

Safe feeding strategies for people with Machado Joseph Disease

*A handbook developed for the
MJD Foundation*



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Positioning for safe feeding

It is important to position people with swallowing difficulties appropriately to ensure safety at meal times. Correct positioning should be maintained during and after meal times.

During meal times



Sit upright in a comfortable position at 90 degrees

This reduces the risk of food going down into the airway.



Keep **head, neck and shoulders in line**

This position is the best for safe swallowing.



Tilt the person's **chin slightly downward**

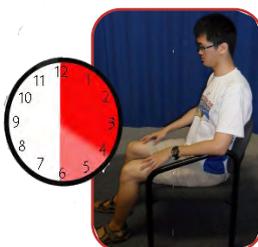
This protects the person's airway and ensures that the food goes down the right way.



Keep **food/drinks within reach**

This ensures that the person stays in a comfortable position for safe feeding without having to move too much.

After meal times



Remain **sitting upright** for **20 – 30 minutes**

This will make sure that the person will have enough time to swallow any food remaining in their mouth or throat.

Positioning for safe feeding

Strategies to ensure that the person is in a safe feeding position



Sit the person in a **chair with arms**

This will assist the person to position themselves.



Use pillows to support the person

This helps the person to maintain an upright and straight position.



Find the best way to **stop the person's head from moving**

Placing pillows behind the head will help keep it still.

Eating environment

The eating environment also has an **impact on a person's ability to eat safely**. A **quiet and relaxed** eating atmosphere will help with swallowing. Having **good lighting** will ensure that all food items can be seen.

Fatigue and stress

Fatigue and stress **worsen a person's ability to swallow**. **Avoid feeding** the person when they are **tired, upset or stressed**. When the person is tired, allow the person to **have short breaks** before going back to eating. Ensure that the person is **not talking** while they have food or drinks in their mouth.

Signs and symptoms of feeding problems

When **food goes down the wrong way**, it can **enter the lungs** (known as **aspiration**) or **become stuck** somewhere along the airway. If food enters the lungs, it may **lead to aspiration pneumonia** which can be potentially life-threatening.

When food has completely **blocked the airway**, this is an **emergency situation** as the person will be **without oxygen**. It is important for actions to be taken to deal with this as their **life is in danger**.

Signs that eating is not going well

These signs show that food may have entered the airway



Gurgly voice when trying to talk and **noisy breathing** sounds.

A gurgly voice sounds like you are gargling water while talking.

Noisy breathing means that the person's breathing sounds louder and rougher than usual.



Coughing or **gagging** when eating.

If the person coughs often, check if they are coughing more than usual during meal times.



Feeling like **food is stuck** in the throat

The person may tell you or try to show you that it feels like food is stuck.

Signs and symptoms of feeding problems

These signs show that food may have blocked the airway



The person's **face may change colour**

Without air, the person's face and lips may turn blue or purple.



The person may **not be able to talk**

Ask the person to say something to check if they can talk.



The person may **have serious difficulty trying to breathe**

If the person is gasping loudly, this may mean that they can't breathe properly.



The person may **become unconscious**

This means that the person has been without oxygen too long and they are in serious danger.

If you see **any signs that the person's airway has been blocked**, you should **seek help from trained personnel**, like nurses, so that they can **begin emergency procedures**.

If the person's life **continues to be in serious danger**, they may even have to go to **hospital for further medical assistance**.

Signs and symptoms of feeding problems

What you can do if you see any signs of difficulty



Stop all feeding and eating

This means that you should stop feeding the person & you should stop the person from eating if they are feeding themselves.



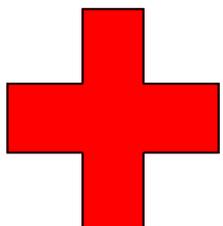
Encourage the person who is having difficulty to **cough strongly**

If the person who is having difficulty coughs strongly, this will help them to clear any food that is stuck in their airway.



Keep the person **sitting** upright and let them **rest for at least 20 minutes**

You may need to refer to the 'Positioning for safe feeding' section for instructions.



Get more help from someone else

If it is an emergency, you may need to get help from a nurse or other trained staff.

Meal time safety

It is important to **follow** the ‘**Meal Time Safety**’ poster **every time** you feed someone. This will help to **reduce the risk** of food going down into the airway for someone who has swallowing difficulties. The following information explains each step of the poster and why they are important to follow in order to **make mealtimes as safe as possible** for the person.

Before feeding check



Is the person **awake and alert**?

It is important for the person to be fully awake and aware that they are going to eat or be fed. It is not safe to feed a person if they are not able to be fully awake for the whole meal.



Does the person **want to eat**?

If the person says that they are not hungry or is refusing to eat, this means that their body will not be ready to eat safely. Try again later when the person is showing that they want to eat.



Wait until the person is **fully awake and alert** and **wants to eat** before feeding them

If possible, allow the person to feed themselves. This will help them to be more aware of the food going into their mouth and stay alert when eating.



Remember!

Make sure the person is awake and alert.

Ensure that the person is actually wanting to eat.

Allow the person to feed themselves if they can.

Meal time safety



Is the person **sitting correctly**?

The person must be positioned correctly before being fed and must be able to sit correctly for the whole meal. Refer to the 'Positioning for safe feeding' section for more information.

It is **not safe** to feed someone if they are **not sitting correctly** as they are at risk of having **food go down the wrong way**. Wait until you can **position the person correctly** before feeding them.



Remember!

Make sure the person is sitting correctly before and during the meal .

Safety during the meal



Does the person **cough or choke** during the meal?

This is a sign that the food may be going down the wrong way. There are some things that the person could be doing that are making them cough or choke.



Talking or laughing makes eating harder

This disrupts your normal swallowing and breathing pattern. It is important to stop the person from talking or laughing when there is food or drink in their mouth.

Make sure they have swallowed their mouthful safely before talking.

Meal time safety



Taking **large mouthfuls** may cause food to go down the wrong way.

Make sure the person takes only small mouthfuls so that they can control the food or drink and swallow it safely.



All food must be clear from the person's mouth **before** they have the **next mouthful**.

This is so there is not leftover food which the person can choke on after swallowing, when they are breathing normally. This also ensures that there is not too much food in the person's mouth when they aren't able to control it.

Feed the person slowly with only **one mouthful at a time**.

If the person is **feeding them self** make sure they **go slowly**.

Check for a **clear mouth** between each mouthful.

Giving the person a **drink of water** may help them clear their mouth.



Remember!

Stop the person from talking or laughing when they have food or drink in their mouth.



Make sure the person takes or is given small mouthfuls.



Make sure the mouth is clear of food before giving the next mouthful.

Meal time safety

Safety after the meal



Keep the person **sitting upright for 20-30 minutes** after they have finished eating

This will ensure that the person will have enough time to swallow any food remaining in their mouth or throat.

This also stops food that has already been swallowed from coming back up.



Make sure that the person's **mouth is clean** after they have finished eating

When people have difficulties swallowing, it is important to keep their mouth clean. If food and bacteria build up in a person's mouth, and it goes down the wrong way next time they are eating, they are more likely to get sick.

Here are some tips to keep the mouth clean



Every **morning and night, brush the person's teeth and gums.**

Everyone should brush their teeth and gums at least twice a day to keep their whole mouth clean and healthy. Make sure that all of the toothpaste is cleaned out of the mouth.



(Medisave UK Ltd, 2007)

Use a big **cotton or sponge mouth swab dipped in some water** to clean the person's mouth out **before and after eating.**

Make sure the swab is not too wet.



(Dynamic Living Inc, 2010)

Before eating, this may help the person produce more saliva, making eating easier.

After eating, this will help people who have difficulties swallowing to clear any leftover food from their mouth. This makes sure that any food does not go down the wrong way after they've finished eating, and stops bacteria from building up.

Changes to food and drinks

Why make changes to foods?

People who have **trouble swallowing** may have some **difficulty with drinks and/or food**.

Eating and drinking then becomes a challenge and **modifications to normal food and drinks may be required**. Swallowing difficulties can make it hard to take in enough food and drink to keep the body healthy.

To begin eating, you **bite off a piece of food and chew it**. Chewing **mixes the food** with saliva. **Saliva softens the food** and makes it wetter **to let the food go down** easily. Saliva also **holds pieces of the food together** so it goes down in **one piece**.

The **tongue helps move the food around** the mouth to make sure it **mixes evenly** with saliva. The **tongue shapes the mixed food into portions** to be swallowed. The **tongue pushes these portions of food to the back** of the mouth. When the food is **pushed back past a certain point**, it **triggers swallow muscles** in the throat. These muscles **move the food down** into the person's stomach.

People can have a **swallowing difficulty because they have weaker mouth and/or throat muscles**. Their **lips may not close** tightly enough. Their **tongue may not be strong enough** to move the food around the mouth to mix with saliva. Moving their **mouth and tongue muscles may make people tired**.

Softer foods need **less chewing** and use **less energy**. It breaks down into **small pieces easier**. **Wetter foods move around the mouth better** and the tongue can do **less work**. The food also **sticks together better** and **less saliva is needed** to make the food easy to swallow.

Drinks are different from food because drinks are **swallowed much faster**. Drinks like **water and tea move the fastest**. **Thicker drinks** like milkshakes are **easier to swallow** because they **flow slower** in the mouth. Drinks that **flow slower are easier to control** in the mouth and allow the person to **keep the drink in their mouth before the swallow muscles trigger**. This prevents the drink going down the wrong way.

Changes to food and drinks

When a person has problems swallowing, the **different types of food** may make **eating easier**. **Soft foods** are **easier to chew** and swallow. **Less energy** is needed to eat them. **Most foods can be changed** to make it easier and safer to eat.

Types of Foods



Tough or dry food is harder to eat. It needs **more chewing**

An example could be steak or potato chips. These foods need lots of sauce or to be cut into very small pieces before the food can be easily swallowed.



Soft foods are easier to eat

Foods like shepherd's pie and cottage cheese are called soft foods. They have been chopped into small pieces, or are wet enough to stick together easily. They can be eaten with a with a fork.



Easiest to eat are foods like **yogurt or mashed potatoes**

They stick together well enough to be picked up with a spoon. These foods have their different parts well mixed together and do not separate. They should not be lumpy or runny.

The **same foods** that you eat can also be **cooked differently** to make them **softer and easier to eat**. For example, **fish can be steamed** instead of crumbed and fried. Or **beef may slow-cooked in a casserole**, rather than being a large piece of steak.



Changes to food and drinks

Difficult Foods



Food like **peas, corn and rice** should be fed carefully to people with swallowing difficulties

They can fall down the back of the mouth and get caught in the person's throat.

Food like rice can be cooked with more water to make it stick together better and this will make it easier to eat.



Dry food that becomes sticky when wet, like bread can also be **difficult to eat**.

They can stick in the person's throat. Removing hard bread crusts and adding spreads will make it easier to swallow.

Foods like **cereal with milk** and **canned fruit with syrup** that have both **solids and liquids** can be **difficult to control** in the mouth.

This is because the solid and liquid need to be separated in the mouth before they can be swallowed.

Some of these foods, like the canned fruit with syrup, can be blended and mixed to become easier to eat.

Others, like the cereal and milk, should be left to soak and become soggy, so that they can be mashed together to make it easier to eat.

This is the reason why people need to be careful when giving tablets with water to people who have swallowing difficulties.

Changes to food and drinks

Types of Liquids

In the mouth, soups and drinks behave differently from food. The tongue controls how the liquids travel to the back of the mouth. This is important to remember when feeding people with swallowing difficulties. Here are some examples of liquids and the utensils that can make drinking them easier. For further examples, see the utensil section of this book.

Thin liquids are **hardest** to drink. They flow **quickly** and need more muscle control to stop it going down the wrong way.

Examples include water, broth or tea. These liquids should be given in smaller sips. A one-way straw can be used to make sure people do not get too tired while drinking.

Thicker liquids are **easier** to drink. They flow more **slowly** and give the person more **control** over the liquid in their mouth.

These include drinking yoghurt, custard, cream soups and tomato juice. They should still be given in small sips. These liquids are harder to drink with a straw.

The easiest to drink liquids are very thick and do not run.

Liquids like thick milkshakes and pudding are thick enough to be picked up with a spoon. These liquids cannot be drunk through a straw.

Difficult Liquids

Care should be taken when giving liquids like thick milkshakes to people with swallowing difficulties, if they have small pieces of ice in them. **Drinks with ice in them can melt** if it stays in the mouth for too long. This **makes a thick liquid thinner**.

Liquids with lumps such as vegetable soup contain **solid pieces making it difficult to control** in the mouth. They **should be blended** so that they are easier and safer to eat.

Safe feeding utensils

There are a **number of utensils that have been modified** for special use by **people who have difficulties swallowing**. Each is designed for a particular difficulty. Below are **some examples of utensils** that can **assist feeding** and utensils that **can assist drinking**. Some would be appropriate for people with MJD. While it is **important to be aware of these utensils and why they are used**, they do not have to be used with everyone.

MAROON SPOON



A **Maroon Spoon** is a special kind of spoon **designed for people** who have **difficulty closing their lips**, or have **weak muscles** in their mouth.

Using a Maroon Spoon makes it easier for the person to get food and drink off, because the spoon is more shallow than a regular spoon.

A normal teaspoon can also be used to make feeding safer and easier. A teaspoon will help the person get the food off the spoon, and to take smaller mouthfuls.

ONE-WAY STRAW



One-Way Straw drinking is best for people who **are able to close their lips together** but **get tired easily** or have **weak muscles** in their mouth.

It will be easier for these people to drink through a one-way straw as the drink will stay in the straw between sips. This means that less effort will be required to suck for each mouthful.

The person will also be able to have better control of the amount of drink in their mouth.

CUT OUT CUP



A **Cut Out Cup** is best for people who **may be slumped over** and have **difficulty lifting their head up** to drink.

A cut out cup can be home-made from a Styrofoam cup (see next page).



The cup is made so that the person does not have to tilt their head back to drink all of the liquid, and the cup will not hit their nose.

Please see our utensil kit for samples of the utensils mentioned above. We purchased these products online from the following websites:

- *Speech Therapy Shop - <http://www.speechtherapyshop.com> (Click 'Eating & Drinking' category)*
- *Sense Abilities - <http://www.senseabilities.com.au> (Click 'Oral Motor' Category)*

How to make a Cut Out Cup

If the person you are feeding **needs to use a cut out cup** and you do not have **one**, here are some **simple steps to make one**.

MATERIALS YOU WILL NEED:

A **Styrofoam cup**

A **pen** or marker

A pair of **scissors**

STEP 1:

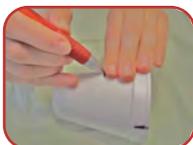


With your **pen**, mark **the top of the cup in the middle on each side**.



Your markings should be **straight across from each other**.

STEP 2:



In **between your markings**, measure with **2 or 3 fingers down** from the top of the cup, and make another marking

STEP 3:



Draw a **curved, dotted line** to join your 3 markings, **making a 'D' shape**

STEP 4:



With your **scissors**, **cut along the dotted line**, until there is a **'D' shape** from the cup

STEP 5:



You now have your **Cut Out Cup!**

Get the person try to drink from the cup, with the **'D' shape** facing away from them. If the cup hits their nose or they have to tilt their head back, you may need to cut a deeper **'D' shape**.

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