New Zealand Speech-language Therapists' Association (Inc.)
Te Kāhui Kaiwhakatikatika Reo Kōrero o Aotearoa

Affiliated to the International Association of Logopaedics and Phoniatrics

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Dear Stephen

The NZSTA welcomes this opportunity to contribute to the consultation around the funding and listings of Special Foods in the Pharmaceutical Schedule. We are delighted that Pharmac are recognising the need for widening the criteria for patients who require food thickeners.

This submission addresses the issues outlined by Pharmac in the Special Foods Consultation Document January 2010.

With respect to the Summary section:

1. We agree with the proposal to remove the renewal requirement for food thickeners.
2. We agree with the proposal that food thickeners could be extended to additional patient groups such as patients with progressive neurological disorders (e.g. Parkinson's Disease, stroke patients still dysphagic after six months of rehabilitation) and those with paediatric dysphagia (of varying causes)
3. We would like to state that food thickeners are an **additional** cost to the patient and cannot be considered a food replacement in any form.

With respect to the background and proposal for Thickened Fluids:

We agree that cornstarch may be an alternative for some patients with swallowing problems, however cornstarch will not be appropriate in many cases for the following reasons:

1. Cornstarch needs heat in order for it to function as a thickener. This will not be feasible and palatable for some food items or cold drinks (for example juice or water)
2. Cornstarch preparation requires the patient to be physically competent (i.e. using a stove)
3. Thickened fluids have two grades, which need to be accurately reproduced when using substances other than the commercially available thickener used for people specifically with dysphagia. There are currently no guidelines for reproducing the correct consistency with cornstarch and it would be difficult to develop these given the variabilities described below.
4. Cornstarch users will need to be educated regarding the possible factors which will affect the cornstarch ability to thicken. Examples such as temperature, amount of sugar and acidity of the product

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a. Temperature

   Cornstarch needs a temperature of 100^0C for its thickening. On cooling, the starch granules recrystallize, forming a solid gel, a process known as retrogradation. As the mixture cools, there is a decrease in kinetic energy, which would cause the product to thicken. This product is not stable for freezing as it will lose its thickened form. Thus it is not safe for patient consumption on basis of making it to the correct thickness and freezing (thus not being able to be made in bulk or kept in the freezer due to Syneresis)

b. Sugar

   Sugar tenderizes a starch gel and reduces paste viscosity because it retards gelatinization. Due to the hydroscopic nature of sugar, the temperature required for gelatinization is raised thus delaying the process. Sugar can attract and hold water molecules leaving less water available to hydrate the starch granules. The starch molecules do not swell as much as they would in the absence of sugar and too much sugar can cause a mixture to not thicken sufficiently.

c. Acidity

   The combination of acid and heat causes a hydrolytic reaction that breaks down molecules of starch into smaller molecules. These shorter molecules are able to move more freely in the thickening paste, resulting in a somewhat thinner paste. If the acid (i.e. lemon juice) be added before the cornstarch, it will take a longer time for the product to thickened.

In summary, cornstarch will not be the first choice recommendation for patients who require thickened fluids. Cornstarch as a thickening agent is not practical for patients who are not trained in how to thicken different foods/fluids. It varies in consistency due to the technique of the 'maker'. It will pose a challenge for older patients who are weak and/or may not have the physical strength to make up drinks or products for themselves without posing a safety risk (for example swallowing safety, food safety and fire safety). Cornstarch may still be a suitable option to use as a thickener for a very small range of foods however; this would necessitate the development of commercially viable preparation guidelines.

With respect to Appendix 6 – Food Thickeners Special Foods Subcommittee minutes

The dietitians and speech language therapists agreed with the subcommittee that the speech language therapist (SLT) is the most appropriate professional to assess a patient's need for a food thickener, and therefore also agree that the SLT should be included as a relevant specialist capable of making an application for thickener.

We note that "the Subcommittee recommended that the Special Authority criteria for food thickeners be amended to include all dysphagic patients on recommendation from a registered Speech and Language Therapist following consultation". The current state of affairs in New Zealand is that speech language therapy is *not* a registered profession (under the Health Professionals Competence Assurance Act, 2003). Until such time as we become a registered profession (indeed, *if* we become a registered profession) it should be noted that the practice of recommending food thickener for patients with dysphagia be carried out by sufficiently competent and experienced speech language therapists (skilled in the diagnosis and management of patients with dysphagia).

It is also agreed that the Special Authority criteria should be widened to include head injury, head and neck cancers, cerebral palsy, dementia as well as progressive neurological diseases (as diagnosed by a Consultant Neurologist) that cause dysphagia. This includes but is not limited to Parkinson's Disease, Huntington's Disease, Multiple Sclerosis, and Motor Neurone Disease. Dysphagia in these patients can lead to hospitalisation for aspiration pneumonia if thickeners are not readily available and easily used when recommended for safe intake of food and fluids.

Further to this, we ask for consideration of widening the criteria to take account of conditions in the paediatric population including but not limited to cerebral palsy, global developmental delay and other syndromes, all of which may include dysphagia among their symptoms.

With regard to the application to widen the Special Authority criteria to include patients with dysphagia caused by stroke we request that consideration be given to funding for those stroke patients who require thickened fluids/food on a long term (greater than six months post-stroke) or permanent basis. As in the above paragraph, hospitalisations may occur in these patients for aspiration pneumonia as a result of the intake of unsafe consistencies of food and fluids.

Additional comments

With respect to the implication that food thickeners may be over-used, we posit that this is highly unlikely. Thickener is thought by many people to reduce the palatability of foods/fluids, with most people preferring unthickened fluids. Those who are recommended to use thickener do so because it is essential to their health and wellbeing rather than out of enjoyment. Speech language therapists often provide people with advice and strategies for alternative, more palatable, methods of thickening fluids.

Additionally, the NZSTA seeks answers to the following questions:

1. If a speech language therapist recommendation is required for an application to be made for a special authority, what provision would be made for those patients who may not have access to SLT? (for example, people in residential care in certain DHBs where access to SLT is denied).
2. What provision is being considered for the pre-thickened fluids currently being produced and marketed for patients with dysphagia?

Overall summary

We agree with the subcommittee recommendations that the Special Authority criteria be widened. We suggest that this be amended to include **all** adult or paediatric patients with dysphagia requiring long term (greater than six months post stroke) or permanent thickened food and/or fluids on recommendation by a qualified speech language therapist following consultation and evaluation. As an SLT is the only health professional who can accurately assess a patient's need for thickened food/fluids using objective instrumental measures, this would be a blanket criterion that encompasses, but is not limited to, all conditions mentioned above.

We believe that adopting this criterion will ensure that all those patients with any condition causing a long term significant deficit in swallowing function will have access to funded thickener or pre-thickened fluids, saving the healthcare system the cost of repeated hospitalisations for related illnesses such as aspiration pneumonia.

We recommend that both dietitians and speech language therapists be consulted for the final wording of any proposed amendments to the Special Authority criteria apply to thickened foods.

Yours sincerely

President
NZSTA

Professional Standards Leader
NZSTA