Submission No. 136
(Inquiry into Obesity)
JE 16/09/08

Submission to the House of Representatives House Standing Committee on Health and Ageing: Inquiry into Obesity in Australia

I thank the Committee for the opportunity to make a submission and give evidence before it. As I understand it I am the only person to give evidence from a consumer/individual perspective and all but three of the submissions received to date have been from health professionals, research professionals or organized groups. To that end I feel it is very important that I speak up for those members of our community who, like me, are overweight or obese and have particular needs arising from that condition.

Firstly we should dispel some myths. In doing so, I am speaking generally, I do not profess to speak for all overweight/obese people and I recognise there are many exceptions to the rule. Not all obese people weight in excess of 150 kg like those described by Professor Katherine Samaras and her colleagues before this Inquiry. Those people are at the extreme end of obesity but are as equally deserving of the community's care, support, human consideration and services as those at the lesser end of obesity and those who are not obese or overweight.

1. Myth: Fat people are jolly.

   This is very wrong. Some people may appear jolly but they do so to hide the truth – they are miserable, ashamed, embarrassed – very often socially isolated and have enormous feelings of self-loathing and poor self-esteem and confidence.

2. Myth: being fat is self inflicted.

   Again, this is very wrong. People are overweight/obese for a range of reasons. This Inquiry has heard and/or received submissions from a large number of professionals working in this area of health and it is therefore unnecessary for me to go through them all. But as a person who has been overweight and/or obese for most of my life and knowing my life story, I am an example of the many factors which contribute to my condition.

3. Myth: fat people are lazy.

   Wrong. This is based on the belief that excessive weight/obesity is a self inflicted condition and if the person got up and did some exercise, they would not be overweight. If only it was so simple.

4. Myth: providing for overweight/obese people demonstrates acceptance of being fat and therefore discourages overweight/obese people to fix their problem.

   This is incredibly offensive. In one of the Sydney Sunday papers this previous weekend, there was an article critical of a major chain department store for now stocking fashionable clothes for young women sized 16 - 24. So called professionals were critical on the basis that by providing clothing in this size range, it would show an acceptance of obesity in young women and discourage them from doing things to lose weight. This logic buys into the myth that people want to be fat: we don't - we hate it. We want to not be fat. We cry and self loath daily and going shopping for clothes for everyday wear and special occasions is an enormously dispiriting, soul destroying experience. We hate the fact that because we are fat the choices available to us mean we have to look matronly. This is but one example- there are many more.

5. Myth: being fat is a demonstration of character weakness.

   In many ways the opposite is true. It takes a lot of fortitude to withstand the ridicule, derogation and discrimination we have to face every day. "Fat" is a derogatory term in our society. How often do we hear a person described as "a fat pig" or "a fat slob" or "she is really fat" when the speaker is being derogatory about another? I cannot tell you the number of times I have felt an overwhelming sense of shame and hurt when such a statement is made by a friend or colleague. I have at times tried to own the word "fat" in an attempt to have it not seen as derogatory or a failure - that is stating categorically "I am fat" but not in a demeaning manner and not in a proud manner either but rather as a statement of fact just as a thin person could say "I am skinny". It is extraordinary how many times the person I am saying it to (friend or colleague) squirms and/or responds with "you're not fat" or similar. The truth clearly makes them uncomfortable because of the negative connation attached to the word and/or concept.

   It has long amazed me that generally people have no understanding or sensitivity to the impact of the social stigma on the psychological wellbeing of obese people. I couldn't begin to count the number of times I have been verbally abused by strangers passing by (usually males) which has included the word "fat". Just as alarming, I have had friends and colleagues who have thought it reasonable to ask me questions such as

"well just how much do you weigh?" I have also suffered the indignity in a social setting of someone telling me I should not eat a particular food item such as bread.

There is a harsh reality for overweight kids and teenagers that they are rarely the first picked for a sports team if picked at all. Overweight/obese people of all ages, are ostracized socially and sometimes in the workplace. As a barrister I have represented and/or given advice to people who have suffered serious indignity in the workplace because of their obesity and its consequences. It takes enormous courage and strength to deal with these situations.

It takes a lot of strength to deal with the fact that your size is a factor in not gaining work opportunities or social acceptance. It takes even more strength not to hide behind and accept the discrimination but develop other aspects of yourself which allows others to look past your size. This is doubly hard for women in many areas of professional life because not only do you have to deal with the glass ceiling but also society's expectations of what a woman should look like.

6. Myth: fat people should be punished – it will make them change.

That is akin to saying people with any other disease, disorder or condition should be punished. No obese person chooses to be obese just as no person chooses to get another debilitating condition, disorder or condition. I recognise that I (and most obese people) have made a contribution to my obesity through poor choices but so do people who smoke cigarettes or drink 1-2 glasses of wine a night 7 days a week. They are not punished, nor seen as deserving punishment for their choices. But through derision, ridicule and discrimination, obese people are punished daily and the financial and social costs enormous. For those of us such as me with significant health complications, the cost of health care (including hidden costs) are enormous.

Due to my obesity and Diabetes, I cannot obtain income protection insurance. As a self employed person, if it is necessary to have any great period of time off work (such as for receiving treatment/care for my obesity and/or Diabetes or indeed any other illness), I cannot receive any kind of income support and cannot access my superannuation to assist the financial strain this causes.

There are also limitations on my general insurance and I cannot obtain life insurance, notwithstanding I have an otherwise clean bill of health.

My Story

I grew up in Alice Springs, the youngest daughter of a baker and tailor. My mother frequently told the story that my sister and I were given the same formula and same quantity as babies and whereas my sister would gain an ounce I would gain a pound. From that evidence, it is clear that I was unfortunately blessed with a genetic disposition towards obesity. My father being a baker was probably not conducive to my body weight but again, my sister had the same diet as I (and nowhere near as physically active) and was not overweight as a child or teenager. Although my sister was four years older than me, I was always bigger than her, both in height and body weight. I was always bigger than my school friends in respect of body weight although I would not describe me as being obese as a child.

I was a very physically active child and teenager. Alice Springs in the 1950's and 60's did not have access to entertainment such as television and theatres. If you did not play sport, your life was incredibly dull and lonely. Going for long rides on your pushbike with your friends was a weekly event in primary school. I participated fully in school based sports (which was an integral part of the school curriculum) which included (for girls) swimming, softball, volleyball, hockey and athletics. From about 11 years of age I played competitive softball. As a teenager I did competitive softball, swimming, basketball, bike riding and water polo (all at the same time) which meant I played and/or trained for sport 6 – 7 days per week. This continued until I was 19 years of age. Throughout this period I remained overweight, if not obese and certainly bigger than all of my friends.

At 19 years of age I moved away from my family and Alice Springs to undertake nursing training in Adelaide. Within 4 months of commencing my training, I stopped all competitive sport (it was incompatible to shift work) and really stopped real physical activity. It was also compulsory to live in the nurses' quarters for the first year and subsequently I could not afford to live outside the hospital. My diet became appalling – hospital food was inedible and directly opposite from the nurses' quarters was a fish and chip shop – my stable diet for 3 years became fish, hamburgers and steak sandwiches – always with chips and usually washed down with Coke. My weight escalated dramatically – gaining around 35 kilos in 3 years. I take responsibility for

the contribution I made to my health deterioration caused by my extremely poor diet and socially sedentary life style during this period and while I can put forward a number of factors which contributed to my dietary habits I don't resile from my poor exercise of choice. Soon after I commenced nursing, I would clearly have been medically described as obese and it soon began to have other health implications, particularly my mental health which, although I sought assistance from health professionals, were never identified or treated.

At the age of 32 I was diagnosed as having Diabetes Mellitus (commonly referred to as Type 2). I was shocked and devastated, I thought life as I knew it was over and my frequent awake dream was of having my leg amputated as I had seen so many times as a nurse. My health, including my psychological health, was not appropriately managed by my general practitioner and I was never referred to a physician or endocrinologist: diet and exercise were seen as the answer. I ignored it – I did not want to change my life style at all and I did not want to face reality. For the next six years, none of the general practitioners I saw in Adelaide or Sydney took any measures to monitor and appropriately treat my Diabetes and associated issues. My diet and exercise regime remained appalling during that time and I lived life as if I did not have either obesity or Diabetes. I remained significantly obese.

I moved to Sydney in 1988 and saw 4 different GP's between that time and mid 1994. None of them took any steps to monitor and/or appropriately treat my Diabetes notwithstanding having knowledge of the diagnosis and my obvious obesity – including no referral to an endocrinologist.

In 1994, I was quite unwell and went to a new GP who took a fasting blood glucose level – 23. I was shocked and terrified. She sent me to an endocrinologist at the Royal Prince Alfred Hospital who told me I could either start on a strict regime of diet and exercise or "go home and prepare to die". That was unbelievably brutal and I cried for several hours. But that brutality was life saving and it started me on the road to recovery.

I commenced seeing this endocrinologist but could only do so as a public patient through the Obesity Clinic. I also saw a dietician through that clinic but psychological support was not offered. Over a period of 18 months I lost about 15 kg and was under

the care of my new GP. The Clinic "released me" from their care after 6 months as I was on the road to recovery and the demand for the service was great.

After 6 years I wanted to return to see the Endocrinologist as my recovery had stalled with menopause but she did not see patients privately and because I had private health insurance, I could not access the services of the Clinic as a public patient notwithstanding I had previously been a patient.

From 1994 I was under the constant monitoring and care of an extremely good general practitioner who has been unbelievably supportive and caring. Even though she ceased general practice a year ago, she continues to stay in regular contact and provides ongoing psychological support. Unfortunately in my experience she is a rare general practitioner. Since having to find a new GP I have been shocked at the lack of interest shown by GP's in the health of patients such as myself and have felt disdain from some for being obese, including a clear attitude of disbelieve as to my efforts to lose weight and control my Diabetes.

From my experience since being diagnosed with Diabetes and obviously being obese for many years, there needs to be considerably more education of general practitioners about all aspects of obesity and the appropriate monitoring and care of patients with either or both diagnoses. This includes appropriate psychological care and most important the absolute need to take an interest in the health and well being of patients in a non-judgmental manner.

I cannot stress enough the need for psychological wellbeing care – there are so many issues which effect the mental well being of obese people which frequently contributes to the problem and the person gets caught up in the most vicious cycle – I can assure this Inquiry a major source of comfort to someone distressed and self-loathing because they are overweight/obese is food and the more fat/carbohydrate content, the more comforting it is. We also hide away from the world because of our feelings of embarrassment, shame and despair – that means we do not engage in the level of physical activity we really need. We don't want to look conspicuous sweating and puffing as we walk outside and feel the scorn of passers-by and so we take a bus – and when we are really overweight we don't want the embarrassment of taking up more

than 1 seat so we just go nowhere – we hide in our homes and trap ourselves further in the vicious cycle.

There needs to be significant recognition of the psychological impact on the individual and there must be a provision of psychological services to those identified by treating health practitioners as obese or potentially obese. This includes full Medicare rebate for psychological services in the private health sector and extensive provision of services in the public health sector.

My GP referred me to Professor Samaras at the time I was unable to re-access the Obesity Clinic at RPA. Professor Samaras has been incredibly supportive and caring. She is firm in her management but not judgmental and is very understanding. The major problem is Professor Samaras is incredibly good and therefore incredibly difficult to get appointments with. Notwithstanding that difficulty, Professor Samaras has helped me enormously and provided endless support to me through my recovery.

Throughout the last 14 years I have tried every diet including weight watchers, Optifast, CSIRO, home delivered calorie controlled meals and so on.

Under my GP and Professor Samaras' care, I increased my physical activity – I joined a gym and hired a personal trainer and changed my diet to a low carb diet. I lost weight initially but plateaued and then gained weight. Ultimately, I mostly stopped eating food – going on a predominantly Optifast diet for about 2.5 years. Again I lost weight in the beginning (but only about 10 – 12 kg) but then plateaued and, once food was introduced, gained weight.

I saw my GP at least fortnightly if not weekly for support, weighing and measuring through all this period – without that care and support I would have completely fallen by the wayside and I don't like to think about the probable consequences of that.

In December 2005, Professor Samaras suggested I have gastric banding and agreed to have the procedure. A week prior to the surgery date in February 2005, I decided I was not psychologically ready and cancelled the procedure and commenced on Optifast full time.

In 2004 I was diagnosed with a frozen shoulder which, the specialist advised me, was directly related to my Diabetes. This required cortisone injections and ongoing physiotherapy for 18 months.

In 2005 I was diagnosed with hypertension requiring medication.

In 2006 I was diagnosed with peripheral neuropathy in my hands which was again indicated by the neurologist as being directly related to my Diabetes. I was diagnosed at the same time as having bilateral carpal tunnel and advised by the surgeon and neurologist that there was a link to my Diabetes. This required surgery – the left being done in 2007 and the right still to be done which means I suffer from the effects 24 hours per day.

In October 2007 I was diagnosed with bilateral peripheral neuropathy in my feet – again directly related to my Diabetes. The effect of the neuropathy negatively impacts on my capacity to exercise.

I knew I had reached the point where bariatric surgery was the only real option for me. I had tried everything and while I wasn't perfect I had for 95% of the time done everything by the book in terms of eating and exercise. Throughout this my Diabetes was not stable with a wide range in BGL's – there were times I was at non-diabetic levels and other times when my BGL's were in the teens – a piece of fruit such as an apple or banana would push my BGL's up and I would feel considerably unwell. Through not eating food and particularly red meat, my Vitamin B12 became very low with resulting excessive tiredness and the necessity for supplements. I remained obese and I can honestly say, totally despairing and struggling to keep out of the vicious cycle.

Further, my lifestyle was seriously impacted upon – I could not go out for a meal with friends, I had to take my food and, when on Optifast, my Optifast when I went to family and other social events. When I went to Court I would have to take my Optifast with me and when not on Optifast, take my food because I could not buy over the counter prepared food. Simple pleasures like going to the cinema were difficult – there is always food around and always advertisements to entice you to the candy bar. I also stopped drinking alcohol – my drink of choice water. Life as a lawyer who doesn't drink can get quite isolating. Friends stopped inviting me out, work colleagues stopped asking me to lunch and would get annoyed when I reminded them that there were certain types of restaurants I could not go to when functions were being

organized. I became more and more miserable and I am certain that affected social and work relationships. I certainly became more socially isolated.

Ongoing management and care of my condition (Diabetes and obesity) has required regular and frequent:

GP visits – at least fortnightly many in excess of 30 minutes

Endocrinologist visits – bi-monthly

Blood analysis – bi-monthly

Ophthalmologist – annually

Podiatrist – quarterly

Cardiologist including tests – bi-annually

My medications were significant, for example in the last 2 years prior to the surgery they consisted of:

Diabex 1000 mg tds

Amaryl 1 mg daily

Mycardis 40 mg daily

B12 supplements – 3 daily

Multivitamins – 2 daily

My chemist bill each month was approximately $90

In relation to the Diabex, Amaryl and Mycardis, those drugs are subsidized and therefore a cost to the Commonwealth.

I have for many years had dental problems associated with my Diabetes. This has cost, and continues to cost me a huge amount of money. While I have had private health insurance at the highest possible level, the refunds have been reasonably insignificant. For example, 2 months ago, from a $350 bill for 2 fillings, I received $138 in refund.

I had bariatric surgery on 11 April 2008 and it was the best decision I have made, I wish I had been psychologically able to have it done in 2005.

I ceased taking Amaryl the day prior to the surgery. My BGL's are now stable although not yet non-diabetic levels but getting there and are within normal range all day each day. I am hopeful that within the next 3 months I will be able to reduce my Diabex and am optimistic that within 12 months I will be able to cease all medications.

Bariatric surgery is not a quick fix. As much as I wanted to wake up the next day and be slim and healthy – that is a fantasy that can never happen and it was never suggested that would happen. I was given realistic advice by Professor Samaras and Professor Lord (surgeon) – lose about one third of what's required to be lost in the first year; maybe off medications within one year.

The research is overwhelmingly to the effect that if I remain committed to the confinements the surgery imposes, my neuropathy will repair itself and the chances of further complications such as coronary and cardio-vascular complications will be significantly reduced. What massive savings to the health system and governments at both State and Federal level.

I have lost weight (and not an insubstantial amount) since the surgery. I would like it to be quicker but the doctors are pleased with my progress and it certainly fits within the advice of one third off in the first year. The possible success has to be considered in the context of my age, genetic makeup, menopause, obesity, Diabetes and medications. Taking those factors into consideration, I am doing very well. But I have to work – success isn't achieved by the surgery alone. I still have to be very careful of what I eat and maintain a low carb, low fat diet. I still have to exercise daily. However the surgery helps that happen. I can only eat small quantities of food and some foods such as apples, bread, raw vegetables are impossible to digest and cause pain and sometimes vomiting. The more weight I lose the more able I am to exercise. I walk to and from work daily (15 minutes each way), I intense walk and run for at least 45 minutes per day; I do an upper body/cardio mix regime for half an hour daily. I went in my first Fun Run/Walk last Sunday – would never have contemplated it previously.

However I remain socially isolated and there is a peculiar phenomena attached to losing weight – the more focused on your weight and body image, the worse you feel about yourself – the view of yourself as fat in a negative way becomes a bit consuming and it becomes extremely important to get professional psychological support which I have just commenced.

There has also been an incredible financial burden. I was without income for three months – this was approximately $65,000 of income I did not get in circumstances where I still had all of the expenses associated with maintaining my practice (which

are substantial) as well as my home expenses (again, living in Sydney, are substantial). I could not access any type of income support or my superannuation.

My medical expenses have been significant. In the last financial year I paid out $16,500 in medical and allied health costs and received in refunds $2,445.

The direct cost of the surgery was as follows:

Cost	Amount	Refunds	My Costs
Surgeon	$ 3,000	$ 767	$ 2,233
Asst Surgeon	$ 600	$ 143	$ 446
Anaesthetist	$ 1,491	$ 450	$ 1,040
Hospital bed 2 nights	$ 200		$ 200
Radiology	$ 185	$ 90	$ 95
Pre admission cost Hospital bed 1 night	$ 200		$ 200
Pathology	$ 218	$ 185	$ 33

Since my surgery, I have had weekly appointments with the general practitioner attached to Professor Samaras' Clinic for 4 months and now fortnightly; I see Professor Samaras and the surgeon every two months; I have now commenced seeing the psychologist fortnightly ($180 per session).

To date this financial year (that is less than a fiscal quarter) I have spent in excess of $5,000 (after refunds) on health and allied health professionals directly related to my Diabetes/obesity and, due to significant dental requirements, a further $3,500 will be spent before the end of September. I only recently became aware of the Chronic or Complex Illness Dental and Allied Health Professionals Scheme and so some of this cost will be offset by refunds - how much is yet to be determined. Unfortunately this is at a time when the Scheme is about to be cancelled, thus increasing my costs once again.

I have recently passed the Medicare Safety Net. What is very annoying about this is that none of the surgery costs are counted for the purposes of the Safety Net because they were inpatient services.

I have been fortunate that I have been able to pay for this care but it has been and continues to be a serious financial burden. I have read the submissions made to the Inquiry and I was so saddened by Submission # 18 - how she is so desperate to do

something about her obesity but the financial restraints, particularly in the current financial climate, prohibit her from doing so.

It is not possible to have this surgery done as a public patient, it can only be done privately and it is considered by Medicare to be cosmetic surgery. My surgeon cost me $3,000 – the Scheduled Fee is $767.20 of which I received $575.40 from Medicare the remainder of the Scheduled Fee through my private insurance. As listed above, there were other costs which were for services provided on an Inpatient basis: they don't contribute to the Safety Net.

With the issues of Obesity and Type II Diabetes at the forefront of the Government's agenda, the cost and lack of refund from Medicare and Medibank Private is a bit outrageous.

Looking at the submissions and research on obesity and Diabetes to this Inquiry, there is substantial evidence to show these two conditions are prevalent in poorer/working class communities but these are the people who could not access the care that I have been able. This is just wrong.

If the Committee is serious about this issue, and I have no reason to believe otherwise, there are a number of recommendations it could make to Government and, more importantly, pursue the acceptance by Government of the recommendations.

The recommendations should include the following.

1. Recognition and acceptance of obesity as a medical condition.
2. The funding for research into the biological mechanisms of obesity and its prevention to an extent commensurate with that of the problem in the community be significantly increased.
3. Government programs must recognise and accept diet and lifestyle change will not always be the answer for each individual to overcome obesity.
4. Provision appropriate and adequate funding for the management of obesity using integrated programs run in both the private and public health systems. Such integrated programs should be based on a holistic model so that there are both specialist and allied health professionals working as a team in the program.
5. Recognise the psychological impact on the individual and ensure the provision of psychological services to those identified by treating health practitioners as obese or

potentially obese. This includes full Medicare rebate for psychological services in the private health sector and extensive provision of services in the public health sector without the requirement of a Mental Health Care Plan and without limitation of 12 sessions.

6. The Chronic Illness Scheme is extended to cover all allied health professionals, include gymnasium membership and personal trainer costs and not be limited to 5 sessions for non-dental care.
7. Make drastic changes to Medicare funding so that a system is in place whereby a person with a chronic condition such as obesity is able to be obtain full rebate for health care services in the private sector including the costs of bariatric surgery.
8. Fund bariatric surgery in public hospitals.
9. Develop mechanisms to stop rorting of the health system through the establishment of 'super clinics'.
10. Provide appropriate training to all health professionals and particularly GP's on all aspects of obesity including the psychological aspects.
11. Ensure appropriate income support for all persons hospitalised with obesity related conditions and/or surgery.
12. Establish an advisory committee which monitors the provision of services specifically targeted to the treatment of obesity as well as assessing outcomes. It should be appropriately funded so that it can engage consultants and researchers to assess outcomes of programs. Further, the advisory committee should have consumer representation.