

Project DMD

Transitioning to Adulthood

EXPLORING THE PERSPECTIVES OF YOUNG PEOPLE WITH DUCHENNE MUSCULAR DYSTROPHY (DMD), PARENTS/CAREGIVERS AND HEALTH PROFESSIONALS

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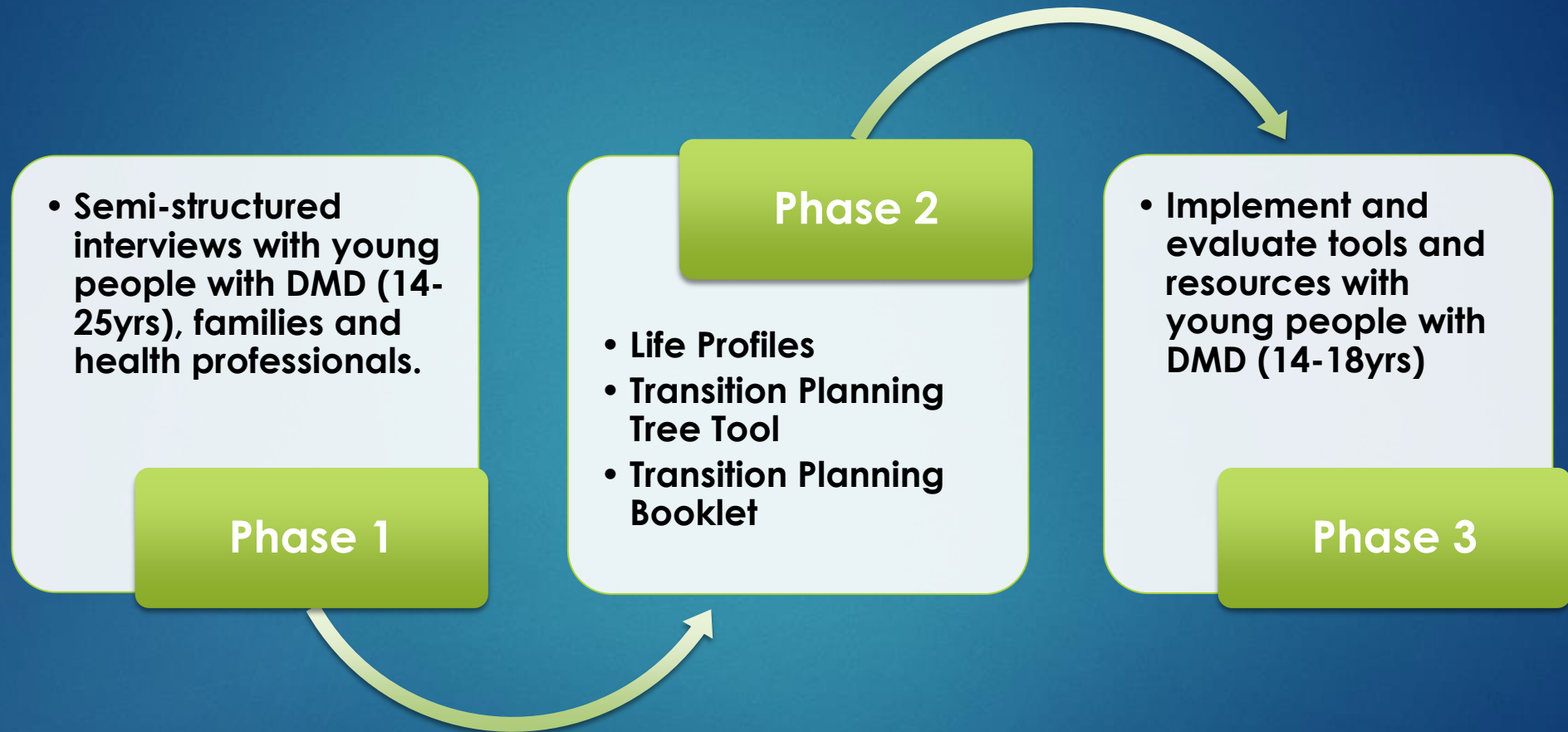
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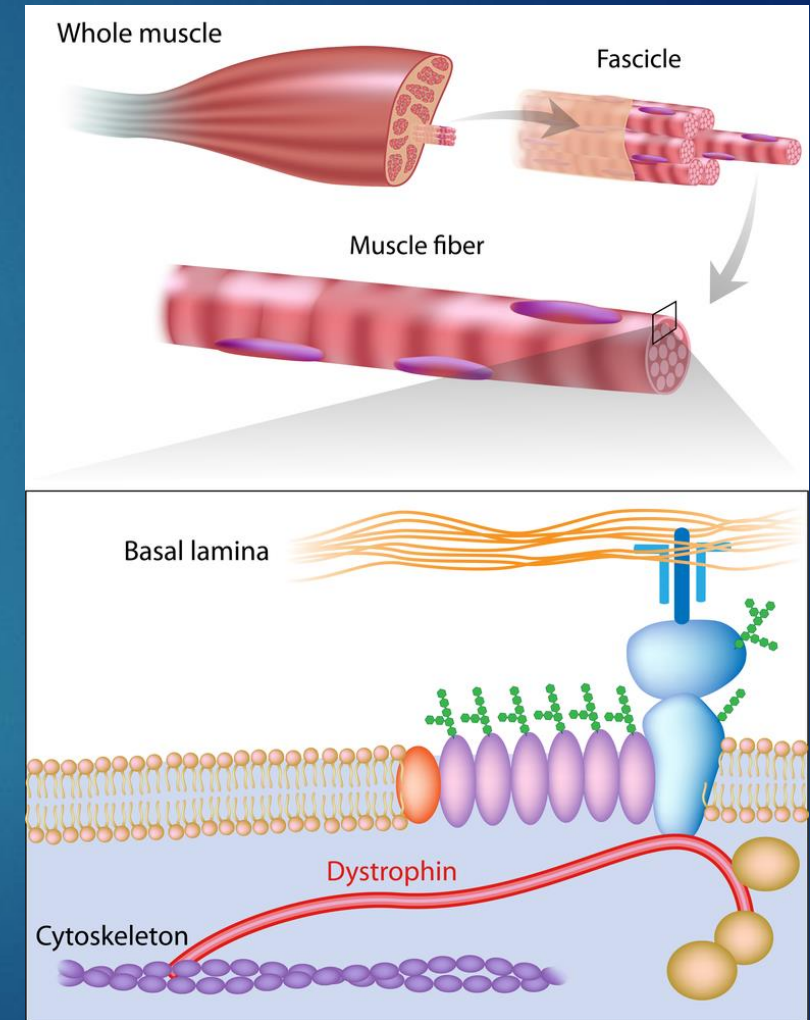
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Project DMD Overview



What is DMD ?

- Progressive muscle wasting disease.
- Characterised by muscle weakness & deterioration (Bushby, 2011).
- ▶ Increased physical dependence at a time of expected increased independence. (Abbott, Carpenter & Bushby, 2009).
- ▶ Loss of typical adult roles due to progressive nature of condition.
- ▶ Life expectancy increasing due to advances in medical treatment. (Wagner et al, 2007)



Plant the seed early on - Create conversations about adulthood



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A photograph of a winding asphalt road with double yellow lines, curving through a dense forest of tall evergreen trees. The road is dark and appears slightly wet, with a red curb on the inner side of the bend. The forest is lush and green, with sunlight filtering through the canopy.

Planning for an unknown future: What's around the bend?

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Sharing what's possible.



Taking a team approach

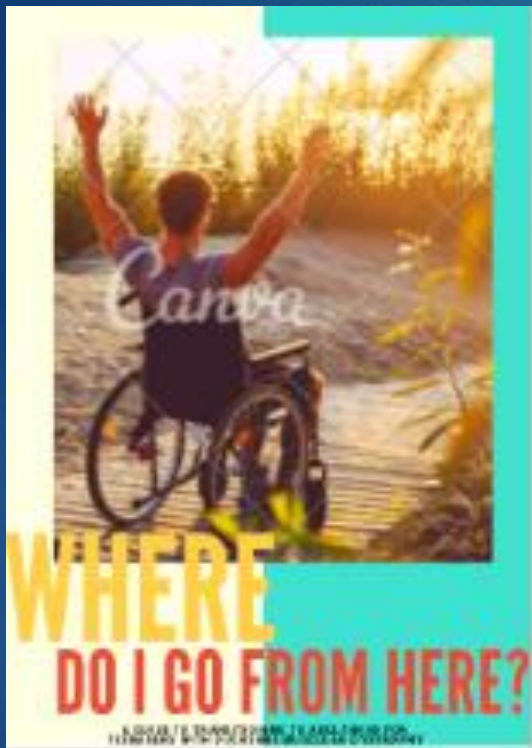


Redefine adulthood : Individualise key milestones.



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Tool Development



Transition Planning Booklet



Life Profile Videos



Transition Planning Tree Tool

Where to now?

- ▶ Currently recruiting for Phase 3 of the project.
- ▶ Young people with DMD aged 14 to 18 years of age.
- ▶ Locations – QLD - Brisbane, Gold Coast, Sunshine Coast, Toowoomba regions.
- ▶ Participation - 2 x interviews & 2 x Skype calls + utilization of provided transition to adulthood resources.
- ▶ Contact me for further information or to participate.



Questions ?

References

- ▶ **Abbott, David., John Carpenter and Kate Bushby. 2009. “Transition to Adulthood for Young Men with Duchenne Muscular Dystrophy and their Families: Final Report to the Department of Health”. Department of Health Policy Research Programme. School for Policy Studies, University of Bristol. <http://www.scie-socialcareonline.org.uk/transition-to-adulthood-for-young-men-with-duchenne-muscular-dystrophy-and-their-families-final-report-to-the-department-of-health/r/a11G00000017sSCIAY>**
- ▶ **Bushby et al, (2011), Diagnosis and management of Duchenne Muscular Dystrophy: Part 1: diagnosis and pharmacological and psychosocial management, Lancet Neurol, published online Nov 30, DOI:10.1016/S1474-4422(09)70271-6. pp. 1-17**
- **Wagner et al, (2007), Current treatment of adult Duchenne muscular dystrophy, *Biochimica et Biophysica Acta*, 1772, pp. 229-237.**