My email correspondence with Journalist Michael Hanlon regarding a proposed Sunday Times article

PERMISSION TO REPOST

Angela Kennedy <u>6th February 2013</u>

I have today seen comments made by Charles Shepherd on the ME Association Facebook wall, regarding an article being written by a journalist from the Sunday Times:

"Had a fairly long and amicable chat this evening with the journalist who is writing the feature on ME/CFS for the Sunday Times. From what we covered this evening in my hotel I don't think this item is going to be looking at anything new in relation to both politics and research.... So it looks as though this article is going to cover the debate re nomenclature and sub-grouping (ME vs CFS), XMRV saga, PACE trial (including 'recovery' paper and House of Lords debate), CBT and GET - what do they involve? why are they so controversial? and all the usual stuff about hate mail: Who does it? (a minute minority - some of whom probably have a personality disorder rather than ME) And why to they do it? (because they are angry at the lack of biomedical research and clinical trials aimed at people who do not fit into the psychosocial model of causation >> an illness perpetuated by abnormal illness beliefs and behaviours + the resulting deconditioning and inactivity). Not that this justifies this type of activity."

In light of Dr Shepherd's extremely worrying revelations here, and recent misrepresentations of patient concerns in an academic journal, I believe that I should now reveal that I was approached by a journalist, Michael Hanlon in regard to this proposed article in December 2012. Below is all the email correspondence I had with Mr Hanlon (my only form of interaction with him). I should also explain that I have heard nothing further from Mr Hanlon after I declined the lunch invitation on 7 December 2013.

I had intended to wait until after the article was published before publicising my full correspondence with Mr Hanlon. However, because I am concerned at the content of Dr Shepherd's post above and its implications for how this article will be written, I believe it is important for readers to understand the exact context in which information was given to Mr Hanlon, before the article is published. I believe that journalists have a duty to make fair and accurate representation of the issues they cover and the people they interview, and at this time I am hoping the transparency and accuracy of my own actions here will be mirrored in the Sunday Times article when it is published.

The email correspondence below is in chronological order.

ANGELA KENNEDY

----- Original Message -----From: <u>Hanlon, Michael</u> To: <u>angelakennedy372@btinternet.com</u> Sent: Monday, December 03, 2012 11:10 AM Subject: ME, XMRV, the PACE trials and Simon Wessely

Dear Angela

I am a science journalist and I have been commissioned to write a piece for the Sunday Times magazine about ME patient-support groups.

This is in the light of recent findings regarding XMRV, the continuing controversies regarding the PACE trials and the recent prize awarded to Simon Wessely.

Would you be prepared to chat with me, either on- or off-the-record?

Best regards Michael Hanlon

----- Original Message -----From: <u>ANGELA KENNEDY</u> To: <u>Hanlon, Michael</u> Sent: Monday, December 03, 2012 1:49 PM Subject: Re: ME, XMRV, the PACE trials and Simon Wessely

Dear Michael,

Thank you very much for your email. I will be very happy to chat with you via email in the first instance, if that is ok. This is because talking by phone is difficult for me because of my daughter's care needs.

I can also send you relevant sources that explain my position in this situation, and if you would like a complimentary copy of my book (of which I presume you are aware) - let me know the address and I will send.

Best wishes Angela Kennedy

----- Original Message -----From: <u>Hanlon, Michael</u> To: <u>ANGELA KENNEDY</u> Sent: Tuesday, December 04, 2012 10:30 AM Subject: Re: ME, XMRV, the PACE trials and Simon Wessely

Dear Angela

Thank you for taking time to reply.

I have to say at the outset where I am, what (if any) agenda I have and what I hope to write about.

Never believe a journalist who says they don't have an agenda - we all do. But at least I will try to lay my cards on the table.

I have been a science journalist for 20 years and, as such, I count myself as broadly 'pro-science'. I tend to side with sceptics and rationalists, materialists and those who obsess about evidence-based medicine. I distrust homeopathy, people who worry about electrosmog and people who claim to have seen UFOs.

But M.E.? I admit I am baffled. When I first picked up on the whole debate, if that is not too polite a word, between the likes of Simon Wessely who believe that M.E is basically a psychogenic condition that can be treated by CBT and other techniques, and those who insist that M.E. is the result of an infection or immune system malfunction, I was mystified.

My initial reaction has been to side totally with the psychiatrists. I have seen some of the emails and so forth that have been sent, told about the FOI requests, reports to the GMC and so on and find it weird, at best, that this is happening.

But clearly people feel very strongly about this and I want to know why. Perhaps you can tell me?

I have written about many controversies - animal experimentation, global warming, MMR and so on but even a brief delve into the Internet shows me that there is a volcano of an issue here.

So, my first question. You are prominent among those who would like to see ME treated as a 'proper' illness (not psychogenic). What informs this view?

Do you condemn - unreservedly - those small number of people who appear to have issued threats, however vague, against people like Simon Wessely? You are quoted as saying that you believe these threats are a storm in a teacup, that Wessely et al are over-reacting. Is this the case?

I have spoken to Simon Wessely and he seems a decent, humane man. Do you accept that he is decent and humane, even if you disagree with his methods and point of view regarding this disease?

How did you react to the recent news that XMRV is probably not the causal agent of ME?

Did you previously believe it was? If not XMRV, then what do you believe causes ME?

Are you still in contact with Jane Bryant?

Have you ever met your opponents and debated with them? Do you believe it is possible to have a mature and reasoned debate over a matter of what amounts to a major scientific and medical disagreement?

I look forward to hearing from you, and your view on any of these issues.

Best regards Mike

----- Original Message -----From: <u>ANGELA KENNEDY</u> To: <u>Hanlon, Michael</u> Sent: Tuesday, December 04, 2012 2:03 PM Subject: Re: ME, XMRV, the PACE trials and Simon Wessely

Dear Mike,

I will hopefully be able to answer your questions within the next few hours. In the meantime I enclose three links which you should look at to get a reasonably clear idea of where I am actually 'coming from':

1. The link to my book on Amazon gives the first few pages of the Introduction on its 'look inside' facility. The first three pages will I believe be most useful to you, though I would also recommend you read the back cover, which also gives my academic research interests as a social sciences lecturer and researcher.

http://www.amazon.co.uk/Authors-Our-Misfortune-Angela-Kennedy/dp/1479253952/ref=sr_1_1?ie=UTF8&qid=1354628800&sr=8-1

2. A publicly available statement I have made about dematory claims made about me with regard to Professor Wessely.

http://mywikibiz.com/images/2/2b/Statement_re_Simon_Wessely_and_claims_of_harassment.pdf

3. My complaint to the Lancet about the PACE trial: <u>http://mywikibiz.com/images/7/74/Complaint_of_25_April_2011_to_Richard_Horton_re_PACE_ar_ticle.pdf</u>

Best wishes Angela

----- Original Message -----From: <u>ANGELA KENNEDY</u> To: <u>Hanlon, Michael</u> Sent: Wednesday, December 05, 2012 1:28 PM Subject: Re: ME, XMRV, the PACE trials and Simon Wessely

Dear Mike,

For ease of reference I have preceded your questions with a Q, and my answers with an A (should make things clearer hopefully!)

Firstly I should tell you that I too count myself as (colloquially) 'pro-science' (though with some caveats), with a rationalist, materialist concern that science and social science, proceeds with empirical adequacy, and rational, coherent argument within a critically analytical framework: and that all underlies my critiques of psychogenic explanations for physical illnesses like ME, particularly the analysis I undertake in my book.

I am concerned that you seem to believe FOI requests and reports to the GMC constitute harassment. These are publicly available legitimate courses of action, through official channels, for people who have concerns or complaints about certain situations. I'm confident you would not think anyone who has ever made a complaint to the GMC, written to an employer, or asked for information under FOI is guilty of harassment *per se*. Journalists use FOI requests, for example. These were mentioned three times on Panorama the other night; and have been used by BBC reporters since 2005:

http://news.bbc.co.uk/1/hi/in_depth/uk/2006/foi/default.stm

There are specific, legitimate and rational reasons people are taking these - again, legitimate - courses of action. As you will have seen from the links I gave you, there are specific reasons I have had occasion to complain about the PACE trial, and write to an employer, neither of which can be remotely considered as 'harassment'. I would say, if I may advise you, that you should dig deeper on those reasons.

Q: So, my first question. You are prominent among those who would like to see ME treated as a 'proper' illness (not psychogenic). What informs this view?

A: Your above comment does not accurately reflect my position. This is why I would ask you to read the first three pages and back cover of my book via the Amazon link I gave you to get an idea of where I am coming from. There are a very important distinctions between your above assessment of my position and what my position actually is, not least being that I do not consider psychiatric illnesses as 'improper' or 'not real', which is what your description implies (whether or not you meant it like that). But to give a summary of where I am coming from: I am concerned about psychogenic misdiagnosis, which leads to psychogenic dismissal of serious physical illness, which leads to patients' lives, health and quality of life being endangered. Psychogenic misdiagnoses have led to tragic, premature deaths, and to prejudicial treatment by health, educational, social and benefits agencies, even communities and families.

It is also untrue that people objecting to psychogenic explanations for ME are doing so out of contempt for mental illness and its sufferers - though that is a myth that gets repeated over and over again.

One thing I think also needs to be remembered is that, no matter what I, or Professor Wessely, the ME community or other doctors think, the WHO classify ME as a neurological illness, and the British government abides by this classification.

1. Q: Do you condemn - unreservedly - those small number of people who appear to have issued threats, however vague, against people like Simon Wessely?

A: I must ask you quote this exactly: "As an academic myself I unreservedly condemn any actual harassment and abuse of researchers. However, raising reasonable objections to something through legitimate means (such as FOI requests or official complaints) is not harassment or abuse. There are specific reasons I have complained about the PACE trial, and written to an employer, neither of which can be remotely considered as 'harassment'."

The other issue you need to consider though - and this is vital - is that hate speech is being waged against a disabled patient group, especially though not exclusively with regard to the claims of 'harassment', that are specifically unsafe i.e. falsely accusing people - who are following legitimate procedures - of harassment, intimidation, and abuse, which is what is being done, when you look carefully at the various claims being made about the community.

ME sufferers are being characterised as 'extremists', 'fanatics', as well as 'malingerers' and 'hypochondriacs'. Their concerns are misrepresented as contempt for mental illness sufferers. They are mocked and told that they cannot be that ill in the first place if they have the energy to comment, an common insult. The historical insult 'Yuppie flu' is repeated as nauseum. Doctors have been involved in inciting this contempt for sufferers, and I discuss this phenomenon in my book.

2. Q: You are quoted as saying that you believe these threats are a storm in a teacup, that Wessely et al are over-reacting. Is this the case?

A: I would be grateful if you could give me the exact place such a 'quote' was made (and by whom), because I have never said this. This is not how I actually speak or write, and it is certainly NOT how I see the situation.

3. Q: I have spoken to Simon Wessely and he seems a decent, humane man. Do you accept that he is decent and humane, even if you disagree with his methods and point of view regarding this disease?

A: It is impossible for me to make an assessment of the character of someone whom I have never met. It's like asking me to say if Robert Pattinson is a 'decent, humane' man. In any case, as both a supporter of the ME community and, importantly, an academic myself, my concern is really not with anyone's 'character', but with highlighting specific problems with claims, and actions, within the fields of science and medicine that might be harming patients.

4. Q: How did you react to the recent news that XMRV is probably not the causal agent of ME? Did you previously believe it was? If not XMRV, then what do you believe causes ME?

A: The vast majority of patients and their supporters are not, and were never, pushing for a 'favorite pathogen'. From my experience, most of us were - still are - merely hoping for science to progress, correctly and ethically, in testing for a possible causative agent. There are, however, reasons to believe there were, and remain, problems with how 'the science' was conducted, following publication of the Lombardi paper.

5. Q: Have you ever met your opponents and debated with them? Do you believe it is possible to have a mature and reasoned debate over a matter of what amounts to a major scientific and medical disagreement?

A: I did try and explain concerns about the PACE trial to Peter White, one of its authors, in a public meeting actually about the trial, but sadly he was not interested in discussing them. It SHOULD be possible to have mature and reasonable debates over this matter, but that is impossible when one 'side', from a position of power (that is proponents of psychogenic explanations for ME), accuses other participants (like patients and their supporters) of harassment, intimidation, and abuse - just because they have raised legitimate objections or concerns through legitimate channels - and misrepresents those concerns, which is sadly what has been happening.

Best wishes Angela

----- Original Message -----From: <u>Hanlon, Michael</u> To: <u>ANGELA KENNEDY</u> Sent: Thursday, December 06, 2012 1:18 PM Subject: Re: ME, XMRV, the PACE trials and Simon Wessely

Dear Angela

Thank you for taking the time to answer my questions.

Would you be prepared to meet with me sometime before Christmas? Happy to buy you lunch on

the Sunday Times!

Best regards Mike

----- Original Message -----From: <u>ANGELA KENNEDY</u> To: <u>Hanlon, Michael</u> Sent: Friday, December 07, 2012 7:39 AM Subject: Re: ME, XMRV, the PACE trials and Simon Wessely

Dear Mike,

Thank you, that's very kind of you :) Unfortunately I'm just not in a position to do that at the moment - certainly not before Christmas, and to be honest after Christmas feels unlikely, for a variety of reasons around caring for my daughter - and to be honest I've not been too well myself anyway (ongoing anaemia of unknown cause).

But anything else you need to ask me I am happy to answer by email.

There is one thing I forgot to mention in my previous email, regarding insults against ME patients that are repeated over and over again by journalists and academics (and Roger Highfield has just used this insult himself in a tweet!), and that is the irrelevant and laboured association, onto the obvious but entirely coincidental similarity, in the English language, between the acronym for Myalgic Encephalomyelitis, and the first person objective, in order to characterise ME patients' characters in dysphoric terms. This manifests in phrases like "the Me Me Me lobby" (Highfield's tweet), or in Elaine Showalter's case, this comment in her book Hystories, that the acronym "reflects the patient's self absorption". This is being done without irony. It's become, I'd say, an institutionalised, highly prejudicial insult against a disabled group. I discuss the characterisation of ME sufferers (and those of other illnesses deemed psychogenic) in dysphoric terms in detail in my book.

Best wishes Angela

END OF CORRESPONDENCE