

# IT'S HARD TO TALK HELP SHEET



## Background

When people have Machado Joseph Disease (MJD) they find it hard to talk. When it starts, it is just a bit slurred when they talk. But then it gets worse.

It is important to remember they can still think the same. The MJD stops their muscles working in their neck and throat.

## Staying Stronger for Longer

Like any muscle, you can exercise your speaking muscles to keep them stronger for longer. You can have fun at home with these exercises in your family. Talking loud and singing are things you can do together.

Other things to help

- Alphabet or Photo boards
- Sign language
- Blinking of the eyes
- Pointing
- Writing notes or Texting
- Apple iPad



## Communication Tips

- This MJD does not affect the brain. You can still think about things the same as before.
- Sit down next to the person and take a lot of time to talk.

- When lots of people are talking or there is lots of noise (loud TV or music) it can be harder. Talk just with that person if you want to understand them.
- If the person uses something to help them talk (like an iPad or alphabet board), make sure it is close by and ask them to use it.
- People with MJD can feel shamed, sad or angry when people do not understand them. Think about how you would feel if you had MJD. This helps you to take more time with the person.

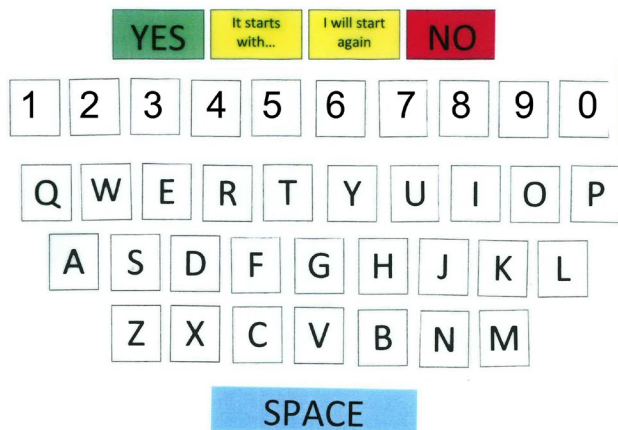
## Does the person with MJD use an Alphabet Board?

### Tips - Using an alphabet board:

- Say each letter as the person points to it.
- Wait for the person to finish spelling the word before you say the word – don't jump ahead and guess.
- Only say the name of the letter when they have pointed to it.
- Ask the person to use the space bar and other buttons at the top of the board (like Yes No).
- When they point to the space bar, say the whole word out loud.
- Recap the message (say the words in the sentence so far) as you go.
- Repeat the whole message at the end.
- If they have spelled something wrong– at the end of the message (so you don't stop their message or chain of thought) – show them the correct spelling of that word so that they can learn.
- Write down their message if you can.

The MJD Foundation is working to make alphabet boards in different languages – Anindiliyakwa, Kreyol, Yolŋu Matha, and Kunwinjku. If you would like to help, talk to someone at the MJD Foundation.

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Alphabet Board - English



Alphabet Board – Yolḡu Matha

## Who can I talk to if I have questions or concerns?

### MJD Foundation staff

Leah Clarke (Darwin) 0499 334 856

Jill Turner (Groote Eylandt) 0499 330 207

Mark Kilpatrick (Alice Spings) 0499 330 238

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Your Health clinic doctors, nurses and health workers.