Dysphagia supports

Quick summary: The Australian health system provides treatment for dysphagia for everyone. We can only fund dysphagia supports if they're related to your disability. We may fund dysphagia supports if your disability means you have trouble eating, drinking or swallowing.

Dysphagia supports might include special cutlery or thickener products to help you eat. They may also include a speech pathologist to make a plan, so you can eat and drink safely. If you need someone to help you to eat or drink safely, we may be able to fund that as well.

Note: When we say 'your plan' we mean your NDIS plan. If you're looking for information about Community Connections, go to Our Guideline - Community connections.

If you're looking for information about your child's early connections, go to <u>Our Guideline – Early connections</u>.

What's on this page?

This page covers:

- What do we mean by dysphagia supports?
- What help can you get to manage your dysphagia through the health system or other system?
- How do we decide what dysphagia supports we fund?
- What types of dysphagia supports do we fund?
- How do you get dysphagia supports in your plan?
- What happens once you have dysphagia supports in your plan?

You might also be interested in:

- Disability-related health supports
- Nutrition supports including meal preparation
- Mainstream and community supports
- Would we fund it guide Home enteral Nutrition.

What do we mean by dysphagia supports?

Dysphagia is the medical word for when you find it hard to or can't swallow. It can mean you have trouble eating, drinking or swallowing daily.

Anyone of any age may experience dysphagia, including young children. You are more likely to experience dysphagia if your disability affects your brain, spinal cord or nervous system.

If you have dysphagia you should talk to your doctor first. They can link you to health services that are paid for through Medicare. You can continue to access health services from Medicare, even when you are a NDIS participant. Learn more about the help you can get through the health system or other services.

Dysphagia supports are what we call disability-related health supports. We can only fund these supports if they directly relate to your disability and help you undertake activities involved in day-to-day life. Learn more about what we mean by disability-related health supports.

Dysphagia supports we may fund include:

- low-cost assistive technology this means equipment, technology, or devices to help you eat and drink
- thickener products
- help to prepare specific foods which you can safely eat
- a support worker to help you eat or drink safely if you can't do this yourself because of your disability.

To help you manage dysphagia, we may also fund a speech pathologist to:

- make a mealtime management plan, sometimes called an oral eating and drinking care plan, which describes how you can eat and drink safely
- train your support workers, family or carers in your specific disability-related dysphagia support needs.

We don't fund:

- supports that aren't directly related to your disability for example, temporary dysphagia caused by a short-term illness or surgery, not your disability
- supports you get through the education system, like a teacher who supervises you to eat and drink safely while at school
- supports for dysphagia while you are in hospital the health system is responsible for this.

The health system is also responsible for any tests to diagnose dysphagia.

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What help can you get to manage your dysphagia through the health system or other services?

Government and community services must ensure all Australians, including people with disability, have access to their supports. We call these supports mainstream and community supports. The NDIS was set up to work alongside government and community services, not replace them. Learn more about Mainstream and community supports.

What help can you get through Medicare?

Medicare helps all Australians with the costs of their health care. Medicare will help pay for services to test for and diagnose health conditions, such as dysphagia. Medicare is also responsible for providing support for dysphagia while you are in hospital. Remember, if another service is most appropriate to fund dysphagia supports for you or they are not related to your disability, we can't fund them.

You may also be able to get short term access to a speech pathologist through Medicare. If your dysphagia gets worse, your speech pathologist or doctor will arrange for you to have tests. The health system is responsible for this. The tests will help to work out what treatment you might need, including if you need to go to hospital. For example, if you develop pneumonia because of dysphagia. The health system will fund these tests and your supports while you are in hospital.

If you don't have dysphagia but are at risk of developing it, your doctor or allied health professionals will keep an eye on that. If they think you may have dysphagia, they'll send you for tests in the health system to confirm this.

If you or the people that help you notice any changes in your ability to swallow, you should tell your doctor or speech pathologist.

Learn more about Medicare.

What can you get through the Pharmaceutical Benefits Scheme?

The Pharmaceutical Benefits Scheme funds some products you may use for dysphagia, including nutritional drinks and supplements. If you can get what you need through the Pharmaceutical Benefits Scheme, we won't fund it.

Learn more about the Pharmaceutical Benefits Scheme.

How do we decide what dysphagia supports we fund?

All NDIS funded supports must meet the NDIS funding criteria.

Dysphagia supports are one type of disability-related health supports we may fund.

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Generally, if you have dysphagia which is ongoing and directly related to your disability, we can fund dysphagia supports for you. We will need evidence to support this, such as reports or assessments from a speech pathologist.

Learn more about how we decide what disability-related health supports we fund.

What types of dysphagia supports do we fund?

What if you need a speech pathologist for your dysphagia support needs?

A qualified speech pathologist must provide some dysphagia supports. You may be able to get short-term help from a speech pathologist through Medicare. We may fund a qualified speech pathologist if you need:

- a mealtime management plan to be prepared or reassessed for you
- swallowing therapy intervention
- a speech pathologist to train the people who support you, such as a support worker, family member or carer.

We can only fund these supports if they relate to the things you can and can't do because of your disability.

The speech pathologist can train the people who support you in each place you normally attend. For example, your home, work, day program or school. Learn more in What if you need someone to help you eat or drink?

Your speech pathologist may also recommend <u>low-cost assistive technology</u> or <u>thickener products</u> to help you eat and drink.

What if you need a mealtime management plan?

Because of your disability, you may need a mealtime management plan to help manage your dysphagia. This may be called an oral eating and drinking care plan where you live.

A mealtime management plan describes how you can safely eat and drink during mealtimes. This may include recommendations on how to sit and hold cutlery to improve how you eat. Or you may need extra support to make sure food is the right texture to reduce the risk of aspiration or choking. Aspiration happens when you breathe objects into your airway, such as food or saliva.

A speech pathologist creates a mealtime management plan for you. They should assess you in the places where you usually eat. For example, your home, school, daycare, work, a family member or carer's house or at a day program.

Your speech pathologist should recommend how long it will take to complete these assessments, create the plan and write any reports you need. We will use this information to

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work out how much funding to include in your plan for the creation of a mealtime management plan.

Your mealtime management plan will need to be regularly reviewed and updated if your dysphagia support needs change. This will depend on how much your dysphagia affects you and if it is likely to get better or worse over time. Your mealtime management plan will say how often it needs to be updated. For each review of your mealtime management plan, we can fund a speech pathologist to reassess and update your plan.

Because of your disability, you may be at risk of not getting the nutrition you need. In this case, you may also need a dietitian to contribute to your mealtime management plan. A dietitian can recommend the foods you need to keep you healthy. If your speech pathologist recommends a dietitian, we may be able to include funding for a dietitian to assess you. We may also include funding for them to write any plans and reports you need.

Learn more about dietitian supports in Our Guideline on <u>Nutrition supports including meal</u> preparation.

Swallowing therapy intervention

A speech pathologist may recommend swallowing therapy to help you keep up or improve your swallowing function. Swallowing therapy aims to help you chew food, move food to the back of the throat, and strengthen the swallowing muscles.

Your mealtime management plan should include your swallowing therapy. This will include:

- the specific swallowing strategies or therapy techniques you need to use during mealtimes
- how often you need to do the swallowing strategies or therapy techniques
- whether you need a support worker or someone else to help you with the swallowing therapies.

Most people will be able to manage their dysphagia with a mealtime management plan. A speech pathologist will only recommend additional swallowing therapy for you if you need extra help.

You may need a swallowing therapy program when you're gradually changing from home enteral nutrition feeding to oral feeding. This is called a tube weaning program. The health system provides most tube weaning program supports. To learn more about home enteral nutrition, go to What if you need thickener products?

What if you need low-cost assistive technology?

Your disability may mean you need low-cost assistive technology to help you eat and drink as independently as possible. Low-cost assistive technology for dysphagia includes things like adaptive cutlery, plate guards, sticky mats and plugs to attach plates to a table.

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Low-cost items are easy to set up and use and are available from local suppliers or nondisability specific retailers.

If low cost assistive technology meets the <u>NDIS funding criteria</u> for you, we can include funding for it in your plan.

Learn more about low cost assistive technology.

What if you need thickener products?

You may need to see a speech pathologist to help you to manage your dysphagia. We may be able to fund a speech pathologist for your dysphagia support needs.

They might recommend thickener products which thicken food or fluids to help you to swallow, eat and drink safely. Thickener products can be added to most foods and drinks, so you can have a range of food and drink choices. They are the most cost-effective way to thicken food and fluids.

The amount of thickener you need will depend on the thickness of food or fluid your speech pathologist recommends. Your speech pathologist will assess how thick you need your food and drink to be. The International Dysphagia Diet Standardization Initiative Framework includes four levels of thickness for fluids. These are:

- slightly thick
- mildly thick
- moderately thick
- extremely thick.

The amount of thickener you need will also depend on whether you can take in food orally, which means through your mouth. Or if you feed through home enteral nutrition, also called HEN.

Home enteral nutrition is a different way of getting your food and drink at home. It is used when you can't eat or drink through your mouth. It can be a nutritional supplement drink, thickened fluids or a special formula given by a tube into the stomach or bowel.

You may also use a combination of oral and home enteral nutrition feeding. If you have a combination, you'll generally need smaller amounts of thickener. Your speech pathologist will describe this in the assessment report they develop for you.

Learn more about home enteral nutrition in Our Guideline on <u>Nutrition supports including</u> meal preparation.

You may have a **full oral feeding diet** or a **combination of oral and home enteral nutrition feeding.** In both situations we may include funding in your plan for:

Slightly thick fluids

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- mildly thick fluids
- moderately thick fluids
- extremely thick fluids.

We'll use reports from your speech pathologist to work out how much funding for thickeners to include in your plan. Your speech pathologist can use our Nutrition and dysphagia assistive technology supports assessment template or write their own report. This will include the amount of thickener product you need. We use this information to work out the reasonable and necessary funds to include in your plan.

You can also get pre-made thickened fluids. But there is only a small range and they cost quite a lot more. We generally don't include these products in the funding for thickeners in your plan. However, you may choose to purchase these products at a cost to you. You would need to think about whether pre-made thickened fluids are worth the extra cost to you.

What if you need someone to help you to eat or drink?

You might need someone to help you to eat or drink if you can't do this yourself because of your disability. This could be a family member, carer, friend or a support worker. If you need support from someone else, we may include funding for:

- a support worker to attend training for up to 2 hours per year on the specific dysphagia support needs described in your mealtime management plan
- training for the people who help you with your day-to-day dysphagia support and care.

We may also include funding for personal care hours for a support worker to help you with:

- your <u>mealtime management plan</u>
- <u>swallowing therapies</u> as recommended by a speech pathologist

How do you get dysphagia supports in your plan?

Do you need to provide us with evidence?

Yes. To get dysphagia supports in your plan, you need to give us evidence that helps us understand the disability related supports you need. Talk to your My NDIS Contact or support coordinator to work out what evidence we need. Learn more about the evidence we need before we create your plan.

You can give us any new information or evidence about your disability support needs when you get it or anytime we talk with you.

We will ask for your mealtime management plan or other reports or assessments prepared by your speech pathologist, if you have them. The plans or reports should explain how much support you need for your dysphagia. We'll also ask you what dysphagia supports you

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currently get. We'll want to know who you get the supports from, and how often you use them.

We'll use this information to decide if dysphagia supports meet the <u>NDIS funding criteria</u>. If they do, we'll work out the amount of disability-related dysphagia support to include in your plan.

Learn more in our Would we fund it guide – Home enteral Nutrition.

What if you don't agree with our decision?

If we decide dysphagia supports don't meet our <u>NDIS funding criteria</u>, we can't include them in your plan.

We'll give you written reasons why we made the decision.² You can <u>contact us</u> if you'd like more detail about the reasons for our decision.

If you don't agree with a decision we make about dysphagia supports, you can ask for an internal review of our decision.³ You'll need to ask for an internal review within 3 months of getting your plan.⁴ Learn more about <u>reviewing our decisions</u>.

What happens once you have dysphagia supports in your plan?

Once you have dysphagia support funding in your plan you can use it to get the disability-related dysphagia supports you need. Your plan will describe how you can use your funding to get dysphagia supports. We will also talk to you at your plan meeting.

If you need help to use the funding, talk to your My NDIS Contact or support coordinator.

Learn more in <u>Our Guideline - Your plan</u>. You can also go to <u>What happens once you have Disability-related health support funding in your plan?</u>

Reference List

¹ NDIS (Supports for Participants) Rules r 7.4.

² NDIS Act s100(1).

³ NDIS Act s 100.

⁴ NDIS Act s 100(2).