My name is:

My condition is:

Thank you for reading my DM support plan 😊

Cure Myotonic Dystrophy
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THIS IS AN EXAMPLE

Miles the Lion Pen Picture
Last updated – 18/07/2026

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Name: Miles the Lion

Date of Birth: 15th September 2015

Contacts:
-Mrs Miles (mum) 07000 123 456
-Mr Miles (dad) 07000 456 123
-Millie (sister) 07000 111 222
-Mr Dave (PA) 07000 333 444

Medical:
-Dr White, Neuromuscular paediatric consultant, Royal White Hospital (RWH), London, 0101 111 222, drwhite@example.org.uk
-Dr Black, Paediatrician, Royal White Hospital (RWH), London, 0101 999 888, drblack@example.org.uk
-Mrs Yellow, Care Advisor, Royal White Hospital (RWH), London, 0101 555 666

Miles is very happy and cheeky, he loves to dance and visit the zoo!

Strengths, Interests & Hopes

Miles is very happy and chatty. He loves visiting the zoo and can talk about lots of different animals including their names and the noises they make. He lives at home with his mum, dad and sister. Miles is very cheerful and loves to be out exploring or in the garden. Miles needs some support with toileting, walking and eating but can do most things independently. He loves to sing, and his favourite song is ROAR by Katy Perry. He is happy to talk about his condition but only has a very basic understanding. He loves younger children, playing with them and making them laugh. When Miles is well, he loves to explore and might need reminding to sit down and relax. He also loves going to the cinema to watch films and his favourite film is Lion King.

Miles has Congenital Myotonic Dystrophy Type 1

Myotonic Dystrophy is multi-systemic and life-limiting, the main and most serious problems being respiratory & cardiac. It is a progressive, degenerative muscle wasting disease that affects the whole body, including the central nervous system and cognition.

Symptoms Miles currently show are:

-Muscular – Miles suffers with low muscle tone in his legs and gets tired quickly when walking and exercising. Miles suffers with Myotonia in his hands when writing/drawing.

-Cognition – Miles is 10 and is working around age 4-5 for his cognitive abilities. He is able to read some simple words and enjoys counting. Miles hasn't got any perception for danger and has to be watched carefully near roads and when outside.

-Miles finds it difficult to express his emotions sometimes and can get dysregulated quickly. Things that help are sensory toys, fidgets, his weighted blanket and snacks.

-Speech – Miles can sing and say some words but prefers to use sign, Makaton or his AAC device to communicate. He also has a hearing aid, so ensure this is on and connected and use good practice when speaking so he can hear you and you are on his level.

-Toileting – Miles is potty trained but can sometimes have accidents. He has to be reminded to use the toilet often and can get distracted which makes him have accidents. Miles also take Movicol to help him go to the toilet.

-Sleepiness – Miles can get very sleepy even if he has a good night sleep. It takes him a while to come around in the morning and may need a nap on busy days. Encouragement to relax is really important for him.

Fears, Challenges & Dislikes

-Miles does not like busy environments and can get overwhelmed with the noise and the amount of people. This can cause him to run away and hide. He likes to wear ear defenders.

-Miles finds concentrating for long periods of time a challenge and is needed to have brain and movement breaks.

-Dysregulation can occur a lot and sensory snacks can help – anything cold like an ice pop or drink or something cold and crunchy like fruit (watermelon, apple, cucumber).

-Miles does not like spiders and is very scared of them.

-Miles can get nervous sometimes when in hospital or when he needs to have injections. Talking to him about things he enjoys, included in this profile, will help to build a relationship with him. He loves stickers and having a play with safe equipment.

Things That Help

-Reminding Miles to use his walking aid or stick when needed and to rest.
-Using simple language to explain what is happening and ensuring he is understanding 'now and next' steps to aid transition.
-Miles loves his family very much so talking about them or looking at pictures in his special family book will help him to stay regulated.
-Remind him to regularly eat and offer him juice. Often his dysregulation occurs when he is hungry, Miles prefers to snack on his safe food, and he loves orange juice/squash.
-Ensuring Miles has his AAC device when communicating, and that his hearing aid is on and working, will aid regulation.
-If Miles is feeling poorly, he will want to go to sleep and watch a film on his iPad.
-Miles is very playful and happy, please do be as playful and happy as you can be with him. He does not understand much humour or sarcasm so please be mindful of literal language and his cognitive age and ability.

Diet

-When Miles is very poorly, he will not eat and sometimes might need encouragement or an NG tube to be fitted when he is in hospital.
-Miles does have a good diet and a safe swallow but he must use his special cup or a bendy straw when drinking.
-Miles has a list of 'safe' and 'maybe' foods in his health care folder. Please make yourself familiar with this list and only offer unfamiliar foods when family is present and he is feeling healthy and well.
-Miles still has all his food cut up for him but is able to use a spoon and a fork independently.
-Miles has smaller and regular meals to aid digestion and will not eat a lot all in one go. He prefers to graze and snack during the day.
-Miles has no allergies or intolerances.

Medical

Congenital Myotonic Dystrophy is a very complex medical condition, and Miles has a large team of supporting medical professionals around him. If you are concerned or have questions, please seek advice first from the details provided.

-Miles has a limited immune system and the common cold or flu will make him very poorly. Please listen to him and his family if he is reporting he is unwell. It takes a lot for Miles to say he is poorly so you must listen to him.

-**NO OPIATES LIKE MORPINE** Even very small doses are likely to cause respiratory distress for patients with DM.

-GENERAL ANAESTHETIC IS VERY DANGEROUS FOR DM PATIENTS please contact his neuromuscular consultant and familiarise yourself with emergency protocol from this pack or the CureDM website..

-MEDICATION 2 sachets of Paediatric Movicol daily in water and cordial.

CureDM - It is important to remember that this form can be used for emergency medical interventions but also can be used when attending first appointments with new healthcare providers. It is helpful to have a copy in meetings, at schools and colleges, or for family and friends. This profile is not just about the condition but the PERSON too, and it should highlight key facts with a personalised focus on the person being cared for, and HOW it affects THEM. Ensure to have up-to-date details for your medical specialists so they are contactable when needed. If you need any advice or have any questions relating to this pen profile form, please contact the charity and we will be happy to help. We recommend you update the form regularly as things change.

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