

The Lothian Clinic : a cautionary tale from Tymes Trust

There is a saying 'be careful what you wish for'. Many local ME groups have assisted with setting up services in their area. Many became disillusioned as the services they ended up with were not specialist ME clinics, as requested, but fatigue clinics offering CBT and GET, with no ME-expert clinician. Yet their involvement was seen as a kind of endorsement, demonstrating patient consultation in the process.

Tymes Trust Scotland Representative Lesley Scott has, through Freedom of Information requests, tracked the timeline for the setting up of the Lothian clinic. We are making this public so that groups considering becoming involved in such a process can see who took part, what happened as a result, and learn from it. *Note: at no time were meetings of the Cross Party Group (CPG), which was running concurrently, informed of what was going on.*

Full Timeline for the ME-CFS pilot service Lothian NHS

- 2011 **17th January:** Letter from James Barbour Chief Executive NHS Lothian, to an MSP; this letter shows no government funding sought at this point “As part of our on-going work in this area, there is a small recurring investment of £25,000 available to support work in support of people with ME-CFS.”
- 2011 **19th January:** Meeting between Professor Alex McMahon, Acting Director of Strategic Planning, NHS Lothian and Sir Peter Spencer Chief Executive of Action for ME. Letter dated 17th January 2011 from Professor McMahon to MSP, Member for Lothian states that “This meeting will allow me to inform him [Sir Peter Spencer] of local plans for ME-CFS and to explore opportunities for partnership working.”
- 2011 **26th January:** last meeting of the Lothian Review Group – EdMESH and AfME both in attendance. The discussion at this meeting was also used to inform the development of the new pilot ME-CFS Rehabilitation Service.
- 2011 **15th March:** Professor Alex McMahon writes to Scottish Government Health and Healthcare Improvement Directorate asking for feedback on the views of the Scottish Neurosciences Council & various other groups in relation to “arrangements for the consultant appointments envisaged in the needs assessment” The letter states: “It would be very helpful to get feedback from this work to help inform our local review. We feel a policy steer would be very helpful to take this work forward”
- 2011 **April:** Scottish Parliamentary Election Manifesto for M.E. – produced by Action for ME and the Association of Young People with ME (AYME). Amongst those MSPs who pledged support for ME was Mary Fee.
- 2011 **5th May:** 2011 Scottish Parliamentary elections also special meeting of CPG on ME to discuss Scottish Good Practice Statement (SGPS).
- 2011 **15th June:** Alex Ferguson MSP chaired a meeting of the CPG committee and a number of MSPs, to discuss reforming the group after the May elections. It was agreed at this meeting that Mary Fee MSP would be Convenor of the CPG on ME with Jim Eadie and Siobhan McMahon as Vice Convenors.
- 2011 **21st September:** **CPG on ME meeting Scottish Parliament.** Jim Eadie said it was important to keep in mind the role of CPGs. Their purpose is to raise awareness in Parliament and use leverage.
- 2011 **1st December:** **CPG on ME meeting Scottish Parliament.** Wider committee disbanded – Convenor, vice convenors, secretary & treasurer only retained with the agreement of the wider committee. Working groups set up to replace wider committee. Mary Fee stated that she hoped parliamentary questions would come from the work of these working groups. Mary Fee informed the CPG that she intended to ask the Scottish Government a number of PQs, based on the recommendations of the Needs Assessment. She read out each proposed question. Members agreed with the proposed questions but agreed that the question on **rehab services should be taken out, as such services are said to have caused problems for some people with ME in the past.** A question on diagnostic criteria was added. [Bold added]
25% Group replace AfME as Secretariat.

- 2012 16th January:** Strategic Programme Manager NHS Lothian responds to letter from Liz Blackadder of EdMESH requesting an update on what is happening in Lothian in relation to ME-CFS since the last meeting of the Review Group at the end of January 2011. This letter details the discussions that have taken place with Lothian NHS, Dr Gregor Purdie and AfME in regards to a new ME-CFS pathway.
- 2012 19th January: CPG on ME meeting Scottish Parliament.**
Overview presentation of the report findings from the feedback exercise carried out by the 25% ME Group.
- 2012 March:** “Proposal – ME-CFS Support Service in NHS Lothian” received by Scottish Government. “This proposal seeks Scottish Government Health Department funding of £70k in 2011-2012 and £70k in 2012-2013 to fund an initial 2-year service to deliver a clinical programme to people living with ME-CFS in Lothian.
“It further seeks funding of £8k for 2011-2012 only to support the Lothian launch of the Scottish Good Practice Statement on ME-CFS and the Lothian ME-CFS pathway and for follow-up training. The launch event is scheduled for 2nd May. Professor Sir Lewis Richie is leading the event and Sir Peter Spencer of Action for ME will be involved.”
- 2012 19th March:** A payment of £78,000 was made to support the ME/CFS service in NHS Lothian. This was funding for the 2011/12 financial year.
- 2012 21st March: CPG on ME meeting Scottish Parliament.** Concerns are raised at this meeting when some members of the Working group for centre of excellence declare an intention to make contact with English fatigue clinics to learn from them and form links with them.
- 2012 22nd March:** Strategic Programme Manager for NHS Lothian sends an email to Scottish Government Health Directorate personnel inviting them to the “General Practitioner Event – Launch of the Good Practice Statement on ME-CFS” on 2nd May stating “As none of our locally planned ME-CFS work would have been possible without your personal and financial support, I would be delighted if you could join us.”
- 2012 29th March:** Response to above email received stating “...I, or one of us would be delighted to attend, however our attendance would be strictly as observers. We wouldn’t want to be seen to be involved, as this is primarily a Lothian initiative. Of course we will be very interested in the outcomes and success of this approach in terms of using it as an example to persuade other Boards to follow suit but it will need to be made clear from the outset that the Scottish Government is not there to get involved or interfere in the development of the service.”
- 2012 End of March:** EdMESH open meeting, Liz Blackadder spoke with Paul Currie, the Chair of the Review Group in Lothian and Strategic Programme Manager for Lothian NHS when she is told that Lothian have received Government funding for a 2 year pilot service.
- 2012 10th April:** Michael Matheson, Minister for Public Health states in a letter to an individual “NHS Lothian has started work on a revised pathway, based on the Scottish Good Practice Statement, on ME-CFS for GPs. The pathway will seek to ensure that people living with ME-CFS are recognised early by their GP and receive the appropriate clinical investigation, treatment and support. This work will be taken forward over the next few months in discussion with the Board’s partners, including patient and carer representatives.”
- 2012 19th April:** Email from Policy Officer with Clinical Priorities Team DG Health and Social Care asking “Please find attached information with regards to FITNET an on-line cognitive behavioural therapy for adolescents with ME-CFS developed by the Dutch. The results indicate a marked improvement in young people living with this condition who had access to this therapy. [...] I want to gauge your response to this on-line approach for people living with ME-CFS and whether in your opinion it should be something that could be piloted in Scotland?”
- 2012 2nd May:** GP training event by NHS Lothian to launch SGPS and present the planned Lothian ME-CFS pathway, Chaired by Professor Sir Lewis Ritchie. Action for ME named as key voluntary sector group and a partner at this event and the organisation’s Chief Executive Sir Peter Spencer presents.
- 2012 8th May:** “It’s all about M.E.” event at Scottish Parliament for ME Awareness week hosted by Mary Fee MSP then Convenor of the CPG on ME. On her webpage for that day Mary Fee stated “The World Health Organisation recognise M.E. as a neurological condition that results in muscle pain with intense physical or mental exhaustion, relapse and specific cognitive disabilities. Taking this definition of the condition one cannot help but come to the conclusion that to simply classify the condition as ‘fatigue’ whether chronic precedes it

and syndrome follows or not, is to trivialise the pain and suffering felt.”

- 2012 24th May:** EdMESH screening of *Voices from the Shadows*. Sheena Spence, (Specialist Physiotherapist, Pain Management Service, Department of Clinical Psychology, Astley Ainslie Hospital) introduces herself as the lead therapist for the new Lothian ME-CFS service – states she will be making contact with other services in England particularly Newcastle.
- 2012 5th June:** Consultant Physician Ward 41 of Infectious Diseases Unit Western General Hospital Edinburgh states in an email response to MSP Complaint 19015 KD that “In reply I think we should change the abbreviation from ME/CFS to CFS/ME and thereafter refer to it as CFS rather than ME, since from a medical perspective that reflects current best practice.”
- 2012 6th June:** The Strategic Programme Manager for NHS Lothian also added these thoughts for the response to the complaint: “On the matter of terminology, I think we need to keep to the use of ME-CFS as that is what is used on the 2010 Scottish Government publications ... On the 2nd May we had a successful launch event. ... The GPs attending all received an ME-CFS resource pack with copies of the Quick Reference Clinical Guide, and Patient Guide ... Following the event, all 124 GP Practices in Lothian received a mailing.”
- 2012 6th June: CPG on ME meeting Scottish Parliament.** Only one MSP present (Mary Fee), so meeting is classified as informal.
- 2012 4th August:** Sheena Spence, Lead Therapist for the pilot ME-CFS clinic at Astley Ainslie Hospital attends EdMESH garden party. AfME representative also attends.
- 2012 13th August:** Email from Strategic Programme Manager NHS Lothian to Scottish Government Health Department stating : “As you know Lothian received funding from your Directorate in 2011-2012 for the development of a planned pilot ME-CFS support service, located in the psychology department of the Astley Ainslie Hospital. The funding was successfully carried forward into this financial year and work is being finalised on the service and associated pathway work.
“The second tranche of money is due this year, with the intention being to carry that funding forward into 2013-2014 to continue the support service.”
- 2012 15th August:** Response to above email: “We have committed to release this funding to Lothian for the financial year 2012-2013 and it would be our preferred choice if you were able to take this funding for this year. However, we’ll have a clearer idea of how our funds will be allocated to Lothian over the next couple of months and should you still wish to delay the receipt of the funding then I would advise you to get in touch with us around about the middle of October again.”
- 2012 16th August:** 3 Committee members of EdMESH have meeting at Astley Ainslie Hospital with Sheena Spence and her admin support who took the minutes. Edmesh had earlier in the week emailed a list of '20 questions' which they then proceeded to go through. (Minutes available)
- 2012 21st August:** Email to Lothian MSPs, subject: “Next Meeting between MSPs and NHS Lothian.” This is scheduled for Friday 7th September. Jim Eadie, Deputy Convenor of the CPG on ME is MSP for Edinburgh Southern, Lothian.
- 2012 29th August:** meeting of CPG sub-group on Centre of Excellence/Lead Clinician in Edinburgh. Meeting originally organised for Dr Chaudhuri (who formerly ran an ME clinic) to present to inform the group discussion re a centre of excellence patient cohort. After Dr Chaudhuri pulls out due to pressure of work, three members ask for a postponement until he can attend. Spokesperson over rules and goes ahead with meeting with Mary Fee in attendance [she was originally only going to attend to hear Dr Chaudhuri]. Mary Fee declares the group deadlocked over the issue of patient cohort and seeks vote from full CPG on remit of group. She asks Tymes Trust to draft up the wording for the vote on the 19th September CPG meeting.
- 2012 7th September:** NHS Lothian meet with Lothian MSPs and discussions include information from "Briefing - ME-CFS Service developments in NHS Lothian" which states: "The planned service will use proven psychology/physiotherapy-based approaches, based on the PACE trial findings. Service development is taking into account the preferences expressed by patients and their representatives in the Lothian review group." It goes on, "The existing physiotherapist has been liaising with patient groups and professional colleagues as part of the planning for the service." 19 MSPs invited to this meeting by email correspondence dated 21st August.

- 2012 19th September: CPG on ME meeting Scottish Parliament.** Vote takes place on remit of the CPG – it is decided by a large majority to focus endeavours on the WHO ICD10 G93.3 neurological disease ME.
- 2012 25th September:** 20 non-MSP members of the CPG put their names to a letter to the Standards Procedures and Public Appointments Committee stating their concerns over the conduct of MSPs and Mary Fee in particular as Convenor of the group over this vote and the indication that MSPs will not uphold the result. More signatories add their names after this including Professor Malcolm Hooper.
- 2012 5th October:** Siobhan McMahon MSP resigns from CPG
- 2012 8th October:** Elaine Smith MSP resigns from CPG
- 2012 17th October:** Mary Fee MSP resigns from CPG
- 2012 23rd October:** Jim Eadie resigns from CPG. No formal resignations are received from any of the other MSPs remaining on the CPG on ME. The group is effectively closed at this point since all office bearers have resigned.
- 2012 October:** A patient Information Sheet titled ME-CFS Service – Astley Ainslie Hospital is produced.
- 2012 8th November:** The new Lothian ME-CFS Service begins accepting patients. It is a pilot, funded by the Scottish Government and hosted within NHS Lothian facilities initially for two years. It is staffed by Specialist Physiotherapists and Applied Psychologists. Dr Lorna Torrens Head of Clinical Psychology championed setting the service up at Astley Ainslie Hospital. The service consists of a self-management lifestyle programme including activity management, pacing and graded activity/exercise based on cognitive behavioural strategies.
- 2012 8th November:** Email from Strategic Programme Manager NHS Lothian to Scottish Government Health Directorates includes the following: “As you know , the pilot is currently utilizing the first year of SGHD funding of £77k (received in 2011-2012) to deliver the service in this current year. I understand that the second year of support (£70k) is available for allocation this year only. In order for this to be available in 2013-2014, to continue operation of the pilot service, approval needs to be given for carry-forward from this financial year into the next.
“Permission for carry-forward requires NHS Lothian Finance Director approval. For this reason, I would be grateful if you would formally request such approval...”
- 2013 22nd March:** EdMESH Open Meeting to look at the ME-CFS service and the potential for future development. Speakers: Sheena Spence (Specialist Physiotherapist), Samantha Arbuthnot (Specialist Physiotherapist), Dr Sally McKenna (Chartered Counselling Psychologist), Keri Anderson (Clinical Associate in Applied Psychology) and Grainne O’Brien (Specialist Psychology Practitioner).

The Young ME Sufferers Trust
www.tymestrust.org
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