



Transitions Planning Prepare to Launch!

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**Parent Project
Muscular
Dystrophy**

JOIN THE FIGHT.
END DUCHENNE.

ENDDUCHENNE.ORG

About me



- No disclosures
- Brief Bio
 - Education:
 - Undergrad: University of California, Irvine and Loyola University, New Orleans
 - Medical School: Louisiana State University, New Orleans
 - Residency: Physical Medicine and Rehabilitation, University of Colorado
 - Fellowship: Pediatric Rehabilitation Colorado Children's Hospital
 - Business Degree: University of Missouri, Kansas City
 - Children's Mercy Hospital
 - Director, Division of Rehabilitation
 - Medical Director, Hospital Wide Transition to Adulthood Program
 - Medical Director, Nerve and Muscle Clinic (a PPMD certified clinic), Limb Differences/Amputee Clinic
 - Faculty appointments:
 - UMKC Department of Pediatrics: Professor
 - KUMC: Clinical Faculty, Department of PM&R
 - Interests:
 - Martial Arts, Japanese Gardening, Sailing, Art

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Objectives

1. Understand the concept of Transition to Adulthood, especially related to Healthcare Transition—AND WHY IT MATTERS!
2. Identify approaches to transition preparation
3. Evaluate tools for youth, parents, medical providers to gain skills and independence
4. Promote communication at each step

Care Considerations: Transitions

Six Domains of Transition Content:

****Health care****

Assistance with ADLs

Education/Employment

Housing

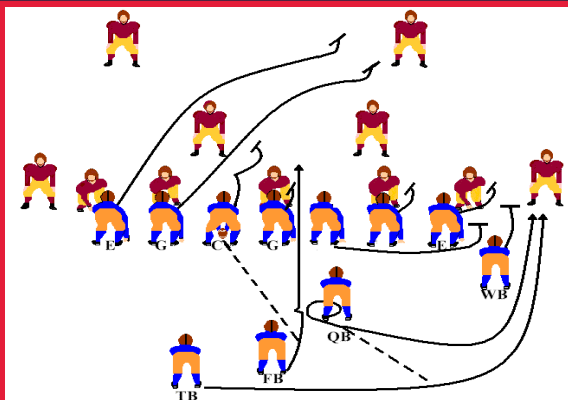
Transportation

Relationships/Social life



OBJECTIVE 1: What is Health Care Transition and Why does it Matter?

The future view is one that all teens and young adults with chronic disease or disability will have *uninterrupted, seamless and coordinated health care*, as recommended by the AAP, AAFP and the Healthy People 2012 initiatives.



This is YOU



Parent **JOIN THE FIGHT.
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SCORE!

Objective 1b. Why Transition to Adult Care Matters

- At time of transfer, many teens/young adults are unable to:
 - **Schedule appointments**
 - **Direct their health care team**
 - **Understand their medications**
 - **Arrange for prescription refills**
 - **Summarize medical history and health needs**
 - **Understand insurance basics**
 - **Make healthy lifestyle decisions**
 - **Manage daily health care needs**

AND MORE...

Why does this happen?

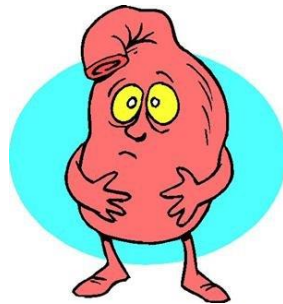
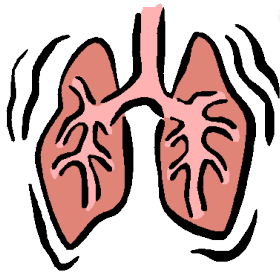
- **DMD, like most chronic conditions was considered a “Pediatric disease”**
- **Clinics did not have Transition Programs**
- **Parents quarterbacked on behalf of their son**
- **No support from Peds or Adult team to get the two together**
- **Teens are given few opportunities for education, training and time to practice and master their health care**
- **Nobody has a coach to guide them through the process**

Objective 1b. Why Transition to Adult Care Matters

Missed Appointments

Missed
preventative
care

Gaps in
medication
prescriptions



Hospitalizations, avoidable
complications, even death



Successful Health Care Transition

Objective 2: Approaches to Transition Preparation



Three primary elements

Preparation—Teens become ready to manage their own health care as independently as possible

Planning—health care transition needs are anticipated and responsibility is clear about who will do what when (teen, parent, physician/provider)

Implementation—smooth and seamless transfer of care from pediatric to adult health care

CDC Care Considerations:

ON STAGE NOW in Quarterbacking Your Care Session

- **CDC Care Considerations (Lancet, 3 parts)**
- **DMD Transition Toolkit – (Pediatrics, Spring 2018)**

Timing of Transition Planning

Objective 2:
Approaches to
Transition
Preparation

Process – not a single event

Future
Oriented

High Expectations

Recommended Health Care Transition Timeline

AGE:	12	14	16	18	18-22	23-26
	Make youth and family aware of transition policy	Initiate health care transition planning	Prepare youth and parents for adult model of care and discuss transfer	Transition to adult model of care	Transfer care to adult medical home and/or specialists with transfer package	Integrate young adults into adult care

Optimistic

Max
Independence

Confidence



Social
Development

Reference: Got Transition (gottransition.org)

Not all Transitions are Created Equally

- **Limited research** showing differences between those who have a formal transition process versus those who do not.
- **Limited research looking at factors that influence “successful” transitions**
 - Example: parenting style, personality characteristics, personal resources, hardships, social determinants, cognitive issues
- **Limited support** from Pediatric and Adult Health Care Centers to promote transitions and relationships.
- **Variable resources** available to facilitate transition based on where you live, payer type and who is involved

**Objective 2:
Approaches to
Transition
Preparation**

Assess for Transition Readiness

Objective 3: Tools to help Transition



1. Tools assess and score a patient's skills, knowledge and readiness
2. All teens have a Core Set of transition-related Goals, and an individual set of needed skills
3. Each specialist will create body part specific training
4. For teens who cannot direct their care, the training will be focused on the guardian
5. Readiness and goal development occur at least yearly
6. Special Communication Tools and Apps

Objective 3: Tools to help Transition

- **Assessment of Readiness**
 - Looks at current skills, and projects future readiness to participate
 - Identifies areas where instruction is needed
 - If young adult with DMD needs ongoing parent/guardian assistance with all medical decision making, emphasis is on caregiver readiness
 - Our Readiness Assessment integrates with the Electronic Medical Record for Tracking and Graphs
- **Transition Checklist**
 - Identified needs for information – very detailed!
 - Charts progress in areas of transition
- **Tools to Explore Guardianship, Durable Medical POA**
- **Three Sentence Summary**
- **DMD Play Book**
 - Many PCPs do not know a lot about DMD
 - Basic care plans
 - Trouble Shooting
 - Resources

- **Wheelchair Medical Tag (*also in your ICE app on your phone*):**
 - Information about you for non-medical folks on one side, Information about DMD for medical people on the other (steroid stress dosing, anesthesia risks, Insurance and Contact information, etc.).
- **Transition App**
 - Customized for YOU (and your avatar)
 - Earn points and rewards for meeting transition goals
 - Symptom Tracker
 - Med Minder
 - Text reminders from your coordinator about upcoming appointments and goal deadlines
 - Interactive
- **My Heath Passport**
- **A Medical Summary**
 - Useful information for the adult care partner and team
 - Medical diagnosis
 - Past & recent medical results and trends
 - Urgent care needs
 - Make sure YOUR wishes are known and communicated
 - Recognizing emergencies
 - List of providers, agencies, vendors (contact info)
 - Equipment & other healthcare/home care supplies
 - School/work information



We are happy to share our tools!

What is a 3-Sentence Summary?

An easy way to discuss important health information with your healthcare team at each visit

How do I use it?

Sentence 1: My age, diagnosis and brief medical history

Sentence 2: My treatment plan

Sentence 3: My question/concern to talk about during this visit

Now it's your turn

Practice with the health-care providers you see the most

Ask if your 3-Sentence Summary is correct and includes all the important information

Example

“Hi, my name is Max Golden”.

1) I am 16 and I have DMD

2) I am on non-invasive ventilation at night and I have stable heart function.

3) I am here today because I seem to be tired more during the day, and I believe I need to have my BiPAP settings adjusted.

Objective 4: Communication for Successful Transitions

1. Teen has time alone with providers

- Promote understanding of medical conditions
- Why medications are used
- How they affect your body
- Teen learns to direct care
- Ask the “sex, drugs and rock-and-roll” questions

2. Communicate with your providers outside of clinic times

- Patient Portal
- Secure texting of Transition Goals
- Interactive App integrating medical tasks and transitioning tasks

3. The #1 Request of our Teens and Parents

- Who are my new doctors?
 - Your peds team should keep lists of DMD friendly adult PCPs and specialists
 - Ask for an endorsement and an introduction, not just a list!

4. Ensure medical records are shared

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- Medical summary at handoff
- Medical care plan (urgent care)
 - Communicate goals of care to others
 - Advance directives when appropriate
 - Phone apps & emergency cards



Summary of Objectives

- **Objective 1:** Transition requires processes and planning so that care is seamless and consistent when going from the Pediatric World to the Adult World of Healthcare. When done well, YOU stay healthy!
- **Objective 2:** While there are differences in clinics and their approach to Transition, the important thing is that you work on it and take charge!
 - Create your Transition Team
 - Evaluate your skills and growth opportunities
 - Establish your goals
 - Set a plan to get there
 - Execute the plan
 - SCORE!
 - **TRANSITION** efforts lead to successful **TRANSFER**
- **Objective 3:** Use basic and DMD specific Transition Tools to make transition easier and more rewarding
 - Good 2 Go
<http://www.sickkids.ca/good2go/>
 - My Health Passport-
<http://www.sickkids.ca/myhealthpassport>
 - Got Transitions?
<http://www.gottransitions.org/>
 - Our Program
 - <http://www.childrensmercy.org/transition>
- **Objective 4:** Make sure communication is clear and information is shared at each step during transitions. A portable medical summary should be available to YOU and your adult receiving team.



Thank you!

