Food with Dignity: A New Menu for Patients with ALS
Nora Blake, Akeisha Hayde, Lindsay Johnson, Chelsea Monfalcone, Shantee Proctor, Cynthia Wagner (Sodexo Food Services and BIDMC Voice, Speech & Swallowing)

The Problem
Food is recognized by many as one of life's pleasures. Patients with ALS or PLS face challenges with chewing and swallowing and are often limited to a pureed or restricted diet for their safety. The need to follow an altered texture diet not only decreases the enjoyment of eating, but affects the self-worth and dignity of patients with ALS.

The ALS support group was identified as the perfect opportunity to trial a new set of safe but delicious recipes for this patient population as previously they were served primarily pureed meats, vegetables and lots mashed potatoes with little variety, increasing their displeasure with food.

Aim/Goal
- Increase the variety and quality of food options for patients with ALS.
- Improve the morale of these patients with regards to dignity and feeling they can regain control over their food choices once again.
- Empower the patients, families and caretakers to select the foods they most wanted to share at monthly luncheons.
- Expand the patients’, families’ and caretakers’ horizons and confidence when preparing meals at home.

Interventions
- Food Service and Voice, Speech & Swallowing leaders met to discuss the needs of the particular population served at the ALS Clinic Connections patient and caregiver luncheons.
- A tasting luncheon was held so ALS patients could try, taste and select new foods to design new menus.
- Food Services prepared a creative new set of recipes focusing on taste and plate presentation ensuring suitable textures varying abilities to chew and swallow.
- Acceptance of the new recipes was assessed by the team at the monthly ALS Clinic Connections patient and caregiver luncheons via anecdotal surveying and food waste measurements.

Results / Progress to Date
In 2012 there was an average of 8 individuals taking part in the ALS Clinic Connections patient and caregiver luncheons on a regular basis. Since the Focus Group began in 2013 there have been upwards of 15-20 individuals participating. This number is hard to gauge as the population / attendance fluxes with diagnosis and lifespan.

Lessons Learned
Improved quality of food has doubled attendance including attendees who come without having medical appointments. Patients now regularly request seconds or take portions home for dinner and caregivers partake in the food as well - realigning food as a family affair.

The safety precautions necessary require special preparation techniques that are not regularly practiced in kitchens. This minimizes delegation to frontline staff and can complicate replication for participants at home. Hopefully via demonstrations we have impacted nutritional intake, quality of life as well as longevity.

Next Steps
- Increase the amount of training and education provided to caregivers and frontline kitchen staff for recreation of recipes with safety and confidence.
- Create survey tool to establish metrics for satisfaction and future improvements.
- Continue to create new recipes for the ALS & PLS patients, consider publishing menus for inpatients and outpatients to use at home (example cook book or video cooking demo).
- Outreach efforts to other clinical staff to encourage more whole foods instead of liquid supplements or pureed factory alternatives.