



Title: Dysphagia Northern Ireland (NI): A partnership approach to support people living with eating, drinking and swallowing difficulties.

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Description

The vision of Dysphagia NI is for dysphagia to be prioritised as the responsibility of all to improve safety, outcomes and experience for people with dysphagia. Through a regional leadership focus, improve expertise and knowledge across the system through training and resources to improve standards and quality of care with a strong emphasis on partnerships.

Dysphagia describes eating, drinking and swallowing (EDS) difficulties in infants, children and adults. People with dysphagia often have other health conditions that they are being treated for, which can affect their eating, drinking and swallowing abilities. Dysphagia is a public health concern due to its link with malnutrition, dehydration, risk of choking and aspiration pneumonia. It can also impact a person's quality of life and lead to feelings of social isolation and decreases the enjoyment of food and drink. The partnership approach used by Dysphagia NI could be transferred to other areas of public health.

Dysphagia NI is a whole system approach with works collaboratively to take forward regional priorities and work together to bring these to meaningful fruition. The work is multi-faceted and addresses gaps in care noted through a thematic review of choking, reports from regulatory bodies and patient experience. Project outputs are available on

the public and professional sections of the PHA website (see supporting evidence). A regional care and training framework for dysphagia with supporting education and resources was co-produced for use across sectors.

Introduction

The aim of Dysphagia NI is to support people to live well with dysphagia.

The purpose of Dysphagia NI is to:

- Develop system wide approaches and models to address the needs dysphagia across Northern Ireland
- Work in partnership with people living with dysphagia, their carers and healthcare professionals.
- Raise awareness of dysphagia
- Develop regional resources
- Develop regional training
- Enhance safe and responsive practice

A thematic review of choking incidents in Northern Ireland between 2010 – 2016 was published in February 2018, it highlighted a number of regional key messages including the need for

- Raise public awareness and staff awareness in relation to the groups of people for whom there is a higher risk of choking.
- Terminology for food and fluid texture descriptors to be agreed regionally across all HSC facilities and by providers of modified meal contractors.
- A regional approach should be taken to agreeing roles and responsibilities along with tailored training & education to the level of competence and skills required by different groups of staff.
- Key safety messages should be shared with relevant stakeholders, especially with those caring directly for individuals with swallowing difficulties.

Dysphagia was identified as a public health priority in Northern Ireland and received funding from the Department of Health to take forward key learning using a regional approach.

Dysphagia affects a diverse range of people within the population right across the lifespan:

- between 26.8 – 40% of infants born prematurely
- between 31-99% for children with cerebral palsy
- between 21-44% for children with childhood onset disabilities
- between 68-72% of children with acquired conditions during the acute phase of care.
- between 50-75% of nursing home residents
- between 50%-60% of head and neck cancer survivors
- up to 50% of people post stroke
- up to 50% of people with Parkinson's Disease
- between 19%-46% of people with mental health conditions
- between 15%-20% of those with chronic obstructive pulmonary disease
- up to 43% of all over 65s admitted for acute hospital care
- 8.1%-11.5% of adults known to learning disability services

(RCSLT 2025)

Method

There are five main strands to the work of Dysphagia NI

Strand 1 System wide approach across Northern Ireland

Following process mapping exercise key stakeholders were identified including:

- Department of Education
- Department of Health
- Regulation & Quality Improvement Authority (RQIA)
- Hospitality
- Community & Voluntary Sectors
- Local Councils
- Health & Social Care Trusts
- Professional Bodies
- Clinical Education Centre

Working across the system ensures ownership and buy in which are essential to identifying priorities and delivering safe and effective standardised care for people living with dysphagia. A regional Dysphagia NI partnership group was established and meets quarterly to provide oversight, trend analysis and direction for the work of dysphagia NI.

Strand 2 Work in partnership with people living with dysphagia, their carers and healthcare professionals.

Dysphagia NI actively engages with community and voluntary groups to ensure involvement and participation of their members to reflect lived experience in any work being progressed e.g. Brain Injury Matters, Mencap, Dementia NI & Parkinson's UK. Clinical expertise is provided by a range of healthcare professionals including speech & language therapists and dietitians.

Strand 3 Raise awareness of dysphagia

A “Swallow Aware” campaign has been on-going since 2019 with a recognisable logo and strong branding. The campaign aims to raise awareness of dysphagia among healthcare professionals and the wider public. The campaign utilises a multi-media approach including

- Use of social media, animations and the development of a user-friendly website.
- Bespoke quarterly newsletters are produced and distributed to the public and healthcare professionals
- Hospitality factsheet and wallet card
- Face to face workshops
- Online community of learning through ECHO network
- “Theme of the Month” message which highlight key messages. These can be found at the following link : [Dysphagia - public information | HSC Public Health Agency](#)

Strand 4 Develop regional resources

A need was identified to develop regionally consistent, evidence-based resources to support people living with dysphagia and their families as well as healthcare professionals involved in their care. A wide range of resources are available these can be found at the following link [Dysphagia - public information | HSC Public Health Agency](#)

Strand 5 Develop regional training

A training needs analysis identified the need for regionally consistent, evidence based, quality assured training packages to raise awareness of dysphagia. Two eLearning training packages were developed.

1. Awareness training for public and non-clinical staff. This training is available on the Public Health Agency website [Non-HSC Universal Swallow Awareness - Overview](#)

2. Targeted training for healthcare staff. This training is available on the regional Learn HSCNI platform for staff to access. In addition to these training packages, bespoke training was developed to support education staff and catering staff.

[Eating, Drinking and Swallowing Awareness for Education Staff](#)

[Eating, Drinking and Swallowing Awareness for Catering Staff](#)

Strand 6 Monitor and Review Adverse and Serious Adverse Incidents

Adverse and serious adverse incidents which occur in health and social care trusts in Northern Ireland are collated regionally to identify trends & themes to ensure learning and inform future priorities and actions. This analysis is shared quarterly at the regional dysphagia partnership meetings and in the healthcare staff newsletter, this ensures wide distribution of learning across the system.

Outcomes: How this work made a difference

Strand 1 Worked system wide across Northern Ireland

Ensuring the active involvement of key stakeholders within the Dysphagia NI Partnership Group (as outlined above) has enabled work to progress effectively and efficiently to improve public health by bringing together multi-disciplinary clinical expertise and lived experience which sets direction and priorities to ensure accountability and governance across the system.

Strand 2 Worked in partnership with people living with dysphagia, their carers and healthcare professionals.

Dysphagia NI work in partnership with healthcare professionals, service users and community & voluntary organisations in the development of our resources which ensures that they meet the needs of those who are using them.

Examples of recent resources developed in partnership with service users, community and voluntary organisations and healthcare professionals include

- Hospitality Factsheet and Swallow Aware Wallet Card
- Eating, Drinking and Swallowing Dementia Guide

Hospitality Factsheet & Swallow Aware Wallet Card



Improving experience for customers with swallowing difficulties (dysphagia)
Top tips for hospitality

Some people have difficulty eating, drinking or swallowing. This is also known as 'dysphagia'. This can affect their quality of life as socialising in restaurants, cafes and pubs may be stressful, challenging and potentially unsafe.

Eating, drinking and swallowing difficulties can affect people with a range of medical conditions, including cancer, dementia, motor neurone disease, Parkinson's and learning disabilities, and can affect children, young people and adults. People who live with dysphagia are at higher risk of food or drink going into the airway, excessive coughing, chest infections and choking.

In the hospitality sector, you can play a vital role in improving quality of life for people who have eating, drinking and swallowing difficulties and we would like your help. When you customer has a good experience they will tell others and come back again!



I have difficulties eating, drinking or swallowing and might be at greater risk of choking.

"Raising awareness in hospitality is invaluable, Alison gave us opportunity to be heard."

(Gemma, Parent at Mencap)




Hospitality Factsheet QR Code



<http://pha.site/hospitality-factsheet>

Eating, Drinking & Swallowing Dementia Guide

Eating, drinking and swallowing
A guide for carers of people living with a dementia



HSC Public Health Agency Swallow Aware

"Dysphagia NI met us and listened to our stories and what we needed, she helped our group have their say on the dementia guide"




Dementia Guide QR Code

Strand 3 Raised awareness of dysphagia

The "Swallow Awareness" campaign has a wide reach across healthcare staff, service users and their carers through quarterly newsletters and monthly themes.



Over 5700 views March 2024 – October 2024 (figures are combined for 3 editions)



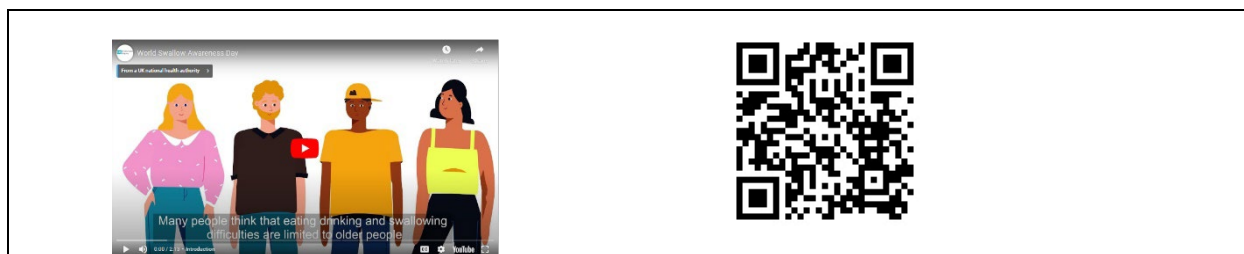
Newsletter example
QR Code (September edition)

Strand 4 Developed regional resources

Regional resources have been developed and are made available on the Public Health Agency Website.

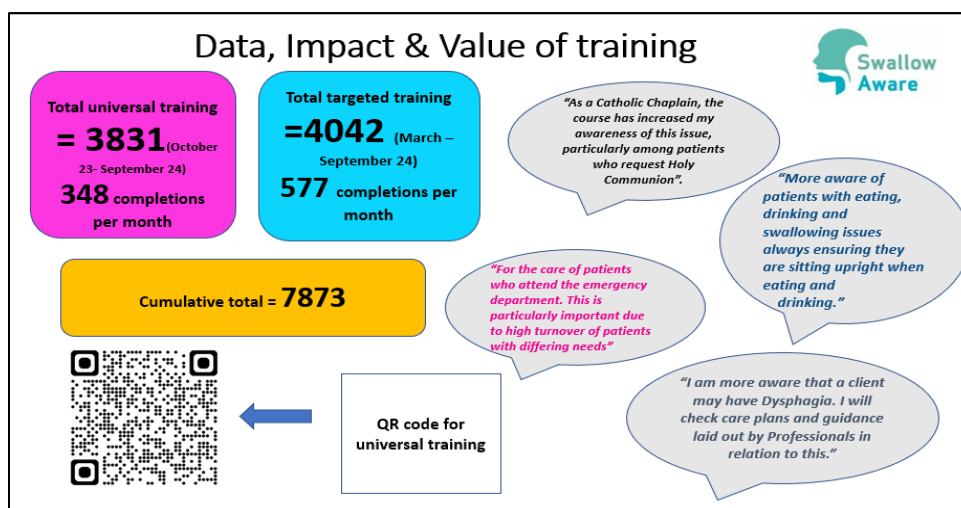
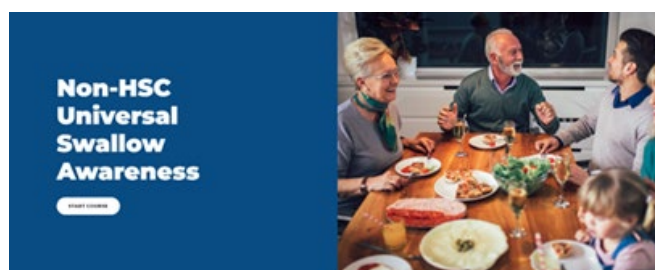
Examples of resources are highlighted below. To view all resources please visit [Dysphagia - public information | HSC Public Health Agency](#)

Signs and Symptoms of Dysphagia in Children and Young People	
 A poster titled "CHILD SAFETY ALERT Signs of Eating and Drinking Difficulties". It lists signs for children under 5, 5-17, and 18+. It includes a QR code at the bottom.	
Oral Care Education Advice for Those Caring for People with Dysphagia	
 A poster titled "Mouthcare Aware Oral Care Advice for Those Caring for Adults with Dysphagia". It features the HSC Public Health Agency and Swallow Aware logos. It includes a QR code at the bottom.	
Raising Awareness of the Signs and Symptoms of Dysphagia and Signposting to Supporting Services https://youtu.be/cWnDCPpiaYQ	

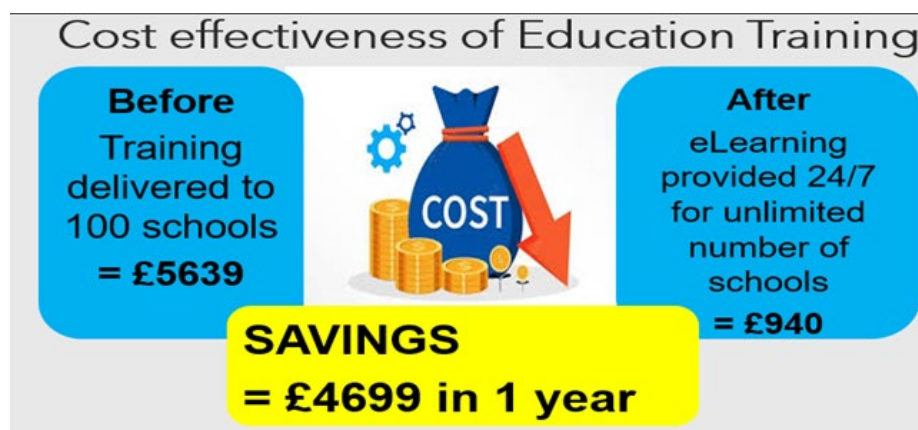
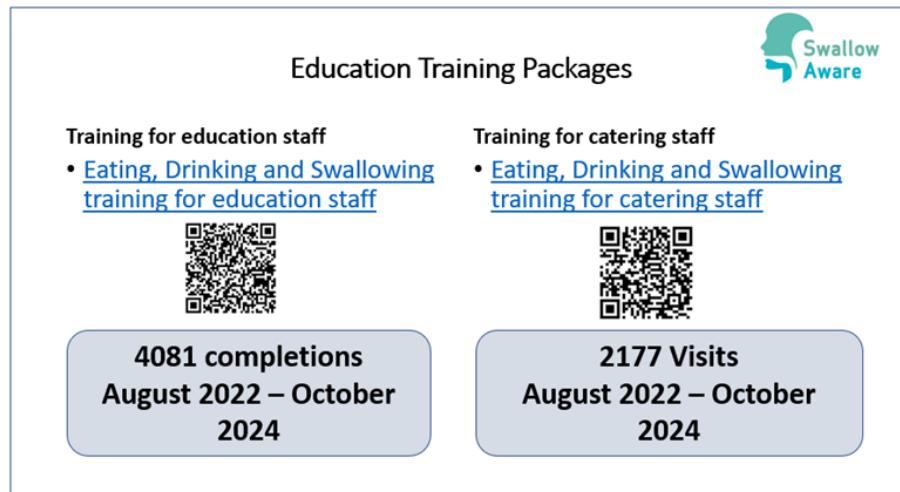


Strand 5 Developed regional training

Regional training was identified as a priority by Dysphagia NI who worked in partnership with the Clinical Education Centre, people with lived experience, clinicians and carers to develop an evidence based, accessible, online training programme.



Additional training packages have been developed for staff working in education settings to support education staff and catering staff to increase knowledge and reduce risks for children and young people with dysphagia. This training was developed in partnership with clinicians, Department of Education, Education Authority, education staff, catering staff and those with lived experience. The training was developed as two e-learning packages and was mandated for staff to complete. The format of the training ensured it was easily accessed by staff and was a cost-effective use of time and resource.

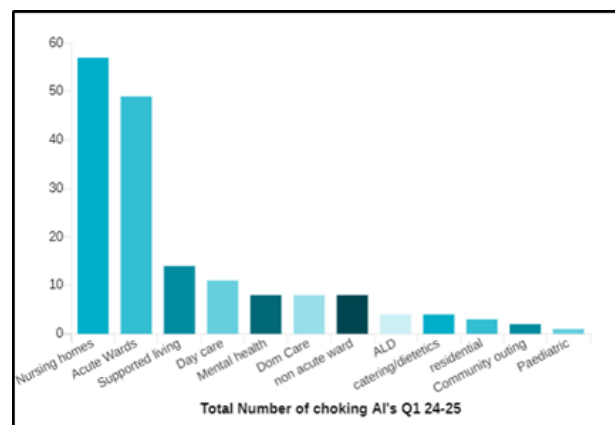
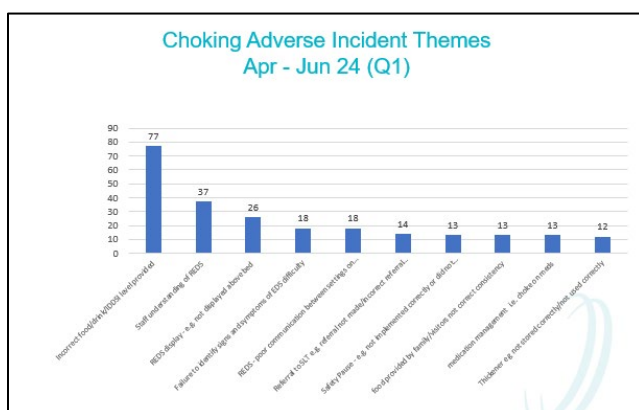


Strand 6 Monitor and Review Adverse and Serious Adverse Incidents

A system was introduced in March 2023 to collate regional adverse incidents to identify trends & themes in relation to location and reason for reporting incident. This information is shared widely to raise awareness of the key themes and identify areas for improvement.

Serious adverse incidents are also monitored and reviewed to ensure learning across the system.

Example of trend & theme analysis of adverse incidents



Key Learning Points

What are the key learning points and what worked well?

The key learning from Dysphagia NI has been the value of partnership working by identifying and engaging with the right stakeholders in order to deliver impact and facilitate improved and sustainable outcomes across all environments to enhance understanding, develop proactive management strategies and enhance safety.

The person with dysphagia needs to be at the core. This is achieved by ongoing engagement to ensure sustained and meaningful involvement.

Dysphagia NI used a top down, bottom up, and system wide approach to ensure all voices were heard and valued. A clear Terms of Reference ensured structure and governance to facilitate effective decision making and prevent misunderstandings. This process demonstrates the best practice approach to dysphagia management and could be adopted by others

What things you might do differently?

Initially Dysphagia NI focused on adults with dysphagia which meant that training and resources for children and young people were not regionally coordinated. This has now been addressed and the dysphagia needs of children and young people and their families are reflected and ensures smooth transition from children's services to adult services.

What future plans do you have to embed this?

We will continue to review evidence and trends at a regional and local level alongside feedback and outcomes from training and resources developed, and seek to widen the reach of the swallow aware campaign by seeking new proactive and innovative opportunities such as sharing this work nationally. There is potential for other nations to learn from this work and follow a similar path.

References

<https://www.publichealth.hscni.net/publications/report-regional-choking-review-analysis-thematic-review>

<https://www.rcslt.org/members/clinical-guidance/eating-drinking-and-swallowing/eating-drinking-and-swallowing-guidance/#section-2>

<https://www.publichealth.hscni.net/directorates/directorate-nursing-midwifery-and-allied-health-professions/allied-health-11>