

Mrs Andrea Leadsom MP  
House of Commons  
London  
SW1A 0AA

02.05.2014

Dear Mrs Leadsom

### **NHS: Conn's Syndrome**

This letter outlines exceptional care that I have received in the NHS (as a constituent of yours), is not a complaint and I also raise two or three issues that I believe should be addressed for the benefit of both the NHS and wider UK Society, largely raising awareness. I relate to my medical history in relation to this horrible disease and this summary can be shared wherever you think fit. I apologise for layman's terminology but the medical issues are so complex that most people cannot understand the medical terminology. I have copied this to my GPs Surgery senior partner, my consultants, Dr Niki Karavitaki at Oxford University/Churchill Hospital and Professor Morris J. Brown at Cambridge University/Addenbrooke's Hospital. The opinions stated are my own as are any mistakes in the way that this subject matters are described by a patient layman.

In the UK according to the Government's own statistics:

#### **Blood pressure**

The prevalence of hypertension in 2012 was 31 per cent among men and 27 per cent among women, remaining at a similar level over the last few years. Between 2003 and 2012, the proportion of the population with controlled hypertension increased from 5 per cent to 9 per cent among men, and from 6 per cent to 9 per cent among women, a slight decrease from 11 per cent and 10 per cent respectively in 2011. The proportion of adults with untreated hypertension decreased from 2003 to 2012 for both sexes (20 per cent to 16 per cent among men and 16 per cent to 11 per cent among women). Whilst the proportion of women with untreated hypertension is about the same as 2011 the proportion of men has risen slightly resulting in a slight increase in the overall figures which had maintained a steady decline since 2003. Source - <http://www.hscic.gov.uk/catalogue/PUB13219>

Conn's syndrome is a far more serious subset of hypertension and published International Medical Research papers I have seen suggests anything from 5 to 15% of the population with hypertension will, or, may have Conn's syndrome and similar but much rarer diseases (Liddle's Syndrome being one).

Based on the 2011 census there were approximately 48.01 million people aged 20 (and over) resident in the UK including Northern Ireland. In simple terms therefore, taking into account the blood pressure statistics above there are in excess of 14 million males/12 million females with hypertension, a lot of it un-diagnosed in the UK.

Hypertension therefore creates massive cost implications for the Country both in NHS and workplace absence terms. Even if you take the lowest suggested research figure of 5% that suggests a Conn's syndrome population of 1.3 million people *may* exist – only experts in their field such as Professor Brown and Dr Karvitaki can confirm such research figures. I understand that those with Conn's are at far higher risk of stroke and heart attack as a result of the stress caused to our BP system and kidney functions.

I summarise my medical history of blood pressure below in terms of NHS treatment and one private treatment (from the NHS) received between 2000 and 2014. In 2000, I was diagnosed in a routine employment health check with slightly raised BP and advised to see my GP. BP and associated problems run in my family on my Mother's side.

Conn's Syndrome is usually associated with small benign tumours on one or both adrenal glands, which in turn causes a high output of hormone known as Aldosterone; This in turn causes one's Renin to go too low and the body to urinate out potassium; that then causes an imbalance in sodium/potassium ratio and sends BP onto an erratic and difficult to control spiral.

Maintaining potassium with this complaint requires specialist potassium retaining drugs and usually potassium supplements or eating potassium rich foods – dried apricots, raisins, baked spuds being the best. Normal BP drugs do not retain potassium, so if un-diagnosed the treatment is incorrect (in my opinion as a sufferer)

If your potassium levels are too low, you eventually die (!) – and if potassium goes too high, you die more quickly (!). Controlling the potassium is difficult because the tumour and drugs are fighting each other and regular blood tests are needed to monitor the levels in your system. Some of the drugs have wonderful side effects particularly for males – male boobs – which are very painful and not pleasant! If they eat liquorice then they can cause this problem temporarily so I believe and they should stop eating it. Coffee in moderate quantities also cause problems like palpitations.

Surgery cures or largely cures the problem if the tumour is only present on one side, dependent on age and length of suffering. Otherwise, as far as I understand it, drugs and constant testing are required for life.

Symptoms are also very erratic and internally speaking (blood) do not necessarily show up in routine blood tests; In my case I have suffered lots of severe muscle weakness and pain, palpitations, chest pain, brain fog, extreme tiredness, severe cramp attacks, sleeping problems, most of the time felt 'under the weather', dry throat and eyes constantly, extreme thirst, constant urination, extremely low potassium levels which were difficult to maintain before the full diagnosis, sleep problems and probably things I have not realized are connected. Some prescribed drugs, in my personal opinion, exacerbated the problem and side effects.

**To date, I have had the following treatment courtesy of the NHS:**

Seen at least 4-8 GPs on a regular basis over 14 years in my surgery;

Attended other local surgeries for locally based tests;

Been a patient and/or tested at Northampton, Milton Keynes, Oxford Churchill and Cambridge Addenbrooke's Hospitals;

Had one emergency admission to Milton Keynes hospital (4 days) plus ambulance and including 6-8 hours in A&E and all the cardio testing that followed;

Had one normal admission for keyhole surgery removing my LH adrenal gland and tumour, stitches, enemas, drugs, drips, catheters and hospital food (6 days) at Addenbrooke's;

Three temporary admissions to day wards;

Had numerous ECGs;

Several echo-cardiograms;

An angiogram;

Had adrenal venous sampling;

An Electromyography test (really good fun that one!),

A suspected deep vein thrombosis;

**And Seen:**

Three Endocrinologists, two of which are very senior medical researchers at Oxford/Cambridge Universities;

Two Cardiologists, one of whom from John Radcliffe (at MK);

Several consultant and/or specialist Radiologists;

An eminent and specialist Hepatobiliary Surgeon;

As well as numerous specialist nurses and surgery nurses;

And, more prescribed pills than I can count;

Given gallons of blood in blood tests;

Had several ultrasound scans, chest/kidney/stomach X rays;

Been injected with nuclear tracers, morphine, saline and God knows what else;

Seen the inside of two CT and one PET Scanners,

Beat medical odds and fainted during one test whilst on flat on my back in a fancy X ray machine, which led to further repeat cardiology testing;

And took almost 12 years to get the **correct** diagnosis;

Learnt a lot of big complicated words and have experienced some **absolutely** world class NHS treatment particularly at Oxford and Cambridge;

In desperation after, by then, 13 years of treatment, had to pay in excess of £2500 to the NHS/Cambridge University to have a private consultation, drugs, prescriptions and combined PET-CT scan at Cambridge to confirm whether a surgical solution to the problem was possible after the failed AVS test. (and would have cost about £1100 more if it was medical insurance as opposed to personal funds – which almost sounds like a banking scam!);

Spent probably hundreds of hours in appointments and travel at times largely for convenience of the NHS rather than considering my convenience (not a complaint);

Travelled hundreds of miles to attend those appointments and spent hundreds of hours in my time and NHS time, and particular workwise, had to seek some serious flexibility after the emergency admission and subsequent diagnosis (which was willingly given);

Hopefully, I am now cured or almost so with some residual issues to sort out etc.

**The question is how much has this cost the NHS? How much has it cost me financially as an individual (irrespective of the suffering or time)?**

In my follow up appointment following surgery, general discussion last week with Professor Brown's research Sister and the Professor, she indicated that it is a good indicator of Conn's to take one blood test to check renin volume; which can be used to consider whether further testing is required. She

indicated this could probably be done in the GP surgery. If such a diagnosis confirms that possibility, patients could be 'fast tracked' to next test rather than have the GP try and work out what is happening and start well-meant experimentation with drugs. **This may be a research issue currently being considered, I'm not sure.**

When I fainted at Oxford, Dr Karavitaki refused, quite correctly, on safety grounds, to re-perform the adrenal venous sampling test (which I quite understand and I accept her reasons why) – without satisfactory results from that invasive test, you cannot proceed to surgery (which reduces further long/er term costs to the NHS). Professor Brown's team had developed the non-invasive PET-CT and as I understand it, the NHS will not pay for such scans. The cost to me for the scan element was £2000. The private consultation and drugs etc; about £600.

I politely suggest that such NHS 'cannot afford to pay' mentality is clearly fundamentally flawed. The scan **was not** available when my problems started, but renin blood test **may** have been or Conn's first diagnostic blood test **must** have been, as this disease has been known about since the late 1950's.

I suggest that Conn's may have been 'testable' many years earlier if my GPs had understood the erratic way this disease presents itself, and so medical developments created by the likes of the two named individuals must be followed up properly and made use of. GPs need to be far more aware, and perhaps, when a patient with erratic BP behaviour turns up, they are immediately referred to have one Conn's blood test, rather experiment with drug regimens etc. trying to solve the unsolvable.

Politicians are always going on about we must embrace advances in technology, and yet Civil Service bean counters are preventing, possibly thousands of patients, receiving modern non-invasive treatment and having to rely on riskier invasive methods, and be subjected to treatment that takes years of trying this drug and that drug and so on.

Logic tells me that the adrenal sampling test alone must have cost the NHS as least as much as the scan (irrespective of me passing out); specialist x-ray facilities, at least 5 staff present including the most senior radiologist; appointments; consultant time; appointment admin time, medical secretaries, changes of drugs for the test for 6-8 weeks, 6-7 hours in a day ward and so on.

In conclusion:

The NHS and wider medical profession **must** train GPs to recognise these symptoms; acting much earlier in my case would have saved the NHS many (hundreds of?) thousands of pounds. This is NOT a criticism of my GPs who worked tirelessly to try and identify the problem.

The millions/hundreds of thousands of pounds invested by various research bodies into work such as that by Dr Karavitaki & Professor Brown is wasted if those facilities are not then used. If the sheer volume of treatment I have had does not demonstrate how much it is costing the NHS, then the NHS needs to be prepared to continue paying out such vast sums to treat all the others with this type of problem, and probably the same with other ailments that are difficult to manage. We already know that obesity and old age is dramatically increasing the burden. Blood pressure must be a major NHS cost issue. As well as any other unusual ailments that take up considerable NHS resources.

I am generally useless with maths and economic theory but this appears to demonstrate to me that the usual wasting of taxpayer's money is endemic when it does not need to be with some simple logic applied. Why does the Professor have to refer me back to GP who then refers me back to his recommended surgeon who probably sits 3 offices away! Not forgetting that puts a totally unnecessary admin burden on the GP. That has happened several times during this 14 year period. A Conns test when I had the emergency admission was the ideal time to test – in A&E they knew I had low potassium and were taking blood samples! Speaking to my GP he advises that is not allowed to seek such tests even if he suspects the particular problem.

Lastly some of this problem can be controlled, according to US experts by reducing salt\* in the diet which is clearly a risk factor. They recommend a maximum of 1.5 grams a day in the US, whereas the UK is 6 grams a day. My favourite soups, for instance (Baxter's), contain about 4 grams in every single can – when is something going to be done to properly regulate food manufacturers eagerness to damage our health? (\*Dr Clarence Grim)

We are repeatedly being told to watch our diet and food manufacturers do everything possible to help us get obese, salt ridden, alcohol ridden etc.

Please try and do something to improve the lives of others afflicted with this terrible syndrome. This link provides some very generic (unreliable factually I suspect) information - [http://en.wikipedia.org/wiki/Conn%27s\\_syndrome](http://en.wikipedia.org/wiki/Conn%27s_syndrome)

I would be happy to outline this in oral evidence to the relevant Health Select Committee if it is felt appropriate. You may choose PMQs to raise the profile of this disease, and if nothing else, praise these fantastic medical people. I apologize for the length of this letter but as you will appreciate this is a highly complex medical issue – put simply your endocrinology system/hormones are a bit like your computer programs – it tells the body how to operate.

Lastly you will be pleased to know that I was successful in becoming a Specialist Advisor to the Transport Committee's Level Crossing Safety Inquiry which has been both professionally worthwhile and highly entertaining.

Yours sincerely

A handwritten signature in black ink that reads "John Tilly". The signature is written in a cursive, slightly slanted style.

John Tilly,