saliva control in children



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Excessive drooling (sialorrhoea) is frequently a major problem in children with cerebral palsy, intellectual disability and other neurological impairments. In young people with cerebral palsy, the incidence of severe drooling has been reported to be as high as 37%. In addition to the social implications for both the child and the parents, excessive drooling can cause significant skin irritation and require frequent changes of clothes and bibs.

This booklet was prepared by the following departments:

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How is saliva produced?

There are three major pairs of glands in the mouth, the submandibular, sublingual and parotid glands. It is estimated that 500 to 2000 ml of saliva is produced per day.

The submandibular and sublingual glands produce saliva through ducts in the front of the mouth just under the tongue (Figure 1). The submandibular glands produce most (about 65%) of the saliva in the mouth and their secretions are watery. The sublingual glands produce a little saliva that is thick and mucousy. The parotid glands produce saliva through ducts which open into the mouth near the second upper molar teeth. These large glands are most active during meal times.





The autonomic nervous system involving both parasympathetic and sympathetic nervous systems is responsible for the overall control of salivation. These nerves are not under conscious control.

The major functions of saliva

- Lubricates food to assist with chewing and turns food into a bolus (soft ball) for ease of swallowing.
- Lubricates the tongue and lips during speech.
- Cleanses the teeth and gums and assists with oral hygiene.
- Regulates acidity in the oesophagus (gullet).
- Destroys microorganisms and clears toxic substances.
- Facilitates taste.
- Initiates carbohydrate digestion.

Why do some children drool?

Excessive salivation and drooling can be a normal occurrence in the first six to eighteen months of life until oral-motor function is developed. It is considered abnormal for a child older than four years to exhibit persistent drooling and this problem is most commonly seen in cerebral palsy or other conditions with severe neurological impairment. There are a small group of otherwise normal children who drool up to about the age of six years. The problem is not normally overproduction but inefficient voluntary swallowing of saliva. In this group there may be a lack of appreciation of external salivary loss, intra-oral sensory dysfunction, intra-oral motor impairment or a combination of these factors.



What is the saliva control clinic?

The Saliva Control Clinic at The Royal Children's Hospital, Melbourne is a multi-disciplinary clinic with speech pathologists, a paediatric dentist, paediatrician, plastic surgeon and nurse coordinator. Information is gathered by having the family complete a questionnaire prior to their appointment. At the clinic, a history of the saliva control problem is taken, the children are observed and an assessment of drooling is made by carers and clinicians using the Thomas-Stonell and Greenberg classification. This consists of a five-point scale for severity and a four-point scale for frequency (**Figures 2 and 3**). Recommendations are made at the conclusion of the clinic visit that may include further management by a local speech pathologist, referral for dental treatment, consultation with an ear, nose and throat specialist, or as detailed below, conservative measures, the use of medication or a recommendation for surgery.

Figure 2. Drooling severity score (after Thomas-Stonell and Greenberg)

| 1. Dry |
|--|
| 2. Mild – wet lips |
| 3. Moderate – wet lips and chin |
| 4. Severe – clothing damp |
| 5. Profuse – clothing, hands and objects wet |

Figure 3. Drooling frequency score (after Thomas-Stonell and Greenberg)

| 1. Never | |
|-----------------|--|
| 2. Occasionally | |
| 3. Frequently | |
| 4. Constantly | |

How is drooling managed?

There are four main methods of managing saliva control problems:

1. Conservative methods

It is important to assess for underlying problems that may be aggravating the saliva control problem, for example, the presence of nasal obstruction, dental disease or the use of medication that may be contributing to the problem. Physiotherapists may be involved in improving posture and seating, for example, wheelchair modifications may facilitate better head control. Repositioning the computer screen and input device (keyboard or switch) may also be helpful in achieving improved posture.

Conservative methods include behavioural approaches and techniques to improve sensory awareness. These two strategies can reinforce each other. The behavioural approach involves teaching the child to recognise the feeling of wetness and be able to either swallow more frequently or wipe the saliva from the lips and chin. It can also include assisting the child to develop lip closure and saliva suction. Strategies include developing the ability to suck up the secretions in the mouth using straws of different thicknesses, and liquids of varying consistencies. Intensive input from speech pathologists and co-operation from the child and other key persons in the child's life such as their parent and teacher, are required for these strategies to be successful.

Many children appear to be unaware of the saliva in or around the mouth and may also be untidy eaters. Brushing and icing techniques are usually implemented by speech pathologists. The aim is to increase sensory awareness around the lips and face. Developing eating skills related specifically to saliva control may also be helpful. This includes developing lip control by increasing the length of time the child can maintain lip closure and developing lateral tongue movements in



Some success has been reported in improving the frequency of the swallow by biofeedback (where the person has worn a beeper and the swallow has been prompted by an auditory cue).

To achieve any substantial change, long term intervention is required which also includes considerable commitment by the child and team members. The success of these techniques depends on factors such as the degree of oral motor disability and the ability to follow directions.

2. Appliances



Figure 4. Two examples of ISMAR appliances

Some children may benefit from wearing an oral appliance to help oral awareness and motor control. This approach needs close cooperation between a dentist and a speech pathologist as each appliance is individually made. An appliance is usually part of a conservative approach to treatment and additional exercises may be necessary. There are a number of appliances that may help the child to better position the tongue in the mouth and swallow more effectively. Appliances can be challenging for children and families and require careful prescription and supervision. Intra oral prostheses such as the vestibular screen are sometimes used. An appliance called the ISMAR (Innsbruck Sensory Motor Activator and Regulator) is designed to provide stability for the jaw in order to develop lip and tongue ability and must be supervised by a dentist with special expertise in this area (Figure 4). It is only useful in a small proportion of young people with drooling. Research conducted at The Royal Children's Hospital indicates that this could be an effective treatment for children with cerebral palsy who are motivated and able to follow instructions. The device is worn for short periods of time every day and it may take over a year for improvement to occur.

3. Drug therapy

Anticholinergics particularly Benzhexol, Benxtropine and Glycopyrrolate, are successful in drying the secretions in some children. These drugs work by blocking the transmission of autonomic (parasympathetic) nervous system signals to the salivary glands as well as many other organ systems such as sweat glands. Side effects, particularly sedation and restlessness, may limit their use. These medications should be introduced gradually at slowly increasing dosages, as the effective dose for an individual varies considerably.

In general, medication appears to be most useful in:

- 1. Young children where maturation of oral function may still occur.
- In older children and adults with relatively milder saliva control problems.
- 3. As an alternative to surgery for those who prefer a non-operative approach.

A new treatment for poor saliva control is injection of botulinum toxin into the salivary glands. This technique is still being evaluated with research trials but may be a good method of providing short term relief of drooling.

4. Surgery

A surgical approach is taken if:

- Drooling is so severe that conservative measures are unlikely to achieve a satisfactory outcome.
- 2. Compliance with conservative measures is unlikely due to severe intellectual and/or physical disability.
- The child is older than six years and conservative treatment is failing. Maturation of orofacial function can continue up until the age of six in children with developmental disabilities, so surgery is not usually offered prior to this age.

Figure 6. Absorbent scarf

The range of surgical options include denervation of the salivary glands, removal of salivary glands, ligation of salivary ducts and relocation of ducts.

Figure 5. Waterproof backed bib







The benefits of denervation (cutting autonomic nerves) are lost within a year, possibly because the nerves regenerate. Nerves transmitting taste sensation are also divided.

Isolated salivary gland removal may result in compensatory overactivity by the remaining salivary glands. Severe reduction of saliva causes xerostomia (dry mouth), increased dental decay and worsening of swallowing problems.

The preferred procedure at the present time is relocation of the submandibular ducts along with excision of the sublingual glands. With any surgical procedure for saliva control, it is important to ensure that good dental health is maintained in the months and years following surgery. All young people who undergo surgery are followed up carefully by dentists as there is an increased potential for the development of dental decay.

Compensatory strategies

Saliva causes staining of clothes and can be smelly and offensive if the drooling is severe. When the child is young, waterproof backed bibs can be changed frequently (Figure 5). As the child grows older, there needs to be more appropriate ways of disguising the dribbling:

Scarves may be worn around the neck to absorb the excess saliva.
These may be backed with absorbent fabric such as towelling.
Matching scarves worn with different outfits can be a sophisticated way of disguising the dribbling. It is a good idea to have several of the one colour as they will need to be changed regularly (Figure 6).

- Towelling panels can be sewn into windcheaters to absorb excess saliva. Waterproof material can be sewn in to line garments to keep the wet fabric away from the skin.
- Vests that are easily changed can be designed to go over dresses.
- Velcro can be sewn onto clothes and motifs/collars attached. When the motif gets wet, it can be quickly replaced with another one.
- Windcheaters that have a raised motif on the front can give the appearance of a windcheater which is drier for longer.
- Plain materials show the dribbling more. Choose patterned materials (Figure 7).
- Towelling sweatbands can be used as cuffs for wiping saliva (Figure 8).

Conservative approaches to saliva control

A number of conservative strategies are considered which aim to:

- Improve/maintain oral health.
- Help the child to be more aware of saliva and oral musculature.
- Help the child to improve the frequency of swallowing.
- Improve oral tone and movements in and around the mouth.

1. Oral health

Saliva protects the teeth from attack by neutralizing the acids that are produced after eating and drinking. Saliva normally provides a protective barrier against sensitivity, erosion and decay. Adverse changes to the quantity and quality of saliva may occur following management of drooling either by medication or surgery. As a result, the teeth are more susceptible to plaque retention and associated dental disease such as decay or gingivitis (gum inflammation). Therefore the maintenance of optimal oral health is essential.





Figure 7. Patterned materials or those with a raised motif disguises wet patches



Figure 8. Towelling sweat bands

Oral care at home

Good oral hygiene can be maintained by brushing thoroughly twice a day with a soft-bristled manual or electric toothbrush and using fluoridated toothpaste. Children with good manual dexterity should be encouraged to brush their own teeth. Parents and carers need to assist with thorough brushing at least once a day particularly when cerebral palsy and/or oromotor dysfunction is present. Replace the toothbrush every three months or sooner if the bristles begin to look worn out. Clean between teeth regularly using dental floss or "flossettes" to remove plaque from areas that the toothbrush cannot reach.

Professional advice and care

Regular dental visits every 4–6 months are important for detection of early signs of dental disease and for appropriate preventive strategies to be implemented. If an individual is prone to plaque build up, bad breath (halitosis), and/or subsequent gum problems, the dentist may recommend the following:

- A professional scale and clean to remove plaque and tartar every 3–6 months.
- Use of a mouth rinse following regular tooth brushing and flossing.
- Placement of dental sealants that fill the pits and fissures with a plastic resin material that prevents plaque from being trapped, thereby preventing dental decay.

When dental decay has occurred, the dentist may recommend some products in addition to toothpaste to provide more protection against tooth decay:

 Topical Fluoride—this may be applied in the form of a gel, tablets or rinse. Fluoride makes teeth more resistant to the acids produced after eating or drinking. Fluoride also puts back minerals that are lost from teeth and can reverse the early signs of tooth decay. Tooth Mousse®—this product contains calcium and phosphate, the major minerals found in teeth. Because these minerals are carried in a special milk derived protein called Recaldent they are available in a soluble form. Tooth Mousse® can protect the teeth like saliva and replace minerals lost by regular acid attack after eating and drinking. It is usually used twice daily after brushing and should be left in contact with the teeth for at least three minutes.

"Tooth friendly" food and drink tips:

- Encourage healthy snacks such as dairy products (e.g. milk, yogurt and cheese), plain popcorn, fruit and vegetables in place of sugary snacks.
- Avoid foods such as honey, dried fruits, lollies, sweet biscuits, jams, cakes, sugary breakfast cereals, muesli bars and fruit roll-ups.
- Keep healthy snacks readily available for children to eat.
- Limit intake of acidic and sweet drinks such as fizzy colas, sports drinks, fruit juices, fruit drinks, cordials.
- Drink lots of water. Note that not all bottled water has fluoride to help prevent tooth decay.

2. Oral awareness

Many children seem not to notice the saliva until it is too late. When we get enough saliva in our mouths we swallow it automatically and thus we do not dribble. This does not seem to happen in children who dribble. Some children seem very unaware of what is in and around their mouths and can be messy eaters. Building up the child's awareness of saliva both inside and outside of the mouth is very helpful. Please be guided by your speech pathologist about which strategies are most appropriate. Battery operated vibrators can be used to stimulate the muscles in the cheeks and around the lips. Vibrators come in all sorts of shapes but you



Figure 9. Stimulation of lips and cheeks with an electric toothbrush







Figure 10. Activities to keep the hands out of the mouth

should use a small one (or one with a small head). The back of the head of a battery operated toothbrush can also be used (Figure 9).

The use of ice can help to improve impaired sensation. Research has shown that touching the arches at the back of the mouth (fauces) with a thin stick of ice increases the ability to swallow frequently.

3. Mouthing

Some children love to suck their fingers and when their hands are in their mouths, drooling becomes worse. Children often suck their hands for comfort and because they like the sensation. It is best to give the child something else to do, for example:

- Provide an activity that requires the use of the hands, for example, a puzzle or toy, a mobile, or playing in water (Figure 10).
- Provide an activity for the hands that gives a very positive sensory feel, for example, a vibrating toy/cushion, a box of scarves or finger painting.
- Engage the child in some other way, for example, reading a book together, singing or playing hand games. Some children will respond to either verbal or visual prompts to take their hands out of their mouths.

For those children who suck their hands habitually to such an extent that their skin gets broken and sore, the following can be tried:

- Ask an occupational therapist for some advice. Sometimes the use of brushes to provide deep sensory stimulation to the muscles and nerves can be very satisfying for a child and encourages them to use their hands differently.
- Wear gloves with a range of different textures attached, for example, bells or pot scourers, so the child plays with these objects rather than their fingers. Make sure the objects are firmly attached.

- Put different tasting or unpleasant substances on the fingers.
- Elbow splints can be used to stop the child putting their hands into the mouth and can be designed so that the hands can still be used.

4. Lip seal

Many children have lax lips that are incapable of making a firm seal. Some children have a retracted and short upper lip or have protruding teeth so that their lips are unable to meet. Inability to bring the lips together makes it more difficult to swallow properly and this may result in drooling.

A series of exercises can be tried and it is important to make them fun. Team games can be used for groups of children.

- Use facial expressions, for example smiling, frowning, pulling faces in the mirror (Figure 11).
- Lip articulations-mmmm, bbbb, ppppp, raspberries.
- Play kissing games—put lipstick on the lips and leave a kiss on a mirror, tissue or hand.
- Blow musical instruments e.g. harmonica, party whistle.
- Hold paper or a spatula between the lips for increasing amounts of time.
- Practice obtaining lip seal around an oral screen (Figure 12) placed in front of the teeth as a "mouth guard".
- Suck liquid up a straw. Start with a short straw. Clear plastic tubing may be easier to use rather than straws. Thicken the liquid, for example, provide a thick shake to make the task more difficult.
- Hold a bent full straw of liquid (with your finger over the top), release small amounts of liquid from the straw into the space between a child's front lip and teeth (buccal cavity). Encourage the child to suck up the liquid.





Figure 11. Games practicing different facial expressions





Figure 12. Oral screen



Figure 13. Blowing games

- Blowing games such as blowing out candles (start with one candle and work up), puffing bits of tissue or table tennis balls across the table. Children can be encouraged to blow out their cheeks and push the air from one side to another. Use a mirror to help them understand what is required (Figure 13).
- Play games that require sucking air up a straw with the objective of picking up a pea or small pieces of paper. Ensure that the peas are larger than the straw! Count how many peas can be placed into a container in 3 minutes.

5. Learning to wipe and recognising when saliva has escaped

Lots of children who drool have difficulty in knowing if their lips and chin are wet and because of this, they do not think to wipe. It is helpful to put in place reminders for them, such as a cue or a reward. It is also useful to teach "swallow and wipe" together because the mouth is cleared of saliva with each wipe. Verbal reminders need to be very frequent. The following suggestions may also be useful:

- Use touch cues; sometimes pressing a finger on the child's top lip helps them to swallow.
- Use visual cues such as coloured dots. When the child sees them, a swallow/wipe occurs. Signs such as parents touching their own lips with their fingers can be a cue.
- Use auditory cues such as setting a kitchen timer and encouraging a swallow/wipe after the buzzer. "Acualarms" are buzzers that fit into an earplug. Speech pathologists can provide further information.
- Read a book. Swallow and wipe every two pages.

Praise is a good reward. Food is not a good reward because it makes the child produce more saliva. However food rewards can be used for a period of time, for example, if the child can stay dry whilst watching television, then a food reward could be offered such as a chocolate milkshake. However, items such as stickers or collectibles are preferable. Always make sure there are plenty of opportunities for success. Make sure to check the child's chin. When it is dry, praise or rewards can be given.

Provide a handkerchief, remembering that many children find it difficult to remove one from their pocket. They can have a handkerchief tied to their wrist for easy access or alternately, a sweat band on the wrist can be used to wipe the chin (Figure 14). People in wheelchairs can have a foam ball on a goose neck stand fitted. A handkerchief is placed over the ball and changed as required.



Drug therapy

1. Benzhexol hydrochloride

Benzhexol hydrochloride (alternatively known as Artane) can help reduce drooling. The dosage required for any individual is quite variable. A low dose is used initially, and if this is not effective, the dose is increased. The medication begins to act within an hour, peaks at 1-3 hours, and the duration of action is 6-12 hours. It is best to take the medication at breakfast, and then either at lunchtime or after school. The tablets should be taken with meals. If they cannot be swallowed, they can be crushed and placed in food. Other management programs, for example, encouraging the child to wipe, should still be continued.

Worthwhile effects can be obtained in many patients. If there are no beneficial effects at all, the tablets should be discontinued after a six week trial.

Side effects are uncommon, but it is important to be aware of them. The side effects include a change in behaviour such as irritability or confusion, blurred vision, constipation, difficulty passing urine and flushed dry skin. As with any drug, other side effects are possible but unlikely.



If there are concerns about possible side effects, it is best to stop the tablets. In addition, it is advisable to withhold the medication on very hot days because of possible impairment of sweating.

The recommended dosage regime is as follows:

- Artane 1 mg (half a tablet), twice daily for one to two weeks (at breakfast and then at lunch time or after school).
- If there is no improvement, the dose is increased to 2 mg (one tablet), twice daily for a further one to two weeks.
- The dose may be further increased to a maximum of 2 mg (one tablet), three times daily (at breakfast, lunch and evening meal).

2. Glycopyrrolate

Glycopyrrolate (alternatively known as Robinul) can also help to reduce drooling. The dosage required is quite variable. A low dose is used initially, and if this is not effective, the dose is increased. The duration of action of the medication is 8–12 hours. It is best to take the medication at breakfast, and then either at lunchtime or after school. The tablets should be taken with meals. If they cannot be swallowed, they can be crushed and placed in food.

Good effects are reported in a large proportion of individuals. If there are no beneficial effects, the tablets should be discontinued after the six week trial.

Side effects are said to be less frequent than with Artane (Benzhexol Hydrochloride). A change in behaviour or confusion, blurred vision, constipation, difficulty passing urine and flushed dry skin are possible side effects but are extremely unlikely. As with all drugs, other side effects are possible. The tablets should be stopped if there are any side effects. In addition, it is best to withhold the medication on very hot days. The recommended dosage regime is as follows:

Glycopyrrolate 0.01 mg per kg per dose. The medication is taken twice daily, and is best given at breakfast and at lunchtime or after school. There is 1 mg of glycopyrrolate in each tablet. The individual dosage will be calculated for your child and will depend on his/her body weight. Depending on body weight, the starting dose may be as follows:

| Child's weight | First dose | If no improvment after one week increase to: | If no improvement after a further two weeks increase to: |
|----------------|---------------------------------|--|--|
| 10 – 15 kg | 1/4 tablet twice daily | 1/2 tablet twice daily | 1 tablet up to three times daily |
| 15 kg – 25 kg | 1/4 – 1/2 tablet twice daily | 1 tablet twice daily | 1 tablet three times daily |
| > 25 kg | 1 tablet twice daily | 1 tablet three times daily | 11/2 tablets three times daily |

The dose may be further increased to a maximum of 0.04 mg per kg per dose three times daily (at breakfast, lunch and evening meal).

3. Botulinum toxin

Botulinum toxin A (e.g. Botox) has been used in the management of spasticity (tightness of muscles) in conditions such as cerebral palsy. The drug works by blocking the transmission of nerve impulses to muscles, sweat glands and salivary glands.

The drug is injected directly into the saliva glands, under the guidance of an ultrasound (non invasive scanner). The procedure is done under a brief general anaesthetic as a "day stay" in hospital. Four injections are given, each of approximately 1 ml.

The drug binds to the nerve endings to reduce the amount of saliva produced from the injected salivary glands after about three days. The effect may last for up to 3–6 months. There may be the added benefit of encouraging some patients to cope with their reduced saliva production and to slowly learn how to manage their drooling as the effects wear off.

In some cases it may not be an effective treatment. A poor response to Botulinum toxin injection does not necessarily mean that surgery will be ineffective. The side effects may include minor bruising and swelling in the area of the injections as well as the possible side effect of a brief anaesthetic. Occasionally speech and swallowing can be affected after an injection in the region of the neck, possibly due to the drug spreading beyond the injected glands and weakening the muscles of the throat.

Our results with Botulinum toxin injections are being carefully monitored. All patients undergoing this procedure are followed up with questionnaires as well as clinical review.

Saliva control surgery

Saliva control surgery is proving to be a very effective procedure at The Royal Children's Hospital. Surgery consists of removing the sublingual glands and relocating the submandibular ducts to a position at the back of the tongue (Figure 15). The aim is for the redirected saliva to be swallowed instead of escaping from the mouth. There is worthwhile improvement in 80% of patients. Patients who do not show any improvement may be offered additional minor surgery.





Figure 16a,b,c. Initial dissection of submandibular ducts and dissection of and removal of sublingual glands. **16d.** Transposition of dissected submandibular duct by passing it posteriorly through the base of tongue. **16e.** Insetting of the submandibular ducts in their new location just anterior to vallate papillae in the base of tongue.

The operation lasts for approximately one hour and requires a general anaesthetic. (Figure 16a to 16e). A temporary stitch is placed in the tongue in order to keep the airway clear and this is left in place for up to 24 hours. There is swelling in the mouth for a few days and intravenous fluids are given to maintain hydration during the first 24 hours. The hospital stay is usually three to four days. Patients should eat soft food for 1–2 weeks after the operation.

Following surgery, children are reviewed by the multi-disciplinary team and drooling assessments are completed at one month, six months, one year, two years and five years postoperatively. Good oral care with regular dental check ups (every six months) is very important after the surgery. Saliva is protective for teeth and moving it to the back of the mouth puts the front teeth in danger of developing decay. Please tell your dentist about this operation. A dentist will check the teeth at the saliva control clinic follow up appointments.

It is a significantly invasive surgery. Possible early complications, which may occur with any operation, include bleeding, swelling or infection. One rarely reported complication is severe or prolonged swelling of the tongue requiring admission to the Intensive Care Unit. Possible late complications are swelling in the glands in the floor of the mouth which may need another operation.

appendix

Appendix A – the most recent surgical results at RCH

Seventy-two patients (36 females and 36 males) underwent bilateral submandibular duct transposition (BSMDT) and bilateral sublingual gland excision (BSLGE) for drooling between 1993 and 2001. The age at surgery ranged from 4 to 19 years with a mean age of 10.4 years. Thirty-eight children (52.8 %) had cerebral palsy, 27 (37.5%) had intellectual disability, 3 (4.2%) had developmental delay and 4 (5.6%) had other disabilities. Thirty-three patients (45.8%) also had documented epilepsy. Five patients were lost to follow-up before two year measures were recorded.



Results at two years

Data were available at two years for 67 of the 72 children. Drooling frequency was improved by one point or more (clinically significant) in 39 patients (58%). The median frequency score fell from 4.0 to 2.9 (p<0.0001) (Figure 17a). Fifty-two patients (78%) had an improved drooling severity score that was clinically significant (one point or more) and 31 children (46%) had an improvement on the severity scale of two or more points. The median score decreased from 4.8 to 3.0 (p<0.001) (Figure 17b). Data on the number of bib or clothing changes per day were available for 56 children. The median number of bib or clothing changes fell from four (interquartile range 2–7) pre-operatively to zero (interquartile range 0–3) at two years (p<0.0001). Carers of 58 patients gave an estimate of the percentage reduction in drooling. The median reduction was 75%. In 44 of these 58 patients (75.9%), carers reported 50% or more reduction in drooling. Only three patients (5.2%) were assessed by their carers as not improving and these children went on to have a subsequent single parotid duct ligation. Two patients had already proceeded to parotid duct ligation prior to the two-year assessment.





Figure 17b. Severity of drooling pre-operatively and at two years post-operatively



Figure 18a.

post-operatively

Frequency of drooling at two years and five years

Results at five years

Fifty-three patients reached the five year follow-up but only 41 had sufficient data for analysis. There were no significant differences in the two year improvement in drooling frequency and severity between the 12 children who were lost to follow-up and the 41 who were retained in the study.

In 27 of the 41 patients (66%), the drooling frequency score was still at least one point below the preoperative level. The median frequency of drooling score of 3.0 was not significantly different from the median at two years (Figure 18a). In 27 patients (66%) the drooling severity score was still improved by one or more points from the preoperative level. Sixteen children (39%) had a reduction in severity score of two or more points. The median score for severity of drooling was 3.0 at five years which was the same as the median score at two years (Figure 18b). Data on the frequency of bib or clothing changes were complete for 29 patients, and the median number of changes was one per day, a decrease of three from the preoperative level and an increase of one from two years postoperatively. Five patients had unsatisfactory outcomes and underwent parotid duct ligation at a mean interval of 26 months post surgery (range 11-48 months).

Complications

Figure 18b. Severity of drooling at two years and five years post-operatively

2 years 5 years

Overall 13 patients (18%) experienced complications. These were minor in six patients (8%) and major in seven (9%) (Figure 19). The complications included minor bleeding in one child and major bleeding in three. Major tongue swelling causing airway obstruction was short-lived in two and prolonged in one child. There was one submandibular abscess requiring drainage, one partial lingual nerve division and one aspiration pneumonia. There were no ranulae (sublingual gland cysts).

Figure 19. Post operative complications

| Major complications | Number of patients |
|---------------------------------------|--------------------|
| Bleeding major | 3 |
| Major tongue swelling | 3 |
| Aspiration pneumonia | 1 |
| Minor complications | |
| Partial lingual nerve division | 1 |
| Submandibular abscess/wound infection | 2 |
| Bleeding minor | 1 |
| Slow recovery/delay to normal feeding | 2 |
| Total | 13 |

Appendix B – assessment and measurement forms

Drooling measures form

Name of child: Date: / /

Form completed by:

Relationship to child:

1. Is your child currently on medication to reduce drooling? (please tick)



If yes, please give name and amount taken during the last week:

2. Has your child been well over the past week? (please tick)



If no, please give details of illness:

3. Rating scale. Please discuss these with anyone who knows your child well and circle the number which best reflects the severity and frequency of drooling over the past week:

Frequency

| 1. No drooling – dry | |
|----------------------|--|
|----------------------|--|

2. Occasional drooling – not every day

3. Frequent drooling – every day but not all day

4. Constant drooling – always wet

Severity

1. Dry – never drools

2. Mild – only the lips are wet

3. Moderate – wet on the lips and the chin

4. Severe – drools to the extent that clothes and/or objects get wet

5. Profuse – clothing, hands and objects become very wet

4. On an average day over the past week when your child was at home:

How many times did you change your child's bib?

How many changes of clothes did your child need?

For questions 5-14, please circle the number between that indicates the extent to which drooling has affected you over the past week.

5. How offensive was the smell of the saliva on your child?

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
|---------------|-------------|-----------|-----------|-----------|-----------|-----------|-----------|------------|---------|--------------------------|--|
| | No smell | | | | | | | | | Extremely offensive | |
| 6. How | much skin i | irritatio | n (rash) | has you | r child h | ad due | to drool | ing? | | | |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
| | None | | | | | | | | | Severe rash | |
| 7. How | frequently | did you | r child's | mouth r | need wip | oing? | | | | | |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
| | Not at all | | | | | | | | | Constantly | |
| 8. How | embarrasse | ed did y | our chile | d seem t | o be ab | out his/ł | ner droo | ling? | | | |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
| | Not at all | | | | | | | | e | Extremely embarrassed | |
| 9. How | much were | you w | orried by | / other p | eople's | reaction | ns to you | ır child's | droolir | ng? | |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
| | Not at all | | | | | | | | | Extremely worried | |

10. How much do you have to wipe or clean saliva from household items e.g. toys, furniture, computers etc?

| | 1 Not at all | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Constantly |
|-----------------|-----------------|----------|------------|-----------|------------|----------|-----------|-------------|----------|------------------|
| 11. Hov | v often did | your ch | ild have | severe | choking | or coug | hing epi | sodes d | ue to sa | aliva? |
| | 1 Never | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Every day |
| 12. To v | vhat extent | : did yo | ur child's | s droolin | g affect | his or h | er life? | | | |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| | Not at all | | | | | | | | | Greatly |
| 13. To v | vhat extent | did you | ır child's | drooling | g affect y | ou and | your fan | nily's life | ? | |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| | Not at all | | | | | | | | | Greatly |
| 14. To v | vhat extent | : did yo | ur child's | s droolin | g affect | others o | outside t | he imm | ediate f | amily? |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| | Not at all | | | | | | | | | Creatly |

15. Was your child on other medication over the past week?



If yes, please include names of medication below:

16. Has your child had saliva control surgery?



If yes, go to question 17

17. Overall, how has the drooling been since the surgery?

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---------|----|---|---|---|---|---|---|---|------------------|
| M | uch wor | se | | | | | | | | Much improved |
| | | | | | | | | | | |

18. How satisfied are you with your child's saliva surgery?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|----------------------|---|---|---|---|---|---|---|---|------------------------|
| Very dissatisfied | | | | | | | | | Extremely satisfied |

19. Would you recommend this surgery to other families in the same circumstances?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|--------------------------|---|---|---|---|---|---|---|---|---------------------|
| Definitely discourage | 2 | | | | | | | | Highly recommend |

| Saliva control assessment form | 5. Lips: |
|---|---|
| Date: / / Name of child: | Can hold lips together easily and for a long time |
| Form completed by: | Can hold lips together with ease for a limited time |
| Relationship to child: | Can hold lips with effort for a limited time |
| | Can bring lips together only briefly |
| 1. Communication skills: | Unable to bring lips together |
| No problems | |
| Some speech | 6. Can s/he pucker lips (as in a kiss)? |
| Uses speech to get message across but with difficulty | Yes No Unsure |
| Has difficulty making some sounds in words | 7. Does s/he push the tongue out when swallowing? |
| Has no speech | Yes No Unsure |
| | |
| 2. Walking: | 8. Straw: |
| No difficulty | Can use a straw easily |
| Has some difficulty, but walks independently without an aid | Has difficulty using a straw |
| Needs a walking aid | Cannot use a straw |
| Uses a wheelchair all or most of the time | Q Enting: |
| | |
| 3. Head position: | Can eat hard foods that are difficult to chew |
| Can hold head up without difficulty | Can eat all foods but is a messy eater |
| Tends to sit with head down mostly | Needs to have food cut into small pieces |
| | Food needs to be mashed |
| 4. Is the mouth always open? | Food needs to be pureed |
| Yes No Unsure | Has food through a tube (nasogastric/gastrostomy) |

10. Is s/he a messy eater?

| Yes No Unsure |
|---|
| 11. Can s/he swallow saliva when asked to? |
| Yes No Attempts Unsure |
| 12. Does s/he notice saliva on lips/chin (perhaps tries to wipe chin)? |
| Yes No Unsure |
| 13. Your child's general health: |
| Does s/he have asthma? |
| Yes No Unsure |
| Does s/he have frequently blocked or runny nose? |
| Yes No Unsure |
| Does s/he have bouts of pneumonia? |
| Yes No Unsure |
| 14. Do you have any difficulties with teeth cleaning? |
| Yes No Unsure |
| 15. Has your child seen a dentist? |
| Yes No Unsure |
| If yes, who? |
| 16. Are there any problems with bleeding gums or decayed teeth? |
| Yes No Unsure |