Location _____

Reason for Visit _____

ASSESSMENTS & EVALUATIONS

(Check all that apply)

- | | |
|---|---|
| ☐ Mental status exam | ☐ Medication review |
| ☐ Depression screening | ☐ Family / caregiver interview |
| ☐ Anxiety screening | ☐ School / work functioning |
| ☐ Suicide risk screening | ☐ Sleep assessment |
| ☐ Behavioral assessment | ☐ Other |

See behavioral health records for details and results.



KEY FINDINGS

Summary of important findings from this visit.



CHANGES OR UPDATES



MEDICATION CHANGES

MEDICATION CHANGES

- ☐ New medication
☐ Dose change
☐ Discontinued

Details: _____



THERAPY / TREATMENT CHANGES

THERAPY / TREATMENT CHANGES

- ☐ New therapy goal
☐ Change in frequency
☐ New treatment approach

Details: _____



EQUIPMENT / SUPPLY CHANGES

SAFETY / SUPPORT PLAN CHANGES

- ☐ Safety plan updated
☐ School / work support
☐ Caregiver support

Details: _____



OTHER CHANGES

OTHER CHANGES

- ☐ Care plan update
☐ Activity / restrictions
☐ Other

Details: _____



FOLLOW-UP PLAN

Next Appointment Date _____

With _____

Recommended Tests / Referrals _____

Other Instructions / Recommendations _____



QUESTIONS

Questions Answered

☐ _____
☐ _____
☐ _____
☐ _____

Questions I Still Have

☐ _____
☐ _____
☐ _____
☐ _____



ADDITIONAL NOTES



INFORMATION SOURCE

This summary was completed by:

- ☐ Parent / Caregiver
☐ Patient
☐ Other _____

Date Completed _____



TIP: Complete this summary during or right after the visit while information is fresh.
Then place visit notes, assessments, and other documents behind this page.

LAST REVISION DATE

____ / ____ / ____





SPEECH THERAPY



PROVIDER INFORMATION

Primary Speech-Language Pathologist _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

☒ Speech / language evaluations

☒ Swallow study reports

☒ Feeding evaluations

☒ Communication assessments

☒ AAC evaluations

☒ Therapy plans and goals

☒ Progress notes

☒ Home exercise programs

☒ Equipment recommendations

☒ Care recommendations

☒ Other Speech Therapy Records

☐ _____

☐ _____



Keep the newest records at the front of this section.



SPEECH THERAPY

Specialty Profile

This page provides an enduring overview of your child's speech, language, and swallowing care.
Update only when information changes significantly.



CARE TEAM

Primary Speech-Language Pathologist _____

Clinic / Hospital _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____



SPEECH & SWALLOW INFORMATION

Primary Communication Concern _____

Primary Swallowing Concern _____

Date Therapy Began _____

Current Therapy Frequency _____

School / Work Setting _____

Uses AAC / Communication Device
☐ Yes ☐ No If yes, type _____

Current Diet / Liquid Texture _____

Services currently part of ongoing care:

- | | |
|---|---|
| ☐ Speech Therapy | ☐ Nutrition / Dietetics |
| ☐ Feeding Therapy | ☐ School-Based Services |
| ☐ Occupational Therapy | ☐ Pulmonary Surveillance |
| ☐ Physical Therapy | ☐ Palliative Care |
| ☐ Gastroenterology | ☐ Other |

Communication / feeding supports used:

- | | |
|--|--|
| ☐ AAC Device | ☐ Modified Diet |
| ☐ Communication Board | ☐ Thickened Liquids |
| ☐ Switch Access | ☐ Feeding Tube |
| ☐ Voice Amplifier | ☐ Other |
| ☐ Adaptive Utensils | ☐ Other |

Current baseline (check all that apply):

- | | |
|---|---|
| ☐ Speech is understandable | ☐ Eats by mouth |
| ☐ Uses communication support | ☐ Needs texture modification |
| ☐ Communicates wants / needs | ☐ Has swallowing concerns |
| ☐ Follows directions | ☐ Uses feeding tube |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives any provider a quick understanding of your child's communication, swallowing, feeding, and support needs.



TIP:

Review this page at least once a year or when major changes occur.



SPEECH THERAPY

Visit Summary

Use this page to capture key information from each speech therapy visit.
Place this summary at the front of the visit records in this section.



Keep your most recent
visit summaries at the
front of this section.



Visit Date _____



Provider _____



Clinic / Location _____

Reason for Visit _____



TESTS & EVALUATIONS PERFORMED

TESTS & EVALUATIONS PERFORMED

(Check all that apply)

- | | |
|--|---|
| ☐ Speech assessment | ☐ AAC / communication assessment |
| ☐ Language assessment | ☐ Oral-motor assessment |
| ☐ Swallow assessment | ☐ Cognitive-communication assessment |
| ☐ Feeding assessment | ☐ Home / school communication review |
| ☐ Voice assessment | ☐ Other |

See therapy records for details and results.



KEY FINDINGS

Summary of important findings from this visit.



CHANGES OR UPDATES



MEDICATION CHANGES

THERAPY / TREATMENT CHANGES

- ☐ New therapy goal
- ☐ Change in frequency
- ☐ Home program updated

Details: _____



THERAPY / TREATMENT CHANGES

COMMUNICATION SUPPORT CHANGES

- ☐ New AAC support
- ☐ Device adjustment
- ☐ New communication strategy

Details: _____



EQUIPMENT / SUPPLY CHANGES

FEEDING / SWALLOW CHANGES

- ☐ Diet texture change
- ☐ Liquid consistency change
- ☐ New feeding strategy

Details: _____



OTHER CHANGES

OTHER CHANGES

- ☐ Care plan update
- ☐ Activity / restrictions
- ☐ Other

Details: _____



FOLLOW-UP PLAN

Next Appointment Date _____

With _____

Recommended Tests / Referrals _____

Other Instructions / Recommendations _____



QUESTIONS

Questions Answered

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Questions I Still Have

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____



ADDITIONAL NOTES



INFORMATION SOURCE

This summary was completed by:

- ☐ Parent / Caregiver
- ☐ Patient
- ☐ Other _____

Date Completed _____



TIP: Complete this summary during or right after the visit while information is fresh.
Then place therapy notes, evaluations, and other documents behind this page.

LAST REVISION DATE

____ / ____ / ____





OTHER SPECIALTIES



PROVIDER INFORMATION

Specialty / Provider _____

Clinic / Hospital _____

Phone _____

Next Appointment _____

Other Providers _____

BEHIND THIS DIVIDER, FILE:

- ☒ Consultation notes
- ☒ Specialist evaluations
- ☒ Diagnostic test results
- ☒ Imaging reports
- ☒ Laboratory results
- ☒ Treatment plans
- ☒ Procedure / surgery records
- ☒ Medication changes
- ☒ Hospital discharge summaries
- ☒ Care recommendations
- ☒ Other Specialty Records







Keep the newest records at the front of this section.



OTHER SPECIALTIES

Specialty Profile

Use this page for any specialist not covered elsewhere in your child's care binder.
Update only when information changes significantly.



CARE TEAM

Specialty / Provider _____

Clinic / Hospital _____

Phone _____

Care Coordinator _____

Phone _____

Clinic Website _____



SPECIALTY INFORMATION

Specialty _____

Primary Diagnosis / Concern _____

Date Care Began _____

Reason for Referral _____

Current Treatment Plan _____

Active Follow-Up
☐ Yes ☐ No Frequency _____

Current Medications _____

Services currently part of ongoing care:

- | | |
|---|---|
| ☐ Primary Care | ☐ Physical Therapy |
| ☐ Neuromuscular Clinic | ☐ Occupational Therapy |
| ☐ Cardiology | ☐ Behavioral Health |
| ☐ Pulmonology | ☐ Palliative Care |
| ☐ Gastroenterology | ☐ Other |

Equipment or supports currently used:

- | | |
|---|---|
| ☐ Manual Wheelchair | ☐ Braces / Orthotics |
| ☐ Power Wheelchair | ☐ Medical Supplies |
| ☐ Standing Device | ☐ Home Equipment |
| ☐ Lift / Transfer Aid | ☐ Other |
| ☐ Communication Device | ☐ Other |

Current baseline (check all that apply):

- | | |
|---|--|
| ☐ Condition stable | ☐ Has activity restrictions |
| ☐ Requires regular follow-up | ☐ Has safety precautions |
| ☐ Uses adaptive equipment | ☐ Recent hospitalization |
| ☐ Needs caregiver assistance | ☐ Recent change in function |



ALLERGIES / PRECAUTIONS



LONG-TERM CARE GOALS

Our long-term goals for care:



IMPORTANT PERMANENT NOTES

Important information every provider should know:



WHY THIS MATTERS

This profile gives any provider a quick understanding of this specialist's role, treatment plan, equipment, and important precautions.



TIP:

Review this page at least once a year or when major changes occur.



OTHER SPECIALTIES

Visit Summary

Use this page to capture key information from each specialist visit.
Place this summary at the front of the visit records in this section.



Keep your most recent
visit summaries at the
front of this section.



Visit Date _____



Provider _____



Clinic / Location _____

Reason for Visit _____



TESTS & EVALUATIONS PERFORMED

TESTS & EVALUATIONS PERFORMED

(Check all that apply)

- | | |
|---|--|
| ☐ Physical exam | ☐ Functional assessment |
| ☐ Laboratory tests | ☐ Medication review |
| ☐ Imaging | ☐ Caregiver interview |
| ☐ Diagnostic testing | ☐ Other |
| ☐ Procedure | ☐ Other |

See specialty records for details and results.



KEY FINDINGS

Summary of important findings from this visit.



CHANGES OR UPDATES



MEDICATION CHANGES

MEDICATION CHANGES

- ☐ New medication
☐ Dose change
☐ Discontinued

Details: _____



THERAPY / TREATMENT CHANGES

TREATMENT PLAN CHANGES

- ☐ New treatment
☐ Change in frequency
☐ Procedure planned

Details: _____



EQUIPMENT / SUPPLY CHANGES

EQUIPMENT / SUPPORT CHANGES

- ☐ New equipment
☐ Adjustment / repair
☐ New support

Details: _____



OTHER CHANGES

OTHER CHANGES

- ☐ Care plan update
☐ Activity / restrictions
☐ Other

Details: _____



FOLLOW-UP PLAN

Next Appointment Date _____

With _____

Recommended Tests / Referrals _____

Other Instructions / Recommendations _____



QUESTIONS

Questions Answered

☐ _____
☐ _____
☐ _____
☐ _____

Questions I Still Have

☐ _____
☐ _____
☐ _____
☐ _____



ADDITIONAL NOTES



INFORMATION SOURCE

This summary was completed by:

- ☐ Parent / Caregiver
☐ Patient
☐ Other _____

Date Completed _____



TIP: Complete this summary during or right after the visit while information is fresh.
Then place the visit note, test results, and other documents behind this page.

LAST REVISION DATE

____ / ____ / ____





SECTION 2

MEDICATIONS

This section keeps your child's current and past medication information together in one place so it can be reviewed quickly and shared accurately with every member of the care team.

Keep medication information current and bring it to every appointment.

Store documents such as:

- Current Medication Profiles
- Medication History Logs
- Pharmacy Information
- Refill / Prior Authorization Notes
- Prescribing Provider Information
- Start / Stop Date Tracking
- Side Effect Notes
- Monitoring Instructions
- Over-the-Counter Medications
- Vitamins / Supplements
- Infusion or Injection Records
- Other medication-related documents



Many families keep a one-page medication list handy.

This can be helpful for emergencies, travel, hospital visits, and appointments when you need to share current medications quickly.





Medication Profile

Complete one page for each current medication.

Keep this information up to date. Make a copy of this page as needed.



MEDICATION INFORMATION

Brand Name _____

Generic Name _____

Strength _____ Dose _____

Instructions (How Often / Route) _____

Start Date ____ / ____ / ____ Stop Date ____ / ____ / ____
(MM / DD / YYYY) (MM / DD / YYYY)

If stopped, reason _____



PRESCRIBING PROVIDER

Provider Name _____

Clinic / Department _____

Phone _____

Fax _____



MONITORING

Check all that apply.

- | | |
|---|--|
| ☐ Labs Required | ☐ Kidney Function |
| ☐ Blood Pressure | ☐ Blood Sugar |
| ☐ Heart Monitoring | ☐ Weight |
| ☐ Liver Function | ☐ Bone Density |
| ☐ Other _____ | |



WHY IS MY CHILD TAKING THIS?

Describe the reason or condition this medication is treating.



COMMON SIDE EFFECTS TO WATCH FOR

List the side effects we were told to watch for.



OUR CHILD'S EXPERIENCE

How has our child responded to this medication?

Notes on benefits, side effects, changes, or anything important.



PHARMACY INFORMATION

Pharmacy Name _____

Phone _____

Specialty Pharmacy? ☐ Yes ☐ No

Requires Prior Authorization? ☐ Yes ☐ No

Notes _____



REFILL INFORMATION

Typical Refill Schedule _____

Prior Authorization Renewal Date ____ / ____ / ____
(MM / DD / YYYY)

Notes _____



TIP:

Bring this page to every appointment.
It helps every provider stay informed.

Together, we navigate today



for a stronger tomorrow.



Medication History Log

A record of all medications your child has taken.

Record each medication as it is started. If the dose changes, add a new line.

When a medication is stopped, complete the Stop Date and Status / Reason for Change columns.

 MEDICATION (Brand / Generic)	 STRENGTH	 DOSE	 INSTRUCTIONS (How Often / Route)	 START DATE (MM / DD / YYYY)	 STOP DATE (MM / DD / YYYY)	 STATUS / REASON FOR CHANGE (e.g., Current, Dose Increased, Discontinued, Switched, Side Effects)



TIP:

Keeping an up-to-date medication history helps every provider understand your child's treatment and helps prevent errors.

Together, we navigate today



for a stronger tomorrow.



IMPORTANT

Share this page with any new provider and bring it to every appointment.



SECTION 3

APPOINTMENTS

This section helps your family prepare for upcoming appointments, keep important visit details organized, and track past and future care in one easy-to-find place.

Prepare before each visit and record appointments as soon as they are scheduled.

Store documents such as:

- Appointment Preparation Worksheets
- Upcoming Appointment Lists
- Questions for Providers
- Referral Notes
- Follow-Up Task Lists
- Visit Planning Notes
- Procedure Preparation Instructions
- Test Scheduling Information
- Provider Contact Notes
- Travel / Lodging Notes
- Calendar Printouts
- Other appointment-related documents



Many families keep the next appointment page in front.

This makes it easier to prepare questions, track follow-up tasks, and quickly find the details you need before each visit.





Appointment Preparation Worksheet

Use this page to prepare for your appointment and make the most of your time.

Complete this worksheet before each appointment.



APPOINTMENT INFORMATION

Date _____ Time _____ Specialty _____

Provider _____ Clinic / Facility Name _____

Street Address _____

City / State / ZIP _____

Building _____ Suite / Floor / Room _____

 Include the exact street address, building, floor, and suite or room when available.



QUESTIONS WE DON'T WANT TO FORGET

List your questions for the provider.

- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____



UPDATES SINCE THE LAST VISIT

Check all that apply and add details in the space below.

- | | |
|---|--|
| ☐ New symptoms | ☐ Medication changes |
| ☐ New concerns | ☐ Equipment issues |
| ☐ Falls | ☐ School concerns |
| ☐ Illnesses / Hospitalizations | ☐ Insurance / Coverage issues |
| ☐ ER / Urgent care visits | ☐ Other _____ |

Details / Notes:



DOCUMENTS TO BRING

Check all that apply.

- ☐ Care Binder
- ☐ Insurance Card
- ☐ Medication List
- ☐ Imaging / Scan Results
- ☐ Lab Results
- ☐ School / Work Forms
- ☐ FMLA / Disability Forms
- ☐ Medication Bottles
- ☐ Other _____



GOALS FOR TODAY'S VISIT

If we accomplish only one thing today, it should be:



BEFORE WE LEAVE...

Use this checklist to make sure we don't leave without what we need.

- | | | | | | |
|---|---|--|---|---|---|
| ☐ Next appointment scheduled | ☐ Medication refills requested | ☐ Orders / Referrals received | ☐ School / Work forms signed | ☐ Visit summary obtained | ☐ Questions answered |
|---|---|--|---|---|---|

Other reminders / notes: _____



TIP:

Taking a few minutes to prepare can help you feel more confident and get the most out of your appointment.



Keep track of all upcoming and past appointments.

Record appointments as they are scheduled. Use one line for each appointment.

[illegible]

Add appointments as soon as they are scheduled.
This helps you plan ahead and stay organized.

Together, we navigate today



for a stronger tomorrow.



SECTION 4

INSURANCE & BILLING

Keep your insurance information, billing contacts, authorizations, and important communication details organized in one place.





Insurance Profile

Record your insurance information in one place.

Update this page whenever your coverage or policy information changes.



PRIMARY INSURANCE

Insurance Company _____

Plan / Policy Name _____

Member ID / Policy # _____

Group # _____

Policy Holder Name _____

Policy Holder Date of Birth _____ / _____ / _____
(MM / DD / YYYY)

Relationship to Patient _____

Effective Date _____ / _____ / _____
(MM / DD / YYYY)

Customer Service Phone _____

Website _____

PHARMACY BENEFIT INFORMATION (If separate)

Pharmacy Benefit Manager

RxBIN _____

RxPCN _____

RxGRP _____

Member ID (Rx)

Pharmacy Help Desk



SECONDARY INSURANCE (if applicable)

Insurance Company _____

Plan / Policy Name _____

Member ID / Policy # _____

Group # _____

Policy Holder Name _____

Policy Holder Date of Birth _____ / _____ / _____
(MM / DD / YYYY)

Relationship to Patient _____

Effective Date _____ / _____ / _____
(MM / DD / YYYY)

Customer Service Phone _____

Website _____

PHARMACY BENEFIT INFORMATION (If separate)

Pharmacy Benefit Manager

RxBIN _____

RxPCN _____

RxGRP _____

Member ID (Rx)

Pharmacy Help Desk



Copies of Insurance Cards

Keep a copy of your insurance cards in the pocket behind this page.



Billing Contacts

Important contacts for billing and financial questions.

Update as needed.



HOSPITAL / FACILITY BILLING

Name _____ Fax _____

Phone _____

Notes _____



PHYSICIAN OFFICE BILLING

Name _____ Fax _____

Email _____

Notes _____



SPECIALTY PHARMACY BILLING

Name _____ Fax _____

Email _____

Notes _____



CASE MANAGER / PATIENT ADVOCATE

Name _____ Fax _____

Email _____

Notes _____



FINANCIAL COUNSELOR / PATIENT FINANCIAL SERVICES

Name _____ Fax _____

Email _____

Notes _____



Claims / Prior Authorization Tracker

Track the status of claims, authorizations, and approvals.

SERVICE / ITEM / PROCEDURE	DATE REQUESTED	AUTHORIZATION / REFERENCE #	TYPE (Claim / Auth)	STATUS (Pending / Approved / Denied / Closed)	NOTES



Insurance Communications Log

Record phone calls and conversations with your insurance and related contacts.

DATE	ORGANIZATION / DEPARTMENT	REPRESENTATIVE NAME	PHONE NUMBER	REFERENCE # (CALL / CASE / CONFIRMATION)	SUMMARY OF CONVERSATION	NEXT STEP / FOLLOW-UP



SECTION 5

SCHOOL

Store documents such as adaptive plans, paperwork, teaching recommendations, and important school information here.

Store documents such as:

- Current IEP or 504 Plan
- Eligibility Evaluations
- Functional Assessments
- Adaptive Equipment Recommendations
- Therapy Recommendations
- Teacher Recommendations
- Classroom Accommodations
- Transportation Plans
- Emergency Health Plans
- Behavior Plans (If applicable)
- School Correspondence
- Progress Reports
- Meeting Notes and Action Items
- And other related documents



Many families eventually create a dedicated school binder.

This section is intended to organize the most important school information during the early years after diagnosis. As school records grow, many families choose to move this section into a dedicated school binder while keeping the same organization.





School Profile

Key information about your child's school.

School Name _____

School Address _____

Main Phone _____ Main Fax _____

Website _____

School District _____

Student ID # _____

Grade _____ School Year _____ - _____
(Start) (End)

General Notes _____



School Contacts – Page 1

Contact information for key school staff and support services.



PRINCIPAL / ASSISTANT PRINCIPAL

Name _____

Phone _____

Email _____

Notes _____



SCHOOL NURSE

Name _____

Phone _____

Email _____

Notes _____



SCHOOL COUNSELOR

Name _____

Phone _____

Email _____

Notes _____



SPECIAL EDUCATION / CASE MANAGER

Name _____

Phone _____

Email _____

Notes _____



TRANSPORTATION COORDINATOR

Name _____

Phone _____

Email _____

Notes _____



OTHER (Specify role)

Name _____

Phone _____

Email _____

Notes _____



School Contacts – Page 2

Teacher contact information. Add additional pages as needed.



TEACHER / SUBJECT _____

Name _____

Phone _____

Email _____

Notes _____



TEACHER / SUBJECT _____

Name _____

Phone _____

Email _____

Notes _____



TEACHER / SUBJECT _____

Name _____

Phone _____

Email _____

Notes _____



TEACHER / SUBJECT _____

Name _____

Phone _____

Email _____

Notes _____



TEACHER / SUBJECT _____

Name _____

Phone _____

Email _____

Notes _____



TEACHER / SUBJECT _____

Name _____

Phone _____

Email _____

Notes _____



School Meeting & Communication Record

Use one page for each meeting, phone call, or important communication.

Date _____

Type of Meeting (check one):

- ☐ IEP ☐ 504 ☐ Eligibility ☐ Parent Conference
☐ Transition ☐ Phone Call ☐ Email Question ☐ Other _____

Who Participated (names and roles):

Topics Discussed

Decisions Made / Agreements Reached

Action Items

Responsible Person	Task / Action	Due Date

Documents Received (check all that apply):

- ☐ IEP / 504 Plan ☐ Therapy Report
☐ Evaluation / Assessment ☐ Behavior Plan
☐ Progress Report ☐ Other _____
☐ Transportation Plan ☐ Other _____

Follow-Up Needed / Next Steps



File Any Documents Related to This Meeting Behind This Page.



IEP / 504 Filing Guide *(Document Cover)*

Use this page as a cover for important school documents.

FILE BEHIND THIS COVER:

- ☐ Current IEP or 504 Plan
- ☐ Eligibility Evaluations
- ☐ Functional Assessments
- ☐ Adaptive Equipment /
Assistive Technology
Recommendations
- ☐ Therapy / Related Services
Recommendations
- ☐ Transportation Plan
- ☐ Emergency Health Plan
- ☐ Behavior Plan (if applicable)
- ☐ Teacher Recommendations
- ☐ Progress Reports
- ☐ Other _____
- ☐ Other _____

DOCUMENT INFORMATION

Document Type _____

School Year _____

Date of Document _____

Review Date (if applicable) _____

Notes _____



TIP:

Replace outdated documents with the latest versions
and keep this cover page at the front.



SECTION 6

CAREGIVERS

Information and tools to support caregivers in their important role. Keep essential caregiver contacts, plans, routines, resources, and important documents together in one place.



Store documents such as:

- Caregiver Notes & Shift Reports
- Emergency Contacts
- Daily Care Routines
- Equipment Guides & Manuals
- Transfer & Mobility Information
- Important Tips & Preferences
- Storage of Important Documents





Caregiver Quick Reference

Essential information for anyone caring for my child.

ABOUT MY CHILD

Preferred Name _____

Date of Birth _____

Pronouns (if applicable) _____

Communication Preferences _____

PRIMARY MEDICAL INFORMATION

Primary Diagnosis _____

Neuromuscular Clinic _____

Primary Physician _____

Specialist(s) _____

Insurance Company _____

Policy / Member ID _____

BASIC INFORMATION

Weight _____ lbs / _____ kg

Wheelchair: ☐ Yes ☐ No

Mobility Level _____

Allergies / Sensitivities _____

IMPORTANT MEDICATIONS

See Medication List for complete details.

EMERGENCY CONTACTS (If parent/guardian cannot be reached)

Parent / Guardian 1 _____

Phone _____

Parent / Guardian 2 _____

Phone _____

Backup Emergency Contact _____

Phone _____

Relationship to Child _____

THINGS OUR CHILD WANTS YOU TO KNOW

Preferences, comforts, and other important information.

If you are ever unsure about what to do,
call a parent or guardian. They are your best resource and want you to feel confident.



Emergency Contacts

Important numbers to call in any situation.

IMMEDIATE EMERGENCY

NOTES

Local Emergency Number (e.g., 911 / 999 / 112) _____

MEDICAL TEAM

CONTACT NAME

DAY PHONE

AFTER-HOURS PHONE

NOTES

Neuromuscular Specialist _____

Primary Care Physician _____

Primary Care After-Hours _____

Cardiologist _____

Pulmonologist _____

Home Health Agency _____

PHARMACY

PHONE

NOTES

Local Pharmacy _____

Specialty Pharmacy _____

24-Hour Pharmacy (if different) _____

POISON & MEDICATION SAFETY

PHONE

Poison Control _____

Pharmacy Help Line _____

Medication Manufacturer _____

Nurse Line (if applicable) _____

FAMILY CONTACTS

PHONE

Parent / Guardian 1 _____

Parent / Guardian 2 _____

Backup Emergency Contact _____

Neighbor _____

Grandparent / Relative _____

EQUIPMENT SUPPORT

PHONE

NOTES

Wheelchair Vendor / Service _____

Respiratory Equipment Company _____

Medical Equipment Company _____

IF YOU CALL EMERGENCY SERVICES, PLEASE ALSO:

☐ Bring the Care Binder

☐ Bring medications

☐ Notify neuromuscular clinic if admitted

☐ Bring charger for power wheelchair

☐ Notify parent / guardian

☐ Other _____



Daily Care Routine

Follow our child's typical routine. Adjust as needed.



MORNING

TIME

TASK / ROUTINE / NOTES



AFTERNOON

TIME

TASK / ROUTINE / NOTES



EVENING

TIME

TASK / ROUTINE / NOTES



BEDTIME

TIME

TASK / ROUTINE / NOTES

ADDITIONAL ROUTINES / NOTES (weekends, school days, therapies, activities, etc.)



Transfer & Mobility Guide

Important information for safe transfers and mobility.

MOBILITY OVERVIEW

Walking Ability _____

Wheelchair Use

☐ Full-Time

☐ Part-Time

☐ For Distance

Power Chair

☐ Yes

☐ No

Independent Driving

☐ Yes

☐ No

Transfer Assistance Needed

☐ None

☐ Some

☐ Full Assistance

Best Transfer Side _____

Weight-Bearing Restrictions _____

TRANSFERS

Transfer Methods That Work Best:

Do NOT:

LIFT / ASSISTIVE DEVICES

Type Used _____

Brand / Model _____

Location _____

Sling Type / Size _____

Notes

FALL PRECAUTIONS

PRESSURE RELIEF

Schedule / Frequency _____

Method _____

Notes

OTHER IMPORTANT NOTES



Equipment Guide

Keep details about all equipment, how to use it, and key contacts.

EQUIPMENT	PURPOSE / USE	HOW TO USE / SETTINGS	CLEANING / CARE	COMPANY / CONTACT INFO	NOTES
Power Wheelchair					
Cough Assist					
BiPAP / CPAP					
Hospital Bed					
Hoyer Lift					
Shower Chair					
Standing Frame					
Other _____					



Things We Do Differently

Helpful tips and important things every caregiver should know.

OUR CHILD LIKES

OUR CHILD DISLIKES / TRIGGERS

COMMUNICATION TIPS

IMPORTANT THINGS YOU MUST KNOW

ADDITIONAL NOTES



Caregiver Notes / Shift Report

Use one page per shift or caregiving period.

DATE _____ DAY OF WEEK _____ SHIFT ☐ Morning ☐ Afternoon ☐ Evening ☐ Overnight

CAREGIVER NAME _____ ARRIVAL TIME _____ DEPARTURE TIME _____

MEDICATIONS

Medications Given (include time):

- ☐ _____ / _____
- ☐ _____ / _____
- ☐ _____ / _____
- ☐ _____ / _____
- ☐ _____ / _____

Medications Missed / Not Given:

ACTIVITIES / CARE PROVIDED

ELIMINATION

Toileting / Diaper Changes _____

Notes _____

MEALS / SNACKS

Breakfast _____

Lunch _____

Dinner _____

Snacks _____

Hydration Notes _____

ANY CONCERNS / CHANGES / QUESTIONS



Document & Equipment Storage Checklist

Keep important paperwork and manuals together in this section.

PAPERWORK TO STORE BEHIND THIS SECTION

- ☐ Equipment manuals
- ☐ Warranty information
- ☐ Equipment prescriptions / orders
- ☐ Vendor contact information
- ☐ Training materials
- ☐ Home modification records
- ☐ Therapy / PT / OT instructions
- ☐ Care plans / routines
- ☐ Transfer training notes
- ☐ Other _____
- ☐ Other _____

NOTES

[illegible]

TIP: Keep all equipment manuals, warranties, and important documents behind the Equipment Guide page for quick access.



SECTION 7

RESOURCES & SUPPORT

This section helps you organize financial assistance, programs, organizations, and people who support your child and your family.

Store and track information such as:

- Benefits and grants
- Applications, awards, and renewals
- Important contacts and community support
- Ideas about future resources and opportunities
- Legal and planning documents



i

HOW TO USE THIS SECTION

A simple guide to organizing resources and support.

1

Start with the Overview page.

Use it to see everything at a glance and keep track of key programs.

2

Create a Benefit & Grant Record

for each benefit or grant and file all related documents behind that page.

3

Use the Applications & Renewals page

to track renewal dates, deadlines, awards, and current status.

4

Capture new ideas on the Future Resources page

so you do not forget opportunities to explore.

5

Record everyone who supports your family

on the My Support Network page.

6

Store legal and planning documents behind the

Legal & Planning Documents page for easy access.

You don't have to do everything at once.

Take it one page at a time — you are in this together.

R

Resources & Support Overview

A snapshot of the programs and support we use.

Program / Benefit	Purpose / What It Covers	Who Provides It	Renewal / Review Date	Status	Contact	Notes

KEY STATUS OPTIONS

- ☐ Active
- ☐ Pending
- ☐ Approved
- ☐ Denied
- ☐ Missing Info
- ☐ Expired
- ☐ Not Applicable

IMPORTANT NOTES / REMINDERS



Benefit & Grant Record

One page per benefit or grant.

Program / Grant Name _____

Purpose / What It Supports _____

Organization / Provider _____

Amount Requested _____ **Amount Awarded** _____

Date Applied _____ **Date Approved / Awarded** _____

Status (check one): ☐ Pending ☐ Approved ☐ Denied ☐ Waitlisted ☐ Expired

Renewal Required? ☐ Yes ☐ No **Renewal Date** _____

Contact Person _____

Phone / Email _____

Notes / Next Steps

File all documents related to this program/grant behind this page.



Applications & Renewals

Track applications, renewals, and important deadlines.

Program / Benefit	Application Submitted	Renewal Due Date	Current Status	Documents Needed	Notes

STATUS OPTIONS

- ☐ In Progress
 ☐ Submitted
 ☐ Under Review
 ☐ Approved
- ☐ Denied
 ☐ Active
 ☐ Expired
 ☐ Waiting List



Future Resources

Ideas and opportunities we want to explore or apply for.

Idea / Opportunity	Source / How We Heard About It	Website / Next Step	Deadline	Priority	Date Added

NOTES



My Support Network

Organizations and people who are part of our support network.

Organization / Person	Contact Person	Role / How They Help	Phone / Email	Notes	Follow-Up

Use additional pages as needed.

This can include organizations, support groups, parent mentors, social workers, faith communities, respite programs, equipment loan programs, advocacy groups, schools, therapists, and more.



Legal & Planning Documents

Important legal, financial, and planning documents for our family.

STORE DOCUMENTS BEHIND THIS PAGE

- ☐ Special Needs Trust Documents
- ☐ Guardianship / Conservatorship
- ☐ Power of Attorney (Medical)
- ☐ Power of Attorney (Financial)
- ☐ Wills
- ☐ Estate Planning Documents
- ☐ ABLE Account Documents
- ☐ Trust Updates
- ☐ Legal Correspondence
- ☐ Other Legal / Planning Documents
- ☐ Other _____

KEY CONTACTS

Estate Attorney _____ Phone _____

Financial Advisor _____ Phone _____

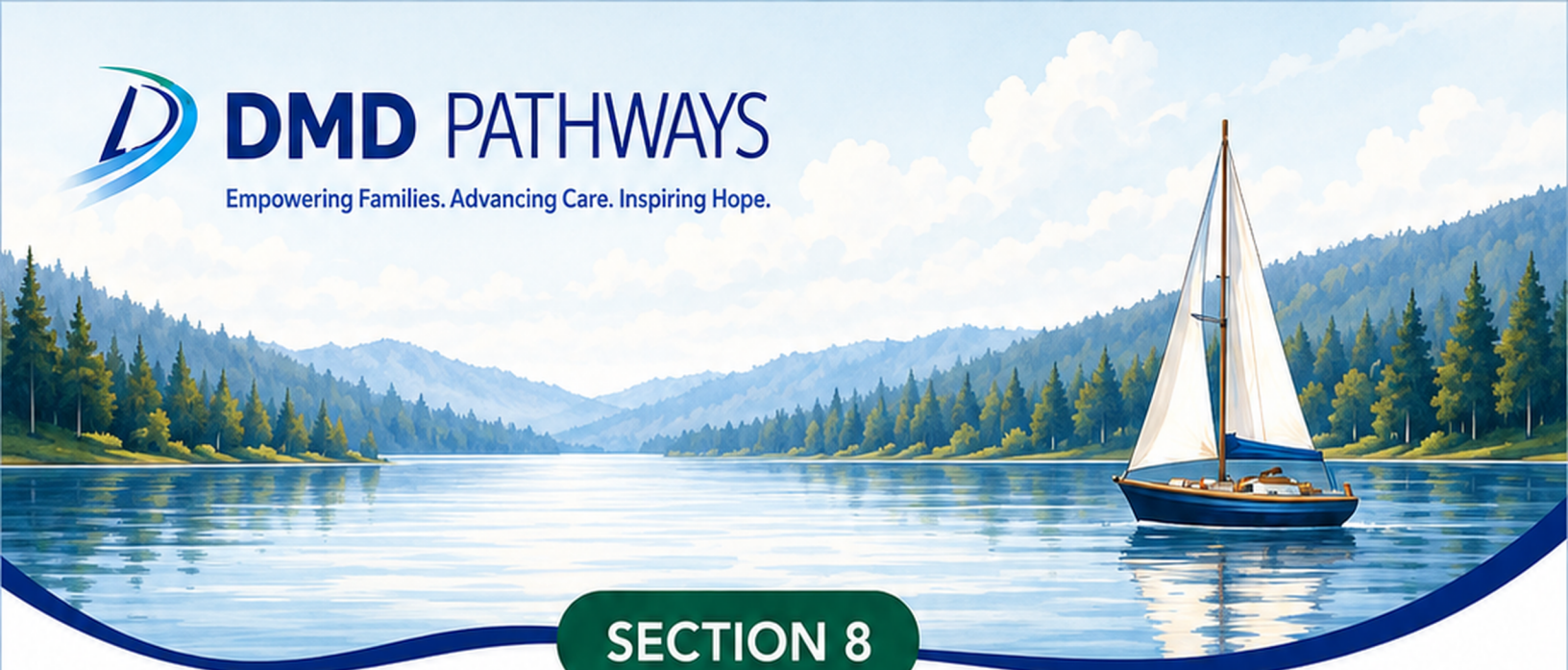
Trust Administrator _____ Phone _____

Accountant _____ Phone _____

Insurance Agent _____ Phone _____

Other _____ Phone _____

NOTES



SECTION 8

OPTIONAL TRACKING & NOTES

Every family's journey is different.
Use this section for information that doesn't fit
elsewhere or for tracking items that are
important to your family.

Examples include:

- ✓ Symptom or observation logs
- ✓ Sleep, nutrition, or weight tracking
- ✓ Travel and overnight checklists
- ✓ Home projects or equipment lists
- ✓ Personal notes and reminders



This section is flexible.
Use what helps your family and skip
what you don't need.





Topic / Subject:



Blank Tracker / Log

Use this table to track anything that is important to your family.

[illegible]

You can customize the column headings to fit what you are tracking.





Symptom / Observation Log

Use this page to keep track of symptoms, changes, or concerns to share with your care team.

[illegible]



Travel & Overnight Packing Checklist

Use this checklist to make sure nothing important is left behind.

ing Checklist

MEDICAL & EQUIPMENT

- ☐ Medications (enough for entire trip + extra)
- ☐ As-needed medications
- ☐ Feeding / nutrition supplies
- ☐ Ventilator / Cough Assist supplies
- ☐ Power wheelchair & charger
- ☐ Backup equipment / batteries
- ☐ Medical supplies (catheters, syringes, etc.)
- ☐ Emergency medication plan
- ☐ Insurance cards
- ☐ Care Binder

DAILY LIVING & COMFORT

- ☐ Clothing (including weather-appropriate)
- ☐ Toiletries
- ☐ Chargers (phone, tablet, devices)
- ☐ Entertainment (books, games, tablet)
- ☐ Comfort items / favorites
- ☐ Snacks / special foods
- ☐ Water bottle
- ☐ Cash / payment cards
- ☐ Important phone numbers
- ☐ Any other must-haves

OTHER ESSENTIALS

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

NOTES





Hospital Stay Checklist

Use this checklist when preparing for a hospital stay.

MEDICAL & EQUIPMENT

- ☐ Medications (labeled, current list)
- ☐ As-needed medications
- ☐ Feeding / nutrition supplies
- ☐ Ventilator / Cough Assist supplies
- ☐ Suction supplies
- ☐ Power wheelchair & charger
- ☐ Back-up equipment / batteries
- ☐ Medical supplies
- ☐ Emergency plan / orders
- ☐ Care Binder

PERSONAL & COMFORT

- ☐ Clothing & pajamas
- ☐ Toiletries
- ☐ Comfort items / favorites
- ☐ Entertainment (tablet, books, games)
- ☐ Blankets / pillow
- ☐ Noise-canceling headphones
- ☐ Snacks / special foods
- ☐ Water bottle / cup
- ☐ Cash / payment cards
- ☐ Phone & charger

IMPORTANT DOCUMENTS

- ☐ Insurance cards
- ☐ ID
- ☐ Advance directives (if applicable)
- ☐ Guardianship / POA documents
- ☐ List of allergies
- ☐ Current medication list

NOTES / OTHER

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

