

Muscular Dystrophy

Condition:

Muscular Dystrophy (MD) is a complex term that covers a wide range of muscle wasting conditions.

These conditions cause muscles to weaken and waste over time, leading to increasingly severe disability. They are part of a group of genetic conditions caused by 'mutations' in the genes, sometimes known as 'genetic faults'. In some cases, the mutation is passed from the parents to their children, while in others the condition is caused by a new mutation. Some conditions affect the heart muscle and vital breathing muscles too.

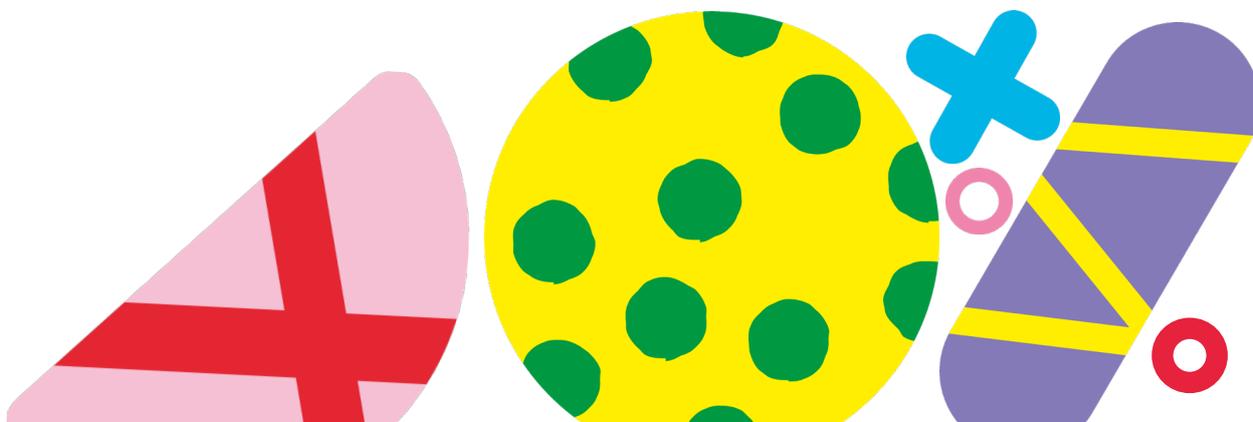
There is currently no cure or effective treatment for muscle wasting conditions, however research is progressing. There have also been many recent and ongoing advances in the management of muscle-wasting conditions.

Problem Areas:

- The many muscle wasting conditions that come under MD can affect children and young people in different ways. It is a progressive condition, so even two children or young people with the same kind of muscle wasting condition may be at different points on the journey.
- They may lose the ability to walk, or if they are still walking, they may tire much more quickly and have painful legs after activity. This can be more acute later in the day.
- They might struggle with other motor skills like writing, changing clothes, etc.
- Some children or young people with muscle wasting conditions may also have learning difficulties, although these are not directly connected to MD.

Support strategies for your Group:

- Children or young people with a muscle wasting condition may have been given some stretches and exercises to do that help to maintain a good balance of movement in their joints and reduce discomfort. Maybe have occasional 'activity breaks' and get all of the group to join in with these stretches and exercises together!
- If a child or young person with a muscle wasting condition is experiencing cramps or muscle pain, applying warmth to the area, or gentle massage, can help.





- Ensure the right balance between activities and rest. This is known as ‘pacing’ or ‘energy management’.
- Let young people communicate when they need to stop and rest and give them space to do this.
- A child or young person with a muscle wasting condition may need to use a wheelchair, so ensure that you carry out an accessibility audit to check that they can enter and move around the building easily.

Further information:

Muscular Dystrophy UK <https://www.muscular dystrophyuk.org>

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‘Invited to Belong’ has been developed in partnership between Urban Saints and Youthscape.



Youthscape

www.urbansaints.org/invitedtobelong