

# Regional Swallowing Difficulties/ Dysphagia NI Project

If you have experienced swallowing difficulties or are a carer with experience in helping those with swallowing difficulties we would like to hear from you.

# **Project Overview:**

#### Who are we?

The Northern Ireland Swallowing Difficulties Project was established as the result of a review that was led by the Public Health Agency. This review looked at choking incidents in people with swallowing difficulties across health & social care settings in Northern Ireland <a href="https://www.publichealth.hscni.net/publications/report-regional-choking-review-analysis-thematic-review">https://www.publichealth.hscni.net/publications/report-regional-choking-review-analysis-thematic-review</a>. A number of recommendations were made which the Swallowing Difficulties Project have been asked to take forward.

#### Why are we undertaking this work?

The Public Health Agency, the Health and Social Care Trusts, professional organisations, the independent sector and service users/carers are working together to develop services and resources which will positively impact the outcomes of adults with dysphagia in Northern Ireland.

We are looking for a group of people across Northern Ireland who are willing to share their experiences and to work in partnership with us, designing and making regional resources for care staff and people with swallowing difficulties.

#### **Programme of Work:**

If you would like to get involve, here are some of the resources and services we are working on and how you can contribute:

- Help us understanding the experience of living on dysphagia friendly foods.
- Assist us in developing eating and drinking (swallowing) care plans for use with adults with swallowing difficulties across all care settings.

- Give us advice and knowledge to develop training for staff, families, and carers working alongside adults with eating, drinking and swallowing difficulties.
- Contribute to the Evaluation of different delivery models for Speech and Language Therapy swallowing assessment.

#### What commitment is expected of me?

If you agree to engage in the project you will be asked to:

- Take part in structured discussions about your experiences and ideas on shaping resources that will positively impact the lives of those living with or caring for someone with swallowing difficulties.
- Respond to information either via email, telephone or face to face. We will of course communicate with you in whichever way you are more comfortable with.
- If possible, attend events such as meetings, information events, focus groups and formal consultation workshops
- Take part in regional events to promote the positive impact that service user involvement can create.

Promote the project through your own personal experience by for example, social media/newsletter etc.

### When will the events or meetings take place?

We have a number of meetings planned to take place up until 31<sup>st</sup> March 2020 which you may be interested in attending. If you are unable to attend, we can arrange to meet you in your own home or an arranged location to give you the information you need. Get in touch to hear more about our planned meetings and events!

#### What support will be available to me?

To support you to fulfil the role, we will:

- Provide an induction on the programme of work and your role within this work:
- Host meetings via video or teleconferencing facilities, if requested;
- Reimburse out of pocket expenses e.g. travel, carer and children care costs;
- Provide support before, during and after meetings;
- Provide adequate information in a timely manner;
- Provide details of meetings such as agenda's in advance;

- Provide home visits or suitable one to one meetings if you are unable to attend events or group meetings.
- Provide you with details of a designated person who you can speak to if you have any questions or queries at any time during the project.

If you have particular access requirements, please make us aware of these in advance of the event and we will work with you to accommodate these as far as possible

## I would like to take part – who should I contact?

Firstly, thank you for your interest. If you would like to participate as the service user or carer representative for your HSC Trust area, please advise Alison McCusker at the PHA. Alison can be contacted by email at <a href="mailto:Alison.mccusker@hscni.net">Alison.mccusker@hscni.net</a> or by telephone on 02895361694.

#### How can I find out more?

If you would like to find out more about this project before committing, please contact in the first instance <u>Alison..mccusker@hscni.net</u> or <u>Elizabethj.thompson@hscni.net</u> who are providing project management support.