
**How best to test pituitary function**

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*A note on the short synacthen test*
The short 250 microgram synacthen test is frequently used to screen for ACTH deficiency. However, it should be remembered that although an abnormal result will indicate a problem in your adrenal glands (Addison’s disease) or your pituitary, a normal result will only indicate that you do not have Addison’s disease. It will not tell you anything about your pituitary gland. If your synacthen test gives a normal result, but you have symptoms strongly suggestive of ACTH deficiency, your doctor should give you an ITT test, and if he does not you should press for one.

Christine’s shocking story below, highlights what can happen as a result of the shortcomings of the synacthen test.

References


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http://jcem.endojournals.org/cgi/content/full/84/3/835

Christine’s Story (Person with ME/ Pituitary Disease/)

After suffering from severe rheumatoid arthritis (RA) for over thirty years, early in 2005 I suffered a virus that would not clear up. Initially I had a sore throat with flu-like symptoms.

This developed into severe fatigue, vertigo, tinnitus, blurred vision, vomiting, feeling faint, palpitations, poor circulation and hot sweats. I felt at times that I was going to die.

I then suffered a DVT, which I had to diagnose myself. I took myself to A & E and I had a clot from my ankle to my pelvis.

Throughout 2005 I paid to see several consultants privately. I also paid for private scans.

My blood pressure was flying about all over the place, but no one could diagnose what was wrong with me. The cardiologist because of the blood pressure problems advised me to see an endocrinologist.

In 2006 I saw an endocrinologist who spoke of a possible pituitary problem; he said if your pituitary is spitting the wrong hormones out, we could correct this by putting them back in. However, when he wrote to my GP he mentioned that my symptoms had been associated with CFS. This amused me as RA causes chronic fatigue anyway.

The endocrinologist arranged for me to have the short synacthen test. This test should start before 9 am. It took an hour to cannulate me and the nurse was about to start the short synacthen test at ten o’clock; when a doctor knocked on the door and said he needed

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The endocrinologist arranged for me to have the short synacthen test. This test should start before 9 am. It took an hour to cannulate me and the nurse was about to start the short synacthen test at ten o’clock; when a doctor knocked on the door and said he needed
her to give assistance to a patient immediately. She said she was just about to start a test on the lady but he insisted that she left me. The test did not start until 10:30 am.

I know now that I was given a massive dose of ACTH, a chemical produced by the pituitary to stimulate the adrenals. Three weeks later I was told the result was normal, but this only proved that my adrenals were working when stimulated.

The short synacthen test should only be used if Addison's disease is suspected. It will not pick up secondary hypoadrenalism caused by pituitary disease. Another consultant has told me this.

Shortly after this test I had a burst vein in my bowel and was rushed to hospital for a colonoscopy.

My condition continued to deteriorate to the extent that I am surprised that I am still alive.

I had a private saliva test in January 2007, which showed my adrenals were at exhaustion stage, pointing to a pituitary problem. The saliva test was a 24-hour test, but one of the times when I had sufficient cortisol coincided with the same time that I had the short synacthen test.

I discussed my problems with the Independent Complaints Advocacy Service (ICAS). They helped me prepare an NHS formal complaint. I contacted Emeritus Professor Malcolm Hooper; a professor of medical science who gave me a report to send to the hospital with my complaint.

My formal complaint was sent to the hospital in May 2007; they would not accept the private test results and ignored Professor Hooper's report. They did not offer further testing.

A very experienced osteopath examined me and said that my spinal fluid was not right and I had a pituitary problem. I did a lot of research and gave a lot more information in a further letter to the hospital.

The reply was that the endocrinologist had done the short synacthen test instead of the more dangerous and complicated Insulin Tolerance Test. I was told once again that I did not have an adrenal or pituitary problem.

My condition was still deteriorating. I became toxic, everything I ate tasted like poison and the only thing I could tolerate was rice pudding.

In October 2007 my NHS complaint was forwarded to the Healthcare Commission to request an Independent Review. They obtained advice from a consultant endocrinologist. He stated that if the short synacthen test was unequivocal, no further testing was necessary. The Healthcare Commission advised me in April 2008 that they had not upheld my complaint.
In the meantime I was getting more and more desperate; I was spending thousands of pounds to get myself better on vitamins and alternative therapies. Every way I turned I hit a brick wall.

In Summer 2007, I consulted an Endocrinologist privately; but you cannot get an honest second opinion, when your GP writes, "she thinks she has a glandular problem, but has been investigated and has been told she hasn't". This consultation alone ended up costing £800. We have spent thousands; we stopped counting at fifteen thousand pounds.

In Autumn 2007, I again spoke to Emeritus Professor Hooper. I told him that I felt so ill I was sure I was going to die. I had just been left ill by the NHS without any help or medication to overcome my problems. I told him that I had spoken to other people who were having the same problem. I could not believe this was happening in Britain in 2007.

Professor Hooper asked me if I could travel. I said possibly if I lay down in the back of the car. He gave me the name of a consultant who he was sure would do the correct test to identify and treat my problems.

I arranged to see the consultant privately, I don't know how I managed the many 90 mile round trips I needed to make. Every visit left me exhausted, but the angels must have been with me. I knew I had to do this not just for myself but also for everyone out there who is having a problem.

In Spring 2008, I eventually had dynamic testing (the glucagon test) and was diagnosed with inflammation of the pituitary gland. This had caused severe deficiency of the Adult Growth Hormone and hypocortisolaemia, which is secondary hypoadrenalism caused by a lack of ACTH from the pituitary.

In August 2008, I at last started getting the appropriate medication from the NHS. The consultant has said that my body has been deprived of the hormones for so long it could take years to restore full health again.

The medical profession saying that no further testing is necessary, if you have had a normal result from a short synacthen test means that pituitary disease is ignored.

Yet NICE Technology Appraisal 64 issued in 2003 stated to prescribe the Adult Growth Hormone you need dynamic testing. So how many people are out there with undiagnosed pituitary disease, because the NHS is not conducting the correct tests. This is disgusting if not evil. I believe this is what is causing a lot of misdiagnosed illness in this country.

I continue to pursue this travesty of justice; my NHS formal complaint was forwarded to the Parliamentary and Health Service Ombudsman in April 2009. The Ombudsman normally takes six weeks to decided whether to conduct a formal investigation into a complaint. It is now midway through August and there is still no decision.

I am left not knowing who to trust or believe and I feel as if the NHS has mentally and physically abused me. The worst thing about it was knowing what was wrong with me, knowing what medication I needed and having to put up the fight of my life when I was so ill to get it.
December 2009, Interim Report on the Inquiry into NHS Service Provision for ME/CFS, by the All Party Parliamentary Group (APPG) on ME. Recommendation 8 highlighted the difficulty of finding a suitably qualified clinician to provide unbiased advice. It noted evidence that there were serious concerns about acceptability, efficacy and safety with some treatments and gave one reason as fixed attitudes about causation among some health professionals.

Jill Mizen’s Response to the article in the ME Association Essentials magazine

I would like to respond to Dr Shepherd’s advice in the Autumn 2012 issue, on the use of the short synacthen test (SST). The test is easy to administer and increasingly popular; and is highly reliable for diagnosing primary adrenal insufficiency (Addison’s disease) when the problem lies in the adrenals themselves. However, it is important to remember that it cannot be used to exclude secondary adrenal insufficiency, caused by the pituitary gland’s failure to stimulate the adrenal glands. You may have a normal result to this test but still have pituitary disease.

In 2011, the Society for Endocrinology (SfE) wrote to the late Mrs Christine Wrightson (whose story can be found on www.investinme.org/mestory0041.htm as follows:

“Our Clinical Committee ... agree with your analysis of the situation that if a patient receives the short synacthen test and the results come back as in the normal range, but the patient still exhibits clinical symptoms of adrenal insufficiency, then further testing to rule out hypopituitarism should be arranged for the patient.”

A convenor of the SfE’s Special Interest Group for Laboratory Aspects of Clinical Endocrinology states:

“The Synacthen test does not test the whole pituitary-adrenal axis”. [1]

A 2003 review covering 36 years of research found that the synacthen test has only 57% - 61% sensitivity for adrenal insufficiency caused by pituitary failure i.e. misses two people in every 5. [2]

My own experience as well as Christine’s supports this. In 2006 and 2010, I had the short synacthen test with normal results. However, my symptoms persisted and in 2012, the glucagon stimulation test [3] confirmed adrenal insufficiency due to pituitary disease. Cortisol was low and I am now benefiting from the prescription of hydrocortisone.


[2] Dorin RI et al, Diagnosis of adrenal insufficiency, Annals of Internal Medicine 2003; 139: 194 –204. This review “searched the Medline database for all research on the topic between 1966 and 2002 and found that the sensitivity of the 250 microg (synacthen) test is 57% and the sensitivity of the 1 microg test is 61%.”

[3] [Joanna Lane wishes to add:] Although the glucagon stimulation test can pick up adrenal insufficiency due to pituitary dysfunction, as it did in Jill’s case, it is not 100%
reliable when used for this purpose. See http://www.ncbi.nlm.nih.gov/pubmed/19996199 . The gold standard test for secondary hypoadrenalism remains the insulin tolerance test.

Jill Mizen, February 2013
Jill Mizen’s Tribute to Christine - February 2012

After Christine’s death in July 2011, her friend Jill Mizen wrote the following account of her brave fight for proper diagnosis of hypopituitarism. Anyone who has illusions that the NHS Complaints system is fair and unbiased should read it.

1. Christine’s legacy

Christine’s story (www.investinme.org/mstory0041.htm) described how she was given the short synacthen test in 2006 by an endocrinologist at York Hospital, and when she had a normal result, was told that she did not have pituitary disease. Instead, she was misdiagnosed with Chronic Fatigue Syndrome. It was only thanks to Professor Hooper’s advice the next year that she was eventually given the more reliable glucagon test [1] in 2008. This test confirmed that she did indeed have hypopituitarism, and she did, at long last, receive the hormone replacement treatment she needed.

My name is Jill and I too was incorrectly diagnosed on the basis of a normal result to the short synacthen test. I read an article by Christine in the support group Thyroid UK’s newsletter and got in touch. We became friends and worked together to highlight the shortcomings of the test, and to urge professionals to address the testing difficulties when cortisol insufficiency is caused by pituitary disease rather than a problem in the adrenal glands themselves.

Eventually, thanks to the glucagon test, we were both diagnosed with pituitary dysfunction caused by autoimmune disease.

Christine wrote her last personal update to her story in February 2010. It is with great sadness that I am writing to report her demise. Since mid-2010, when her bladder stopped functioning, she had been wearing a catheter. She battled bravely with the problem, her stamina and determination were always a wonder to behold, but in March 2011 she received a bitter blow. She had been pinning all her hopes on a leaflet which the Society for Endocrinology (SfE) were producing, which she thought would clarify once and for all which tests should be used for diagnosing low cortisol in adrenal insufficiency from whatever cause. When the leaflet came out it was an utter disappointment. This was when her bowel burst and she lost all hope. It was devastating to see. She discharged herself from hospital and there can only be praise for her husband whose devoted care continued until her death in July 2011.

Her final wish was that the battle she started would save people from being left to suffer because of the inadequacies of the short synacthen test to identify cortical deficiency in pituitary disease. I think she would also wish to broadcast as widely as possible the events that led up to the publication of the SfE leaflet – events which deeply shook our faith in the NHS complaints system.

2. The NHS complaints procedure

In 2007 we each made a complaint about the York Hospital endocrinologist. The Chief Executive did not uphold our complaints. In Christine’s case he wrote, “This is a definitive test used for investigating adrenal failure and these results excluded the possibility of a
pittuitary abnormality causing your adrenal insufficiency.” In my case he wrote “There was no evidence clinically or biochemically to support pituitary dysfunction.”

We then made separate NHS complaints to the Healthcare Commission (HCC), which again were not upheld.

In Christine’s case they obtained medical advice from a Consultant Endocrinologist. He stated [sic] “That the short synacthen test, which is used for Addison’s disease, is the standard test for adrenal insufficiency widely known by trained endocrinologists in the UK would, to the best of his knowledge, not agree that your test was unequivocally normal.”

The independent endocrinologist for my own complaint wrote, more guardedly, that a Short Synacthen test was often used as a first-line conventional test of adrenocortical function.

In April 2009 we made a joint complaint to the Parliamentary and Health Service Ombudsman (PHSO) that a ‘normal’ result from the short synacthen test did not rule out cortisol deficiency caused by pituitary disease. Our evidence proved that the endocrinologists’ statements to the HCC had been incorrect. We wrote that we were particularly concerned since the first medical witness was believed to have been nominated by the professional/specialist and patient/care groups as a clinical expert and patient advocate [2].

We were hopeful that because the PHSO was promoted in their “Principles” document as an independent, customer-focused, open and accountable body, we would receive fair treatment.

However, in September 2009 the PHSO reported that they could not find an endocrinologist to comment on our complaints, and in October, after taking six months rather than the normal six weeks, they did not uphold our complaints. Their response did not even mention the word pituitary. In contrast to the HCC they did not provide the name or medical qualifications of the Professional Adviser they had used.

The Independent Complaints Advocacy Service (ICAS) wrote that if the PHSO hadn’t missed or misinterpreted any aspect of our complaint we had reached the end of the NHS procedure.

We had followed the complaints procedure for over three years and were disillusioned not to obtain justice. We could have applied for a Judicial Review, but rejected the idea because we were uncertain where the responsibility lay and an earlier Judicial Review had been unsuccessful [3].

We wrote to ICAS and the PHSO, including the Ombudsman, Ann Abraham, pointing out that significant information in our complaints had been missed and misinterpreted. We also wrote to Andy Burnham at the Dept of Health, all members of the Houses of Lords and Commons, the Strategic Health Authorities (SHAs) and Patient Safety Groups.

We asked the PHSO in November 2009 under the Freedom of Information Act for full details of their Professional Adviser. They did not respond within the statutory 40 days, and when they finally did in February 2010, it was to provide the adviser’s qualifications – MD, FRCP (Retired Consultant Physician & Endocrinologist) – but not his name. Their excuse
was “in considering whether to disclose the information the public interest test was applied, the interest can be met without disclosing the name of the adviser, which would cause an unwarranted invasion of their privacy.”

Our reaction was that the PHSO should have treated as suspect, advice from someone who did not support the customer and wished to remain anonymous. A person paid by a public body to give clinical advice should not be entitled to privacy. However the PHSO wrote they would challenge as premature any application to the court before their internal review procedure was completed.

We were also concerned that a retired health professional would not have up-to-date knowledge and would be likely to have the “fixed attitude about causation” which a recent report had pinpointed among health professionals treating ME. [4].

The PHSO asked for a recent acknowledgement by the SfE of the failure of the 250 mcg Synacthen test and of the SHAs’ failure to provide facilities for pituitary disease, which we duly supplied.

In April 2010 the SfE Clinical Committee Chair wrote to me that they would be providing information that would describe reliable ways of measuring a person’s cortisol level (including information on the synacthen test) and that would clarify the relationship between cortisol deficiency and endocrine disorders. We were further encouraged by a letter to Christine in January 2011 from the SfE Public and Media Relations Office, agreeing with her that if a patient received the short synacthen test and the results came back as in the normal range, but the patient still exhibited clinical symptoms characteristic of adrenal insufficiency, then further testing to rule out hypopituitarism should be arranged for the patient. Christine and I were jubilant, believing that our battle had been won.

However, in March 2011, the long awaited leaflet from the SfE was published and all our hopes collapsed. It did nothing to resolve the problem of testing for cortisol in pituitary disease. Despite everything, it implied that the synacthen test was a suitable tool for diagnosing pituitary disease. We were totally frustrated by the NHS complaints procedure. No one would tell us we were wrong, but nothing was being done.

And nothing has been done since then, despite protests to the SfE and the PHSO. Christine’s only consolation was that when she wrote to the CEO of York Hospital to ask whether changes had been made to prevent the problem recurring for other patients, he responded “The question raised was whether hypopituitarism is considered and tested for in someone who receives a normal short synacthen test but still exhibits clinical symptoms characteristic of adrenal insufficiency. The straightforward answer to this question is yes; in these circumstances pituitary insufficiency is most definitely considered as a possibility. Our practice is certainly in line with national guidance.”

By the time Christine received this letter she was too ill to query why the Ombudsman had not advised her of the changes, or why the SfE’s leaflet was inconsistent with their statement in January. Four months after the publication of the leaflet, she died.

Mr Wrightson wrote to his MP, but neither he nor I have been told that lessons have been learned from our complaints.
3. Education

We have to take responsibility for our health. Christine’s and my experience prove that by educating yourself and others, which is not easy when you are not well, you can receive help. It should be remembered there are advances in the medical world all the time; it is not always that our symptoms are ignored for financial reasons.

We are dependent on health professionals to help us solve our problems. No matter how frustrated you get, act in a reasonable manner, remember we are all human and none of us respond well to aggression. Also it is negative to think all health professionals are deliberately obstructive.

The problem is more that medicine is becoming “evidence based”, which can stop health professionals using their clinical expertise of patients’ signs and symptoms when making a referral/diagnosis because the patient has “normal” test results. But it should be remembered that health professionals do have a legal and contractual duty to act in the best interests of the patient.

When you have unresolved health problems there should be meaningful repeat investigations. It may be we have to accept that the answer to our problems cannot be found, but the health professional must explain why. For a patient it is of utmost importance for health professionals to show a caring attitude and give hope.

My case is unique in my hospital’s endocrine department and GP Practice and has taken from 1987 to be diagnosed correctly. My experience leads me to believe that some diseases are considered rare because the medical profession does not know enough about them. It is only if health professionals are willing to open their minds to widen their knowledge when faced with patients with problems as complex as ours that they will be able to arrange correct referrals and investigations.

The Countess of Mar has been regularly updated on Christine and my endeavours, and she considers the problem will only be resolved from the “bottom up”. Minds must be opened, so if you are having difficulties obtaining help, educate yourself, write to your health professional with full details of your medical problems. This helps both you and them assess the situation and if you are unable to obtain help, the papers will be useful if you need to make an NHS complaint or legal claim. Have faith in yourself and never give up hope.

Early in July 2011, the long-standing principle that an expert witness was immune from being sued was overturned in the Supreme Court decision of Jones v Kaney. The Medical Protection Society (MPS), Director of Policy and Communication, Dr Stephanie Brown said, “Having lost their immunity, experts are now exposed to the risk of evidence given in court”. MPS indemnity extended to expert witness work and they would be monitoring whether the ruling would open the floodgates in terms of court proceedings.

Hopefully, this will ensure in future medical advisers respond truthfully, rather than protecting their colleagues from legal action for negligence and misdiagnosis.

4. A message of hope
There is hope, the Department of Health (DoH) wrote in March 2010 that the government recognised CFS/ME as a debilitating and distressing condition. It was a chronic illness and health and social care professionals should manage it as such.

In December 2010, in response to a letter sent to Andrew Lansley, the DoH agreed with the WHO classification of CFS/ME as a neurological condition of unknown cause with many different potential causal factors, including those of a neurological, endocrinological, genetic, psychiatric, and infectious nature.

My endocrinologist in June last year used his clinical expertise, not just evidence-based medicine. He wrote about my TSH blood test results, “Although your TSH is slightly lower than the normal range I would not recommend a change in the dose of Levothyroxine unless you exhibit symptoms to suggest overactive thyroid. During the clinic your thyroid status appeared normal but if this changes and you develop symptoms to suggest overactive thyroid then I would suggest that you reduce the dose of Levothyroxine to 75 mcg and 100 mcg on alternate days.”

With such complex causal factors, each of our journeys will be different. From my experience, it is difficult to imagine there is an easy cure for such chronic illness, but once your problems are acknowledged you will receive help and hopefully it will not be too late for you to lead a good life.

The Pituitary Foundation www.pituitary.org.uk are trying to raise awareness of the long and difficult journey patients face trying to obtain a diagnosis of pituitary dysfunction.

In the November 2012 issue of the ME Association (MEA) Essentials magazine, there was a misleading article about the synacthen test. The MEA agreed that they would print my response letter sent in the February issue of the magazine. I have given this letter as an appendix to this account. If your symptoms are indicative of pituitary dysfunction and the endocrinologist confines himself to conducting only the synacthen test, please show him a copy of the letter, which explains why further testing needs to be done to rule out a cortisol deficiency.

Christine and I were a great support to each other; we could not have made this journey on our own. Our passion to fight to make people aware of how and why people with pituitary disease suffer before they get a diagnosis, with your help will continue despite Christine’s untimely death. Good luck.

[1] The glucagon test is advocated in NICE Technology Appraisal 64 to identify growth hormone deficiency. It also tests for cortisol, which is one of the adrenal steroid hormones essential for life. [Note from J Lane: See http://www.ncbi.nlm.nih.gov/pubmed/19996199 for a discussion of this use of the glucagon test.]

[2] Appendix B, para C of NICE Technology Appraisal 64)

One problem is that the bulk of the endocrinology budget is spent on diabetes. People with glandular problems are being neglected.

Another problem is the psychiatric lobby saying that chronic fatigue is "all in the mind" and patients are just put in the dustbin without appropriate testing. This is something that should be referred to the European Court of Human Rights.

I have said to my endocrinologist that the effects of RA are nothing compared to the horrendous effect of pituitary disease; my personal experience makes me a good judge on this point.

Prior to 2005, I was having a reasonable life, but since then my husband and my lives have been devastated because of the treatment I have received. Without the care and support provided by my husband I would not have been able to survive.

My local MP has taken an interest in my case over the last three years. He has pledged to do all he can to help me, and I am urging him to ask questions in the House of Commons.

I am indebted to Professor Hooper, I have lobbied other people in high places, and they don't want to know.

There are approx. 250k people diagnosed with CFS, I wonder how many of those have got pituitary disease.

If the NHS doesn't care about all of the people out there I do. I will go on campaigning because my conscience will not let me do anything else.

**An Update from Christine - February 2010**

Since Christine’s story was posted online, she has lobbied 1400 members of the House of Commons & the House of Lords, so there is not one MP or Peer who doesn’t know what is going on in the country.

She has also written to all 10 Strategic Health Authorities in England & has had: -

3 very good responses, 2 mediocre & 2 are still investigating & 3 have not yet replied at all.

Some very significant comments from these have been made.

- As you rightly identify, NICE guidelines require that patients have an I.S.T. test for growth hormone deficiency and should receive hormone treatment for other pituitary hormone deficiencies. Thank you very much for reminding us of the importance of proper diagnosis for patients with this condition.
- You are right to point out that the largest number of patients referred to Endocrinology will have Diabetes. This could prevent the needs of patients with Pituitary disease being met. It is therefore important that some members of the
Endocrinology team specialise in pituitary disease. I know this is happening in this area.

- Short synacthen tests are commonly performed in this region, but as you correctly suggest this is just to rule out disease such as Addison’s of the adrenal gland and does not give any information about the pituitary gland.
- You raise two important issues, the first relates to the possibility of Pituitary disease in patients who have symptoms associated with CFS, the second relates to the diagnostic tests for Pituitary disease particularly the role of dynamic function testing.

- **Message from Christine**

If you are not happy with the way you have been treated, write to your S.H.A. & tell them about it, it’s the only way they will find out. They are public servants, funded by the taxpayer, so they are obliged to reply to your letter.

If you have had severe fatigue for more than 6 months with other undiagnosed symptoms, not necessarily the same as mine, as people are all different as we don’t come in jam jars, do we! See your GP. Tell them you would like to be referred to an Endocrinologist, take my story with you & let them read it. Let the Endocrinologist read it! Tell them you want the Gold Standard Dynamic testing. It is your right to receive the best diagnostic test.

I put my heart & soul into my story. I wrote it to help you. I think of you all each & every day now & forever.

**Hippocrates - First do no harm**

Sincerely Christine

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**An Update from Christine - February 2011**

On 25 January 2011 Christine received a letter from the Society for Endocrinology. It said “...I forwarded your enquiry to our Clinical Committee and they agree with your analysis of the situation that if a patient receives the short synacthen test and the results come back as in the normal range, but the patient still exhibits clinical symptoms characteristic of adrenal insufficiency, then further testing to rule out hypopituitarism should be arranged for that patient.”

For the full text of the letter, click on the links below:

[Letter from Society of Endocrinology page 1](#)
[Letter from Society of Endocrinology page 2](#)