## Inquiry into Dental Services in NSW

Organisation:		
Name:	Ms Alexandra Clark	
Telephone:		
Date Received:	3/06/2005	
Theme:		
Summary		

## SOCIAL ISSUES COMMITTEE

3 JUN 2005

**RECEIVED** 

STANDING COMMITTEE INTO SOCIAL ISSUES NSW PARLIAMENT MACQUARIE STREET SYDNEY 2000

1 June, 2005

## [INQUIRIES INTO DENTAL SERVICES]

Dear Sir/Madam,

Re: Inquiry into Dental Services in NSW

For what it's worth, I would like to contribute my thoughts and experiences in relation to the dental services in NSW, and in particular with regards to my own personal experience with both Liverpool and Westmead services.

I am, however, concerned that once I have done this I am not likely to be greeted with a welcome note. This is a particular concern with me as I still take my son to the Paediatric department and, although part of the same system, I have no major complaints about this department.

First a little history on my health background. I suffer from scleroderma – a condition that initially affects the connective tissues within the body, causing scarring and shrinking of tissues. It affects most of the internal organs, and my case is no different, with one of the main affected part is the oesophagus. For this, I have been on prednisolone for the past 22years or so. This has eventuated in osteoporosis, easy bruising, and thinning of my skin, often described as 'tissue-like'. This is also a fair description of the surface within my mouth and gums. I also suffer from Sjörgens – dryness of the mouth, tear glands and similar fluid secreting glands.

This affects my mouth/teeth in the following manner: My gums are shrinking and receding, exposing more and more the root of each tooth, which does not have the same enamel protection as the top part of the teeth. My mouth (lips) is also shrinking, which means it is getting more and more difficult to maintain a high degree of dental-care for me, particularly as I also have arthritis on the hands. The dryness of the mouth also means I have limitations as to my food and nourishment intake and need to maximise this.

Should I have the need to remove all teeth, false teeth is not an option, as I would more than likely have constant tears, and ulcerations through the mouth.

Over 24 months ago, I began to drastically and inexplicably lose weight, my weight falling to an alarming 44kg around twelve months ago (I am 167cm tall). Nutrition intake and the need of good dental care could not have been more obvious and necessary to me.

Having only one income to the household, and my disability payment of just \$56 per week, to support a working man, myself and a 9 year old child who has autism and therefore special needs (my Carer's Allowance is also just \$46 per week), I opted for care with the public system - first approaching Westmead to be told I had to go through Liverpool.

At that particular time, I had a very sore tooth (a lower molar) so I made an appointment for Liverpool on a Monday.

When I was examined, and my health history taken, it was suggested to me I return the next day, as the Westmead specialist (Anastasia Giourgio) was attending Tuesdays at Liverpool and she had knowledge and interest in patients with scleroderma.

I returned the next day and Dr Giourgio examined me, gave me an outline of possible care and steps to take, and asked if I was happy to have my file transferred to Westmead as this is was her base. Some of her suggestions were to have some of the outer teeth removed to allow me to better care for my teeth, and to make it easier to work in my mouth as, with the progression of time, we would expect to see further shrinking of the mouth. She also showed concern that there were hardly any proper teeth left for chewing. I suggested I would be happy to look at tooth implant (1) if necessary, and happy to pay for it myself, only asking for assistance in the time allowed to pay for it. She said this is certainly something we could investigate in the future, but did not give me a certain response – which was fine with me. She said she would take my file and have someone contact me with an appointment in the near future. This gave me hope – at least I had come across someone who understood the complications I faced as the result of my health condition. The importance of my teeth and mouth in general had not been more of an issue with me.

I stopped seeing my regular dentist – the cost was getting far too much for me – and waited for my appointment for Westmead, still nursing a now very painful sore tooth.

Time passed on and still no word from Westmead, so I contacted *them* instead, having Dr Giourgio's name as my only key link. After a few phone calls within as many days, I was contacted and given an appointment time.

However, it was another doctor who saw me, and I was told that Dr Giourgio did not actually see patients. As a matter of fact, the doctor I saw was even reluctant in listing me to have any teeth removed (even discouraging me in saying that there would probably be a wait of about 2 years for me) Personally, I don't think he had much knowledge of scleroderma and the overall effect on teeth, or for that matter much interest in helping me.

A relatively short time later, my 'sore tooth' (which was actually a frail amount of enamel surrounding a very old filling) crumbled and I had to go in quickly to have it removed. I saw yet another doctor. I was now left with only nine teeth on the bottom jaw, four counting from the centre to the right side. The upper jaw had two teeth on the right hand side and one on the left-hand side, which had nothing to bite against.

After this incident, I was once again given an appointment at Westmead, and after a 'thorough' examination, this time it was suggested I have 3 teeth from the upper jaw taken out – no consideration given to the fact that I would have nothing to chew with! - And again I was told that there was over a two year wait because the procedure was seen as 'selective'. There was no care, no compassion or consideration, given the fact that I was still very much underweight and actually relied on my teeth heavily for my food and nutrition intake.

I was also 'complimented on 'how well' I looked after my teeth and that they were fine... until I pointed out that the last tooth removed actually exposed what felt to me as a huge hole on the side of the tooth.

Without so much as a comment or apology, the doctor finished his notes and told me to wait outside, where later on a dental nurse approached me and told me I needed an appointment for a filling (the one that I had pointed out).

The filling was at a later date done, but even to me it felt rough and rugged – almost as if rushed. After much emphasis from me, explaining my situation and condition, appointments and arrangements were made for me to have two teeth removed (one from either side) of the upper jaw. I still had to make sure they did not take the third.

After surgery, I was allowed to go home and – again despite my condition, my long history of prednisolone and therefore the possibility and probability of bleeding, I was refused a piece of gauze for

each side of the mouth and was told that it was hospital policy. I actually had to go home and get my own gauze, and if I bled on the way... tough luck. Let me point out at this stage that I also have hepatitis C (obtained through a blood transfusion in the early 80s). Imagine my dilemma and feelings at the thought of 'what if I bled' as I walked down the corridor towards the car.

A follow up check-up showed the stitches healing quite well, and therefore the 'job was done' – that is, there was no more to do with me or my dental care.

When I asked about having the teeth properly cleaned, fluoride treatments and follow-up appointments (referring back to the exposed tooth roots) I was told that 'they don't do that any more as it is not seen as a necessary procedure'. The doctor even went as far as telling me that it has been concluded that fluoride treatments are basically a waste of time and effort.

I have since given up on the public system and have had to go back to my usual dentist who, on reexamining me, discovered there were still 3-4 tooth decay spots which she had identified in 2003. Westmead doctors and staff had given me the 'all-clear' even with new x-rays taken, and only did one filling after I pointed it out.

In all honesty, I am disgusted with the system – the lack of care, concern, or interest on behalf of the doctors, at least the ones I encountered, except for Dr Giourgio. I was also annoyed at the way in which I was treated upon insisting to be marked as Dr Giourgio's patient. I was told that she was still my doctor, that is, overseeing what was being done. I even doubt if she was aware that I did get any treatment.

A lot of time was wasted following 'protocol' which in my view is cost and time consuming. Too much run-around given to me even from my original inquiry as to how to get treatment.

No care seems to be given for individuals – no interest in helping persons who, like myself, want to do all possible to save their own teeth, to avoid the possibility of the need to have more teeth removed and to be able to maintain that part of the digestive system which weights heavily on our food, energy and nutritional intake, and is therefore crucial to the rest of the body and to our being and well-being.

I don't know if the solution is more funds, more training for staff, more training of medical dental staff who deal with the more complicated of conditions such as mine, more 'dealing with the public' training, more awareness of dental care as being not so much a 'vanity' issue, but an essential part of our existence and health.

For myself, I have concluded that better teeth means better nutrition and therefore (although not a cure in my case) at least a great contributor in preventing matters from getting worse.

After all, the bottom line is that everything falls back on our taxes. A little more here now may even represent a lot less there and in the future.

Sincerely

Alexandra Clark