

Transition

The Journey From the Pediatric World into Adulthood

Parent Project Muscular Dystrophy

End Duchenne Tour

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Nothing to Disclose

References Available Upon Request

What is Transition?

Your Future and A Lot of Work

No longer a Kid? Welcome to the mysterious world of Adulthood

We call it transition – You call it growing up

- Normal to feel excited and nervous
- New responsibilities of adulthood
- Many decisions to make and skills to learn
- Be your own advocate



Transition is Complex



Medical –

- New adult providers
- Family centered to patient centered care
- Medical interventions - involves primary care and specialty care

Psychosocial –

- Social and cognitive development
- Quality of life
- Patient and family functioning including what happens at home
- School
- Work

Six Domains of Transition Planning



Health Care

- Pediatric to adult providers
 - Primary care, multidisciplinary team
 - Records transfer, medication and equipment management
 - Family centered to patient centered care
 - Durable power of attorney for health care
 - Age related changes in benefits
 - Advanced Care Planning/Palliative Care

Got Transition www.gottransition.org

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

Transition is a process, not an event; it happens over time.

Activities of Daily Living

- CEO – You're the boss
- CFO - Funding and benefits
- COO - PCA's and schedules
- Respite for family caregivers
- Leisure/Recreational
- Need for guardianship/conservatorship



Education and/or Employment

- Plan early for future education or vocation
- Evaluate strengths, weaknesses, talents
- Funding
- Post-secondary – accommodations
- Online classes vs on campus
- Employment or vocational planning resources

Housing

- Family home or elsewhere
- Accessible residence/safe residence
- Dormitory with accommodations
- Use of assistive technology – modified phones, switches

Transportation

- Wheelchair
- Public transport
- Driving with vehicle modifications
- Van – funding
- Travel

Relationships

- Develop skills over time
- Community Integration/socialization
- Communication skills
- Sexuality
- Work toward desired level of autonomy and independence
- Spirituality

Barriers to Transition

- Abrupt with little or no preparation
- Reluctance to leave familiar and trusted providers
- Delay in re-establishing medical care with adult providers
- Lack of insurance for adult services
- Limited adult providers with knowledge and expertise in neuromuscular disorders
- Lack of communication between pediatric and adult providers
- Difference between pediatric and adult care

Resources

- Medical Team
- Family/Friends
- Social Work
- Physical Therapy
- Psychology/Neuropsychology
- Therapeutic Recreation
- Occupational Therapy
- Nurses
- PPMD – Toolkit Soon!



Your Mission Should You Accept It

