



## Help Stop Choking Choking Awareness Project

### Introduction

Co-production helped to transform choking awareness by developing resources to encourage safe eating behaviours, safe food choices and help foster safe eating environments. This project aimed to develop resources to provide formal risk advice to increase awareness of choking in people with a learning disability. Sharing choking risk information in a standard way is a matter for public health and health prevention. The overall purpose of increasing awareness of choking is to lead to behavioral changes which will reduce individual risk factors and potentially save lives. The resources contain a series of accessible video clips, activities, advice leaflets, posters and recording forms available for free download.

### Context

Anyone can accidentally choke at any time. The risk of choking increases when someone is eating or drinking. People with swallowing difficulties and/or learning Disability have a further increased risk of choking (Thacker, 2007). Every year people with a learning disability die from choking while eating and drinking which could be prevented (Glover, (2010)).

Choking is an acute episode in which the patient coughed incessantly or experienced a colour change (with inability to speak or cough effectively) while ingesting food or drink. The solid or liquid usually has to be expelled to terminate the event. Fioritti et al 1997.

There is much evidence of the size of the choking problem this project tried to evaluate the extent to which an educational intervention is effective at ameliorating it. John is a service user with a learning disability, epilepsy, cerebral palsy and swallowing difficulties who experienced a number of choking events. He was referred to Speech and Language therapy (SLT) and following a swallowing assessment received direct therapy to help him reduce his risk of choking. John felt that his positive experience of SLT saved his life. He was inspired to share his successful story to help other people reduce their risk of choking.

### Method

John's story was developed into a power point presentation and co-delivered at a number of events with positive feedback. The project was then successfully awarded money from the Public Health Agency for a Patient and Public Involvement project to develop John's story into an educational DVD resource. The DVD is an accessible learning resource for people with a learning disability, their staff and carers. It aimed to help people know and understand choking and how to reduce the risk of choking. The DVD includes collaborative working across professionals who share their perspective on

reducing the risk of choking. This includes SLT, Community Nurse, day care worker, health improvement officer for oral health and social worker. As well as the accessible DVD a number of resources were developed including an easy read Information book, activities, posters and a choking awareness campaign song and music video, 'Help Stop Choking' song.

The choking DVD was put in front of potential users to measure effectiveness. The pilot was to evaluate the ease of understanding and accessibility of the DVD and resources. The workshops were conducted over a 2 week period between the 15th of May and the 29th of May 2014. A total of 13 workshops were completed with a total of 140 participants. 11 carers, 40 service users, 85 staff and 4 who did not record their designation.

An easy read 10 question survey was developed for participants to self-rate their awareness, knowledge, applied skills and confidence before and after the choking awareness workshop.

### Outcomes

The evaluation showed that in the short term there was an increased understanding of choking and ways to reduce the risk the results of the survey showed that the DVD and other easy read resources are effective, i.e. following the implementation all participants had an increased understanding of choking and ways to reduce risk. The pilot showed evidence that accessible information makes a difference. Service users valued the learning, see sample of feedback below. Overwhelming support for John as an expert by experience

The project won the top prize at the Patient Safety and Care awards 2014 under the category Preventing Avoidable Harm. Presenting the award, the judges said that this DVD should be used by all Learning Disability services across the UK as core training and awareness raising for both staff and service users.

Following the success of the choking awareness DVD further funding was awarded to develop and launch the help stop choking app and Help Stop Choking Website as a digital solution to make the DVD and resources available to a wider audience.

### Key learning points

The key learning point here is to value the patient voice. Listening to John talking about his experience and what he learned brings the subject of choking to a human level. John could see that other service users would be safer if they knew about choking and it could help to save lives.

John said "before I worked with speech and language therapy I didn't know choking was so serious. This is me telling my story and how I feel being through it (choking), even if I help one person it will be fantastic."

Storytelling can be very powerful. John is an expert by experience, talking about what matters to him. Listening to him talk about his experience brings the subject of choking to a human level. The learning point is that you have to want to engage, co-production has to be about what you do together not what you produce for someone.

It is important to make connections and build relationships with like-minded people who also want to make a change. This project was all about Knowledge management, looking at how you capture, organise, share our collective knowledge about choking. Care for service user safety is at the heart of

this project with a motivation to improve services and the quality of care that's delivered every day. Lessons within the DVD are broad and we hope will have appeal across the health sector.

A limitation of this project is the lack of robust tangible long term outcomes. It is hoped that this innovative project will not only save lives and reduce harm but will make savings to the health service by reducing admissions to hospital. Reduced choking events and admissions related to choking are difficult to measure. Measurements of the incidence of choking before and after the intervention, taking into account the cost of the intervention, would likely to be appropriate. However with the increase in choking awareness there is the possibility that recording of choking events may also increase. It may be more appropriate to look at the incidence of serious adverse incidents. On a single case study level, John has not had any choking events since his choking awareness education. His survival from a potential choking event and his quality adjusted life years has allowed this positive project to occur.

### References

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