

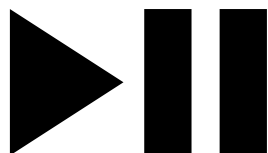


# Research Report: Entering Adulthood with Duchenne Muscular Dystrophy



**This is an Easy Read report made by Pathfinders Neuromuscular Alliance in November 2023. It's about becoming an adult with DMD.**

# Pause and check before reading the report



1. **Duchenne Muscular Dystrophy (DMD) is a condition we are born with. It is caused by the lack of a protein called dystrophin. Dystrophin helps to keep our muscles strong.**
2. **Being confident means that you feel positive about yourself and believe that you can do things.**
3. **When we say "Pathfinders" we are talking about the organisation called 'Pathfinders Neuromuscular Alliance'.**



# About Pathfinders

Pathfinders is a group for people with muscle weakening conditions.

This includes DMD and other types of muscular dystrophy.



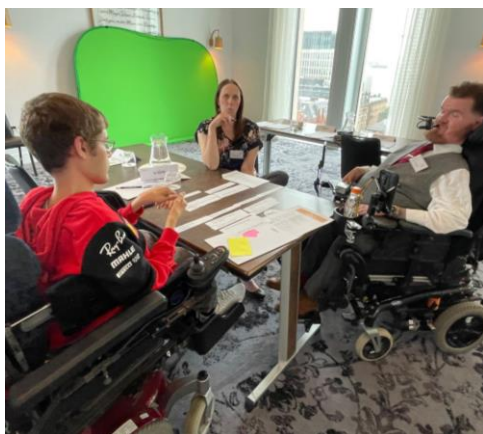
Some of the staff and Peer Researchers who work at Pathfinders have DMD.

The role of a Peer Researcher is to find out about important issues by doing research.

# About the Research



**The Pathfinders' Peer Researchers designed a research project about what it's like to become an adult with DMD.**



**They asked 15 different young adults with DMD about their thoughts and feelings about adulthood.**



**Pathfinders' Peer Researchers and university researchers wrote reports about what they found. This is the Easy Read report.**

# What did people tell Pathfinders?

There were lots of good parts in the young adults lives such as powerchair football, friends, music and gaming.

They also said about what they would like to change about themselves and the world.

## Education:

Some enjoyed learning and meeting new people, but others said they felt left out of education.



## Employment:

3 people had a job. Other people said they would like to get a job. But they didn't know what jobs they could do.



## Barriers:

But there are lots of difficulties (like buildings without ramps or lifts), that make it harder to meet people.

## Feelings:

Sometimes having DMD was difficult to get used to. At times they felt angry.



## Having control:

They thought having choice about care and their future is important.



## Confidence:

Being more confident would mean they could be involved in education and social activities.

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## Staying in touch with others:

They said staying in contact with friends can make you feel good about yourself.



# What needs to be changed to help people with DMD?

1. More emotional support should be available.



2. Children and young people need help to become confident.



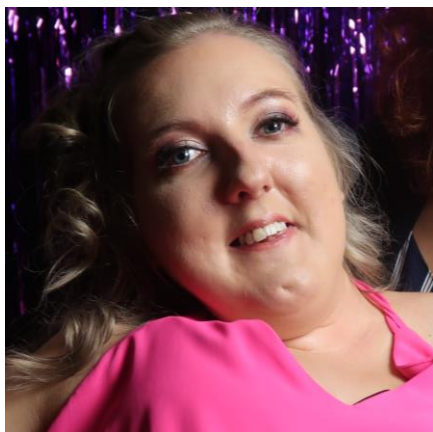
3. The Government, schools and NHS should listen to the thoughts and feelings of young adults about their care and support.



4. There should be more support to get personal assistants and assistive technology.



# How to find out more



Chat with Research Officer, Suzanne. She can tell you about how you can get involved in research.

Email:  
[suzanne@pathfindersalliance.org.uk](mailto:suzanne@pathfindersalliance.org.uk)



This easy read booklet was made by Dr Suzanne Glover (photo above) and Brendan Casey who has DMD.

## General Information



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Read the full report on our website by scanning the QR code on your camera.

