



SWALLOWING IN

NEUROMUSCULAR CONDITIONS

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**I acknowledge the Traditional Custodians of the
land on which I work, the Gadigal people of the
Eora nation. I pay my respects to Elders past
and present.**

TODAY...

- Swallowing – what it is and how it works
- What is a swallowing problem (dysphagia)
- Why swallowing problems are such a big deal
- NMCs and swallowing
- Why can swallowing go wrong?
- How do know if I have a swallowing problem?
- Aspiration and aspiration pneumonia
- What do Speech Pathologists do?
 - Oral hygiene/oral care
 - Texture modified diets and thickened fluids
 - Positioning and other strategies
 - Can exercise help?
- Medications
- When to see a Speech Pathologist
- Choking and aspiration emergency management

What I won't be discussing

- Speech / communication difficulties
 - Many neuromuscular conditions impact on communication
 - Communication problems need early, skilled assessment and management by a Speech Pathologist
 - There are several things Speech Pathologists can do to help communication difficulties
- Swallowing, speech, language, cognitive or social communication difficulties in children who have neuromuscular conditions
 - My experience is with adults, but many things are relevant to kids too

swallowing awareness day

Dysphagia: A difficult diagnosis to swallow

Thursday
16 March 2023



PEOPLE SWALLOW

700+

TIMES PER DAY

(ON AVERAGE)

Swallowing uses

26
muscles

More than
1 million
Australians
have difficulty
swallowing

A swallowing disorder may affect:

15-30% of people aged 65+ living in the community

50% of older adults in nursing homes

84% of people with Parkinson's disease

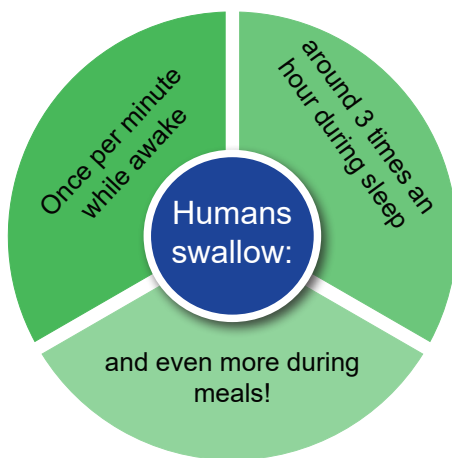
100% of people with Alzheimer's, at some point in their disease progression

20% of adults with mental health disorders

45% of patients with head and neck cancer, post chemoradiotherapy

40% of stroke survivors have an ongoing need for support for swallowing

25% of patients with Multiple Sclerosis have swallowing difficulties-increasing to as many as 65% of those with severe Multiple Sclerosis.



dysphagia

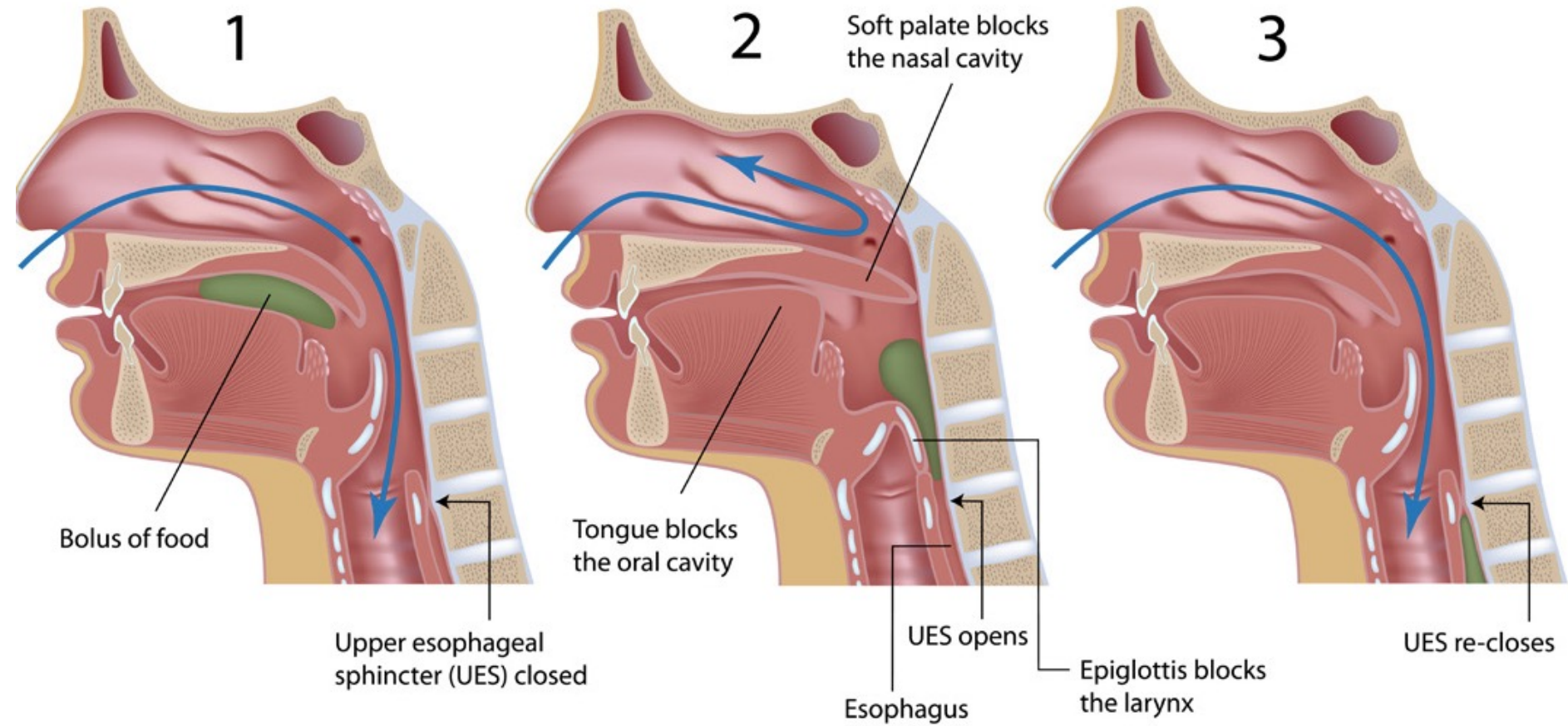


One in 17 people will develop some form of dysphagia in their lifetime.

Dysphagia

(dis-fay-juh)
noun, difficulty or discomfort in swallowing.

Swallowing



Normal & impaired swallowing

<https://youtu.be/fqG0QmlaFMs>

Source: Humbert (2020)

https://youtu.be/cUsBMb1ij_M?t=740

Source: Cichero (2019), IDDSI Australia Project
Officer and IDDSI Co-Chair

Why is dysphagia such a big deal?

- Dysphagia can lead to serious illness and sometimes death due to:
 - Choking (airway is occluded, unable to breathe)
 - Aspiration
 - Food, fluid, gastric contents, or bacteria-laden saliva entering the airway, leading to chest infection (aspiration pneumonia)
 - Sometimes leads to coughing, sometimes not
 - Weight loss/malnutrition
 - Dehydration
 - Risks associated with multiple hospital admissions
 - Poor quality of life –embarrassment, withdrawal, isolation

“ I avoid dinner with friends because it is just too embarrassing. ”

Swallowing problems adversely affects patients' quality of life.

As many as 36% of individuals with dysphagia avoid eating with others due to their swallowing problem.

DRS Dysphagia
Research
Society
Advancing the Science of Swallowing

Ekberg, O., Hamdy, S., Woisard, V., Wittge-Hannig, A., & Ortega, P. (2002). Social and Psychological Burden of Dysphagia: Its Impact on Diagnosis and Treatment. *Dysphagia*, 17(2), 139–146. <https://doi.org/10.1007/s00455-001-0113-5>

For more information on the Dysphagia Research Society, go to www.dysphagiaresearch.org/
#JuneDysphagiaAwarenessMonth #dysphagia

Neuromuscular conditions

- Neuromuscular conditions affect nerves, neuromuscular junctions, and muscles, leading to impaired communication and control between the nervous system and muscles.
 - The neuromuscular junction is the connection point where the nerve endings release chemicals (neurotransmitters) to stimulate muscle contraction.
- Muscles that control breathing and swallowing are often affected to some degree and in different ways in many neuromuscular conditions

Neuromuscular conditions

Duchenne muscular dystrophy

Becker muscular dystrophy

Myotonic dystrophy

Amyotrophic Lateral Sclerosis
(ALS)

Myasthenia Gravis

Charcot-Marie-Tooth Disease
(CMT)

Guillain-Barré Syndrome (GBS)

Spinal Muscular Atrophy (SMA)

Multiple Sclerosis (MS)

**Oculopharyngeal Muscular
Dystrophy (OPMD)**

Friedrich's Ataxia

Polymyositis and
Dermatomyositis

Motor Neuron Diseases (other
than ALS)

**Facioscapulohumeral muscular
dystrophy (FSHD)**

Hereditary Spastic Paraplegia
(HSP)

Inclusion Body Myositis (IBM)

Lambert-Eaton Myasthenic
Syndrome (LEMS)

Mitochondrial Myopathies

Limb-girdle muscular dystrophy

Swallowing in NMCs

- Dysphagia is common in many neuromuscular conditions
- Dysphagia can be easily missed, especially early signs that can be missed or dismissed
- Complicated by respiratory difficulties, physical challenges, oral care/hygiene, mobility, general level of immunity
- Can lead to social and psychological consequences and can impact on quality of life

Why can swallowing go wrong in NMCs?

Anything that interferes with the strength, timing, speed, and/or range of movement of the muscles involved in swallowing can lead to food, fluid or saliva being **misdirected** and/or **left behind** in the mouth and/or throat.

Respiratory muscle weakness, reflux, and physical positioning can complicate the situation.

Why can swallowing go wrong in NMCs?

- Swallowing is all about how muscles work together to move food through the mouth and throat into the food pipe (oesophagus)
 - Timing (coordination) of movement
 - Strength of movement
 - Amount of movement
 - Speed of movement
- Nothing should be left behind anywhere
- Everything should go where it's meant to go (not be misdirected)
- The airway should be kept clear
- Breathing and swallowing must be synchronised
 - Shared structures
 - Airway protection (cough) can be problematic

How do I know if I have a swallowing problem?

(Argov & Visser, 2021)

- Coughing, choking, or throat clearing during or between meals
- Recurring/unexplained chest infections (even with PEG)
- Weight loss/dehydration
- Breathless after swallowing
- Taking longer than everyone else at meals – slow eating/drinking
- Difficulty chewing
- Difficulty moving food in the mouth
- Drooling/excess saliva
- Food/fluid coming out through the nose
- Feeling of something stuck - mouth or throat
- Choosing not to eat in public

Aspiration and aspiration pneumonia

- Entry of food or liquid into the airway below the vocal cords
 - Into the lungs
 - Can causes infection – can be very serious
- 2% of people aspirate!
 - Most people cough, but some people don't (silent aspiration)
- Aspiration does not equal pneumonia – you need:
 - Altered oropharyngeal flora
 - Aspiration – food, fluid, reflux, saliva – especially if includes bacteria; frequency, volume and type of aspirated material play a part
 - Decreased host resistance e.g. reduced pulmonary clearance, multiple medical issues -> decreased immunity

What do Speech Pathologists do?

- A Speech Pathologist is a university-trained allied health professional
- A Speech Pathologist is the go-to person for skilled swallowing assessment and management
- A Speech Pathologist will:
 - Gather relevant information – medical history, swallowing history, weight, oral care, respiratory illnesses, current food/fluids, difficulties with eating/drinking
 - Examine the muscles of swallowing
 - Do a mealtime observation
 - If more information is needed, refer for a Videofluoroscopic Swallow Study (VFSS) or Fiberoptic Endoscopic Evaluation of Swallowing (FEES)
 - Form conclusions and develop a management plan in conjunction with you and your team
 - Discuss risks and benefits of the various options to make mealtimes safe, accessible, and enjoyable

What do Speech Pathologists do?

- Dysphagia management strategies may include:
 - Swallowing exercises
 - Swallowing manoeuvres
 - Improved oral care
 - Texture modified diets and thickened fluids
 - Recommendations about changes to medication delivery
 - Safe eating/feeding techniques (e.g. positioning, feeding strategies)
- Sometimes you may want to continue to eat/drink particular things even though it's risky
 - A SP will support your decision-making by discussing with you the risks of eating/drinking and will help make eating/drinking as safe as possible
 - It's best to work with your team to make this decision

Speech Pathologists work as part of a team, which includes the person who has the swallowing problem, and any combination of the following: neurologist, GP, respiratory specialist, rehabilitation specialist, dietician, physio, OT, support workers, and family.

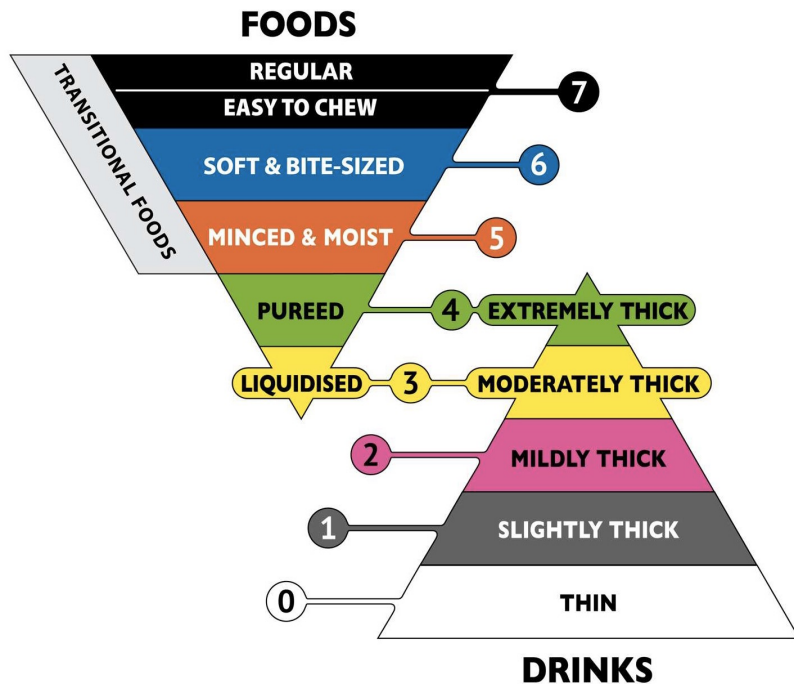
We collaborate to create a person-centred management plan in accordance with the person's goals.

Oral hygiene / oral care

- Unwanted bacteria in the mouth/throat can enter the lungs along with saliva, food, or fluid
- Major cause of aspiration pneumonia
- Poor oral health risk factors:
 - Modified diet/fluids
 - Dependent for feeding
 - Neurological impairment/disease
 - Tube fed
 - Dependent for oral care
 - Decayed teeth

Good oral care reduces the incidence of pneumonia

Texture Modified Diets & Fluids / IDDSI



- Texture modified foods can help reduce choking risk and make food easier to chew and swallow – less left behind/misdirected
- May help compensate for problems with efficiency and effectiveness in the swallowing process

Positioning and other strategies

- Wherever possible, sitting comfortably upright is best for eating and drinking
- Sometimes putting your chin down towards your chest can help
- Sometimes swallowing twice helps shift food from the throat
- Sometimes sipping drink every 1-2 mouthfuls of food can help shift food from the mouth/throat
- (there's more...)

**A SPEECH PATHOLOGIST WILL TAILOR AN APPROACH THAT IS
BEST FOR YOU**

Can exercises help improve swallowing?

- It depends... there is very little research in the area
- There is a very small amount of evidence for respiratory muscle strength training BUT
 - It's not for everyone because of the underlying neuromuscular issues in different conditions
 - Needs medical team clearance
 - Needs careful monitoring during training
 - Delivered with the right dose and intensity
- There is also a small amount of evidence for tongue strengthening exercises BUT
 - Ditto above

Tablet dysphagia

- Medications can be hard for people with dysphagia to swallow
 - Tablets/capsules can get stuck in the mouth or throat
 - Liquid medications may not be thick enough for those on thick fluids
 - Can use alternate forms of the medication to bypass the need to swallow
- Many medications can be crushed
 - But lots can't – e.g. slow release/enteric coated
- Many crushed medications are often given with dairy or other products
 - But different mediums (apple puree, thick water, etc.) can affect the bioavailability of the medication, leading to inaccurate dosing

Medications – to crush or not to crush

- Gloup is a medication lubricant
 - Does not impact on absorption/bioavailability
 - Can help tablets and capsules go down more easily
- Pharmacist and medical team can recommend any available alternate forms of medication
 - E.g. patches, liquids, melts
- Pharmacist can tell you which medications can/can't be crushed
 - “Don't Rush to Crush” - Australia's most comprehensive guide to giving solid oral medicines to people who are unable to swallow.

When to see a Speech Pathologist

- See a Speech Pathologist if you or someone else notices you:
 - Cough during/after eating/drinking
 - Throat-clear during/after eating/drinking
 - Feel like food/drink gets stuck in your mouth/throat
 - Food/drink comes out through your nose
 - Choke (airway blocked off by food)
 - Have a gurgly “wet” sounding voice after swallowing
 - Need multiple swallows to clear food/drink from the mouth or throat
 - Have rapid or gurgly breathing or shortness of breath during or after meals
 - Have elevated body temperature/fever (unrelated to another infection)
 - Have repeated and/or unexplained chest infections/pneumonia
 - Have unexplained/unintentional weight loss (more than muscle wasting)

What about emergencies?

- Choking – airway occlusion – cannot breathe, cannot cough
 - This is a medical emergency that needs a Triple Zero call
 - **First Aid training – family members and support workers SHOULD get first aid training to learn how to manage choking events**
- Aspiration – can still breathe but something has gone the wrong way or is stuck in the throat (NOT in the airway)
 - **First Aid training**
 - Speak to your GP or go to the Emergency Department



First aid fact sheet

Choking adult or child (over 1 year)



If the patient becomes blue, limp or unconscious, follow DRSABCD and call **Triple Zero (000)** for an ambulance.

Signs and symptoms

- clutching the throat
- coughing, wheezing, gagging
- difficulty in breathing, speaking or swallowing
- making a whistling or 'crowing' noise, or no sound at all
- blue lips, face, earlobes, fingernails
- loss of consciousness



5 back blows



5 chest thrusts

What to do

- 1 Encourage the patient to relax. Ask the patient to cough to remove the object.
- 2 If coughing does not remove the blockage, call **Triple Zero (000)** for an ambulance.
- 3 Bend the patient well forward and give up to 5 sharp blows on the back between the shoulder blades with the heel of one hand.
- 4 Check if the blockage has been removed after each blow.
- 5 If the blockage has not cleared after 5 back blows, give up to 5 chest thrusts.
- 6 Give chest thrusts by placing one hand in the middle of the patient's back for support and the heel of the other on the lower half of the sternum. Thrusts should be slower and sharper than CPR compressions.
- 7 Check if the blockage has been removed after each thrust.
- 8 If the blockage has not cleared after 5 thrusts, continue alternating 5 back blows with 5 chest thrusts until medical aid arrives.
- 9 If the patient becomes blue, limp or unconscious, follow DRSABCD and call **Triple Zero (000)** for an ambulance.

In a medical emergency call Triple Zero (000)

DRSABCD Danger ▶ Response ▶ Send for help ▶ Airway ▶ Breathing ▶ CPR ▶ Defibrillation

You could save a life with first aid training • www.stjohn.org.au • 1300 360 455

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QUESTIONS

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REHABILITATION IN PRACTICE

Dysphagia in Duchenne muscular dystrophy: practical recommendations to guide management

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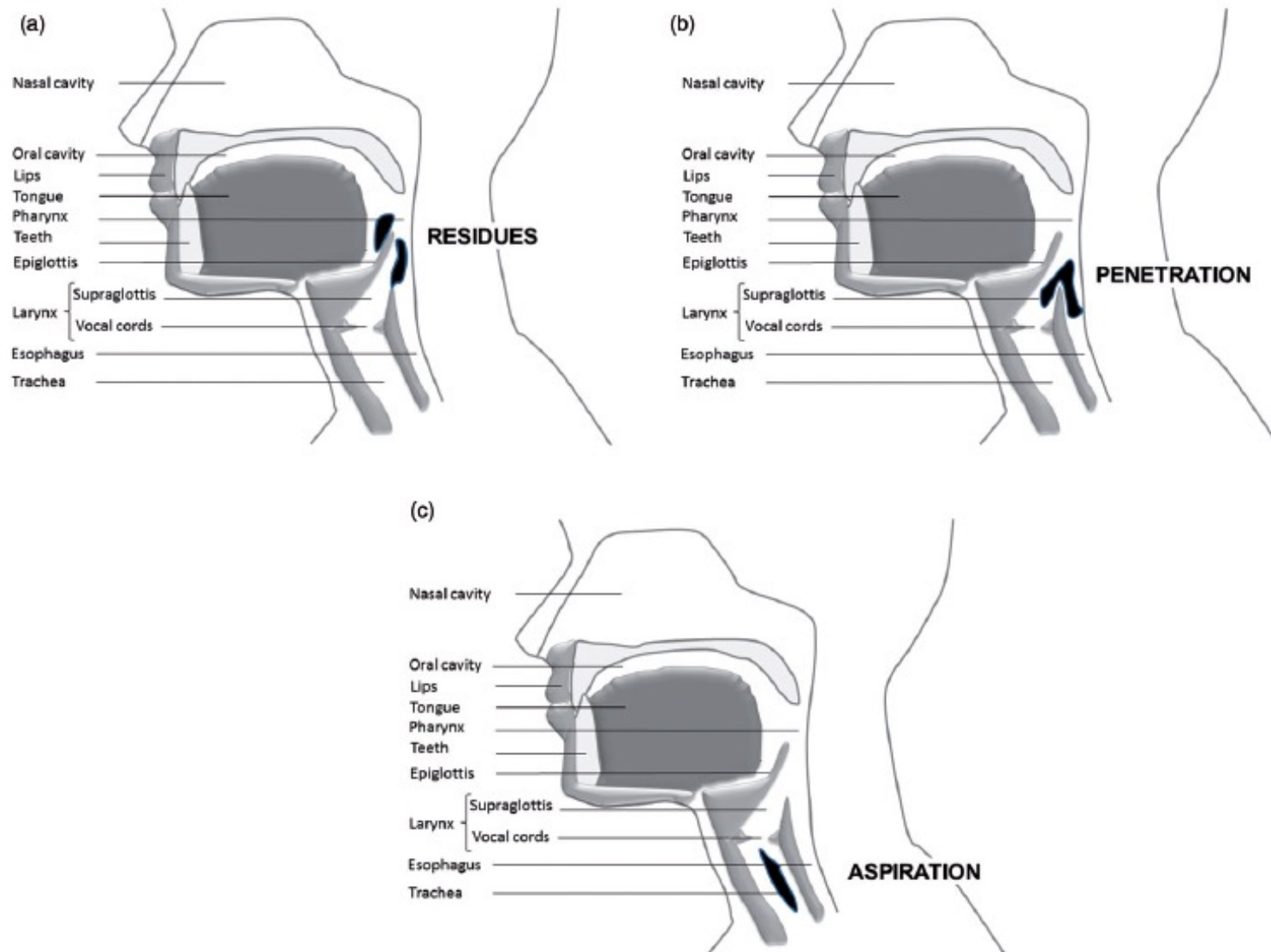


Figure 1. Oropharynx lateral view. (a) Accumulation of residues. (b) Penetration of bolus. (c) Aspiration of bolus.