

GREG CROWHURST: SPINNING THE WEB

By John Sayer
M.E. Support-Norfolk
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Greg Crowhurst – Grossly Irresponsible Indefensible Behaviour

Greg Crowhurst has a wife who, like this writer, suffers from M.E (Myalgic Encephalomyelitis). He is also a resident of Norfolk - but there the commonality ends.

As with Kevin Short (another Norfolk resident) before him, judging from his recent actions Mr Crowhurst seems intent on using the internet to damage the reputation of an active and highly-regarded local support group, 'M.E. Support-Norfolk' (MES-N).

Indicative of an ongoing collusion between Kevin Short and the Crowhursts, Linda Crowhurst had a letter published on 25 June in the Norfolk press lauding Short's "momentous victory" in securing a Judicial Review of the NICE guideline on 'CFS/ME', while omitting to mention anyone and everyone else involved in the process - let alone the other Judicial Review being pursued with the help of the One Click Group, and which is supported by MES-N.



Kevin Short - Ongoing Irresponsible Collusion

Service Design Project Group

Further indication of the Short/Crowhurst collusion is that some time back committee members of MES-N received a 'confidential memorandum' (copied to unnamed other parties, so there's nothing confidential about it) from Kevin Short,

urging support for Greg Crowhurst as the representative of severe M.E. sufferers in a group of Norfolk and Suffolk residents collectively known as the Service Design Project Group (SDPG), whose aim is to negotiate with our Primary Care Trusts (PCTs) with regards to a local service.

The committee of MES-N decided not to become involved with the SDPG - not because we disagree with its aims, which we share, of course - but mainly because we have more than enough on our plates already (two of the five of us are severe M.E. sufferers, for one thing) and have been doing our own lobbying of the health authority for some considerable time already, a point which has clearly escaped Greg Crowhurst's notice so far.

At one stage Mr Crowhurst was Chair of the SDPG, but not, it transpires, for very long. Kevin Short, likewise, is also no longer a member. The motivation behind both these gentlemen's otherwise inexplicable behaviour concerning MES-N seemed at one point to be simply that we won't do *their* bidding and won't toe *their* line when it comes to dealing with 'political' issues. What they also have in common, however, is support and praise for the '[Gibson Inquiry Report](#)', a stance which is not shared by those who view that report as being at best unhelpful, and at worst harmful, to M.E. sufferers and their carers.

Greg Crowhurst - Grossly Irresponsible Indefensible Behaviour

Having had his defamatory allegations and accusations against MES-N refuted on the internet, Mr Short has gone quiet on that front. Mr Crowhurst, however, appears to have picked up the baton in his place:

On 25 May, Andy Croft, at that time a committee member of MES-N (he has since resigned and not renewed his membership of the group), sent an e-mail about a meeting he'd attended of the "Norfolk Coalition of Disabled People" to the rest of the committee.

He copied this e-mail to Greg Crowhurst, who is not - and to my knowledge never has been - a member of MES-N, let alone on its committee, because, as Andy subsequently explained, he wanted to "acknowledge issues" he'd discussed with Greg and to show that he was "making an effort to bring the issue of local patient consultation with the NHS to the committee's attention..."

The same day, 25 May, Greg sent a one-line response to Andy, which he also copied to the committee:

"Andy, Exactly what is MESN doing for the severely affected?
Greg"

The committee had not been aware that Greg had been sent Andy's 'NCODP' e-mail until we received copies of Greg's response to it. In my own opinion, Greg's question was sarcastic. I nevertheless sent my personal response to him (28 May 2008):

"Hi, Greg! I don't know why/how you received a copy of Andy's e-mail to the MES-N committee about the 23 May NCODP meeting, but since you did, a couple of points need to be cleared up. (I have no comment to make on the references ascribed to me regarding either Kevin Short or EAME.)

"I have appended below MES-N's 'mission statement' {1}. Andy writes that he is 'unhappy with MESN not supporting its [the service redesign project] current aims and actions which are for biomedical provision and diagnosis testing with no CBT or GET and perfectly aligned with MESN's stated aims and objectives.'

"You will see from 'M.E. SUPPORT-NORFOLK: WHO WE ARE' that we make our position perfectly clear on these very points. Our stance is, indeed, the same as that of the service redesign project; we just happen to be pursuing these matters on our own initiative and under our own name. I anticipate the argument that MES-N should join with others to put pressure on the powers-that-be, but it can equally be argued that others ought to join MES-N, for the same reason. (Indeed, I personally find it intriguing that there are M.E. sufferers/carers in Norfolk who are *not* members of either 'West Norfolk M.E. Support' or 'M.E. Support-Norfolk', but that's by the by.)

"In response to Andy's e-mail you wrote, 'Exactly what is MESN doing for the severely affected?'

"This question cannot be answered directly, since 'the severely affected' is an abstract concept. If one were to ask, however, 'What is MESN doing for severely affected M.E. sufferers?' the answer would be 'Whatever, within our power, our severely affected members ask us to do for them.'

"What we do generally, other than in response to specific requests from individuals, is documented in our literature and monthly newsletter.

"Best wishes, John"

Greg responded that day:

"Dear John, As you know I meant severe ME sufferers. I just want to know exactly what issues MESN, on your own initiative and under your own name, as you stated, are pursuing on behalf of severe ME sufferers in Norfolk? I do not have access to your newsletters and information. and meanwhile my wife is in utter torment. Best wishes, Greg"

My reply to this (29 May 2008) was:

"Hi, Greg! Yes, I realise that by 'the severely affected' you mean 'severe M.E. sufferers'. I wasn't trying to be facetious (if that's what you thought), only pointing out that your question was too abstract to be answered in a direct way: we do what we can for individuals, with their individual needs.

"As for the general picture, we follow our constitution's Aims and Objectives, which are 'to provide information and support to people with M.E., their carers, families and friends; to raise awareness of M.E. locally within the media, health care

organisations and the general public; and to campaign for more recognition, research and better care and benefits for people with M.E.'

"I can't go into many specifics here because I can't remember them all and I would need to go through all our committee minutes, correspondence and back issues of MEMO (our newsletter) to compile a comprehensive list.

"Off the top of my head I can refer to the talks by Dr Carruthers and Prof Hooper we sponsored in 2005, along with the DVDs produced from those talks and distributed to health centres and surgeries throughout Norfolk; the various speakers (eg Betty Dowsett, Jane Colby, Nigel Speight) we have had following our AGMs over the years; leafleting campaigns we have conducted, usually in M.E. Awareness Week; putting our literature in hospitals and surgeries; informing the county's MPs; lobbying various departments within the health service, including the PCT; issuing press releases and writing to the media; and challenging the DWP, NICE etc.

"I don't know that we've done anything specifically for the severely affected as such, any more than we've done anything specifically for the mildly or moderately affected. We just do what we can, when we can, on behalf of M.E. sufferers generally. Of course, in day-to-day individual practical terms, that means for our members, since we are obviously not in contact with non-members so don't know what their specific needs are.

"I was helpless, bedridden and almost praying for death in the first few months of becoming ill. Thankfully, I improved gradually for a year or so (and honestly believed at the time that I was 'recovering' and would soon be back teaching). However, since first reaching a peak back in 1995 I have slowly but steadily declined and live with the realistic possibility that I will regress back to that earlier hell. If things continue as they are, it is only a matter of time before I am unable to continue producing MEMO, serve on our committee or do anything at all on behalf of myself or other sufferers. In the meantime I (as do the other members of the MES-N committee and individual members of our group who are able and motivated enough) keep at it, and it consumes the major part of my life.

"Best wishes to Linda, with whom I fully empathise.

"Cheers, John"

To which, that day, Greg responded:

"Thanks John. Very best wishes. Greg"

And that, one would have thought, was that. Sorted.

But no.

Mr Crowhurst then took it upon himself to post the following to various places on the internet, selecting only a partial quote from my original response of 28 May 2008 and missing out the critical second sentence of the paragraph, which explained why his question to Andy Croft couldn't be answered directly, i.e. "If one were to ask, however, 'What is MESN doing for severely affected M.E. sufferers?' the answer would be 'Whatever, within our power, our severely affected members ask us to do for them'" - and failing completely to mention the detailed information I had subsequently furnished him with:

"From: Greg Crowhurst gregcrowhurst@yahoo.co.uk

"There is a place beyond anger

"Greg Crowhurst, 9th June 2008

"There is a place beyond anger. While my wife sits, hunched in pain, while there is nothing I can even make her to eat, while she sits tormented by noise, by movement, in silence, Andrew Dillon, Chief Executive of NICE, through my MP, Norman Lamb, writes to me. He says:

"Our guidance does not recommend CBT/GET for those with severe ME/CFS, instead it recommends activity management administered by phone, email or in person, to be reviewed regularly and often."

"Activity management - oh, so that is what she needs?"

"Activity management', as recommended by NICE, is based upon the three principles of: prioritising, planning and pacing.

"Where, I wonder, would Mr Dillon begin ??

"No matter, do you know what my wife's response would be why not read it on: <http://www.metraining.co.uk>

"You probably cannot imagine what it is like to be trapped in a cycle of never ending opposite:

"Where rest leads to increased dysfunction. Where sleep leads to a complete ceasing of your body's ability to move and an agony of increased pain. Where touch, noise, communication, even tenderness are experienced as an assault on your physical and mental processes.

"If you want to engage with people with severe ME then try imagining a world that responds completely the opposite way to your intention, where exercise leads to inability and increasing disability. Get your sleep under control; Control the pain; Pace your energy; Just relax your muscles; these things are nonsense"

"Linda Crowhurst: Get Over It.

"NICE's recommendation that people with severe CFS/ME 'should be offered an individually tailored activity

management programme as the core therapeutic strategy, which may: 'draw on the principles of Cognitive behavioural therapy and Graded exercise therapy (1.9.3.1), is extraordinary, and has led to the guideline being condemned by many patient groups.

"There is a place beyond anger:

"1. when the psychiatric lobby are reported declaring that ME no longer exists.

"2. when I hear that Action for ME are calling for more, and better trained 'therapists'.

"3. when I wrote to my local group, ME Support Norfolk, and asked them to tell me exactly what they are doing for the severely affected and they responded:

"This question cannot be answered directly, since "the severely affected" is an abstract concept.'

"I am an artist. Yesterday I painted my rage: my eyes are tight shut, my brow knotted up, as if in agony, my mouth wide open in a teeth-bared scream.

"There is a place beyond anger, where I sit, for hours and hours, every day, just holding my wife, when I can. Trying to ease her physical torment.

"What hope is there of getting proper medical tests and treatment or validation for this severely disabling, multi-dysfunctional, neurological disease, when these are the attitudes and views of the people who represent ME to the world ?

"When severe ME sufferers are alone and off the radar?"

I posted a response to this uncalled for sullyng of our support group on the internet, pointing out that the "abstract concept" quote had been taken out of context and that *before* writing his "There is a place beyond anger" posting Greg had received an even fuller reply to his question {2}.

The fact is that Greg Crowhurst did not, as he claims, write to 'his' local support group: he simply wrote a response to an e-mail sent to him by Andy Croft.

It is also a fact that my response to the question "Exactly what is MESN doing for the severely affected?" was just that, *my* response - and not, as Greg claims, that of "M.E. Support-Norfolk".

So when Mr Crowhurst says that he asked 'his' local support group a question and 'they' replied, he is not telling the truth - and he knows it.

One might think that the matter having been clarified for him, Mr Crowhurst would at least admit that he'd got things wrong.

But no.

Mr Crowhurst chose to make matters *even worse* by posting the following 'apology' (and this time the sarcasm is unmistakable) to the internet:

"An Apology .Greg Crowhurst 16th June 2008

"(may be reposted)

"I am sorry, for asking my local group what they are doing for the severely affected. for being angry they are not involved politically. ME is a political issue, that is its travesty. If you are not involved politically, then you are not being effective. You are not helping. You are not giving us any hope. You are not challenging, changing, overturning. You are not taking a stand, fighting our corner, walking your talk. You are not walking your talk.

"For where I sit, faced with yet another day of my wife's pain and suffering, I am not sure I have much patience anymore. For that I am sorry. From where I reach out these hands that long to heal, I am not sure I know how to cope; not that I ever did.

"I live in the moment, it's best not to stand back too much, for then, surely after 15 solid years of never-ending agony shaking every inch of my wife's ravished body, I would go mad with despair.

"If I thought about it too much. But I have my faith and my anger. That is why I dared to ask."

My comment on this was:

"Dear Greg

"I'm sorry too, for assuming that your remarks, both here and in your 'beyond anger' posting, were aimed at 'M.E. Support-Norfolk'. I tend to forget that we have 'West Norfolk M.E. Support' and 'BRAME' also here in this county.

"You refer to 'your' local support group. Since you are not a member of 'MES-N' (despite a number of invitations to join), I guess your reference is to one of the other two groups.

"However - if you really *are* talking about 'MES-N', can you please explain what you mean by 'being angry they are not involved politically'?"

"Especially since you are not in any way involved in what we do, where on earth do you get that idea?"

"BW, John"

There was no response forthcoming - but my attention was recently drawn to a short video entitled "Walk your Talk!" which Mr Crowhurst had placed on YouTube at the beginning of June (i.e. after he'd received my detailed response to his question to Andy Croft), in which he repeats the same falsehoods contained in his written postings.

Sitting in front of a painting of his wife, he says:

"Recently I wrote - a couple of days ago really - to my local M.E. support group, because I'm really worried about Linda, and I said, 'What are you doing [holds up hands as if in supplication/prayer] for the severely affected?' and I can't tell you how shocked I am, and disturbed, by the reply I got. This is a big group, I believe there's over a hundred members, I think maybe a hundred and thirty, something like that, and they wrote back initially and they said, 'Well, the severely affected - um, that's an abstract concept' [snickers and points behind to painting]. There's nothing abstract about this!

"Anyway, I wrote back and said, 'Look, I'm talking about people with severe M.E. What are you doing for them?' And I got a long e-mail back, without much substance really, and anyway, it ended up, they're not doing - they don't really, it seems to me, trying to make sense of it - they don't really recognise severe M.E., and at the end of the day they're not involved politically, as far as I can see, in the struggle. They're providing support for people, which is good, and gardening, and helping people in those sort of ways, but it's not up to political involvement. Actually, this particular organisation, paradoxically, puts out a very political newsletter.

"So the issue really is, 'Walk your talk'. I really do believe that given the situation, which we all know about, it's not enough just to know about it, just to talk about it, just to publish radical articles. In my mind it *is* a political fight. As well as providing the practical and emotional support - obviously people need that - we have to be there, in the health authorities, we have to be there at the highest level, pushing and pushing and pushing and fighting this politically because after all this time I don't see things getting better, I just see the psychiatric lobby going from strength to strength and infiltrating more and more and more and I'm just so shocked by the response I got from this little organisation locally.

"And I would just like to ask, in this video, if anybody's watching, what is it like where you live? What is *your* local organisation doing for the severely affected? Perhaps you could write to your organisation or if you're part of an organisation you could write to *me* and tell me what *are* you doing for people with severe M.E. It would be really, really good to find that out, really interesting, and I wonder if what is happening here locally is happening up and down the country, and no wonder we're getting nowhere. Thank you."

The following are among the subsequent negative responses, posted to the comment facility on YouTube, engendered by "Walk your Talk!":

"Abstract concept?" Wtf??? That group clearly isn't working in the best interest of patients. They need their @sses kicked."
(neelubird)

"too many people diagnosed with ME/CFS have no idea what the illness is. They have no burning pains, exacerbated by illness. They are the ones who recover, and are well enough to run these local groups. They never had ME, that's why exercise, diet and relaxation worked for them. That's why serious is an abstract mythical term for them."
(temperance123)

'patrick3235' posted his own video, which begins, "Hi, I was totally dismayed and completely disgusted by the response that Greg and Linda got when they contacted their local ME group to find out what support they might offer for someone who is suffering from severe ME..."

On the positive side, 'MEAgenda' posted the following supportive comment:

"On 4 July, a mission statement from M.E. Support-Norfolk was published on WordPress blog ME agenda. On 18 June, the site published a note of thanks to the committee of M.E. Support-Norfolk for devoting eight pages of two of its Spring newsletters to raising awareness of the concerns surrounding the RSM 'CFS' Conference and for promoting two separate initiatives which had been organised in protest against this conference. A response has been published by the Chair to unwarranted criticism."

A nod in the direction of fairness, one might think.

But no.

The above statement was rapidly deleted by Mr Crowhurst and a subsequent attempt by 'MEAgenda' to post a further comment was blocked.

So Greg Crowhurst, who, by his own admission, does not "have access" to our "very political newsletter", alleges that "M.E. Support-Norfolk" is not "involved politically...in the struggle" and he is "shocked by the response" he got "from this little organisation locally", wanting to know if "what is happening here locally is happening up and down the country..."

Well, if it hasn't sunk in yet from the e-mail which was "without much substance really", I have news for Mr Crowhurst: "M.E. Support-Norfolk", as well as providing information, practical help and support, has been fighting politically on behalf of M.E. sufferers for over two decades - considerably longer than he has been spending time defaming us on the internet, and we won't be deflected from that struggle through being forced to expend valuable time and strength in dealing with the kind of insidious attempts at sabotage he seems determined to engage in, irrespective of any inconvenient truths.

Perhaps he also needs reminding of the ninth Commandment:

"You shall not give false evidence against your neighbour."

If Mr Crowhurst has asked BRAME, "West Norfolk M.E. Support" or the "Great Yarmouth Drop-In Support Group" (all in Norfolk) what *they* are "doing for the severely affected", he hasn't made the dialogue public.

He should, above all, consider the plight of M.E. sufferers who turn to local support groups for genuine practical help and support because they are not getting it elsewhere, and further consider the possibility that his unfounded and unjustifiable defamation of "M.E. Support-Norfolk" will deter Norfolk M.E. sufferers and carers from accessing that help and support when they most need it.

His behaviour is grossly irresponsible and indefensible.

John Sayer
M.E. Support-Norfolk

Notes:

{1} M.E. SUPPORT-NORFOLK: WHO WE ARE

Myalgic Encephalomyelitis has been categorised as a neurological disorder by the World Health Organisation (at ICD-10 G93.3) since 1969.

"M.E. Support-Norfolk" - the initials in our name stand for Myalgic Encephalomyelitis - has adopted the '[Canadian Guidelines](#)' definition of M.E.

We have been in existence for over twenty years now, having originally begun as a local branch of one of the national M.E. charities and since 2000, when our current name was adopted, have been an independent, self-financing support group.

We have our own library of books, videotapes, DVDs and audiobooks for members to borrow. Most of these are naturally M.E.-related, but some are purely for enjoyment! Members (membership is currently £6.00 per year) also receive our monthly newsletter "MEMO".

Each April we hold an Annual General Meeting for members, which is sometimes followed by a guest speaker whose presentation is open to the public.

We have also sponsored the occasional presentation at times other than our AGM; for example, Dr. Bruce Carruthers (principal author of the 'Canadian Guidelines') and Prof. Malcolm Hooper (Emeritus Professor of Medicinal Chemistry and leading champion of M.E. & Gulf War Syndrome sufferers) gave talks in Norwich in 2005. Both presentations were filmed and made available on DVD and videotape and a special DVD double-pack was also distributed to all GP surgeries and health centres throughout Norfolk.

Regular informal monthly support meetings are held in Norwich, sometimes with presentations on topics such as nutrition and complementary therapies, and individual members also host their own occasional get-togethers as well as organising various events throughout the year, particularly during M.E. Awareness Week, to raise funds for M.E. charities and research.

We have a web site presence at [M.E. SUPPORT-NORFOLK](#) which includes a selection of relevant articles.

"M.E. Support-Norfolk", in line with the World Health Organisation, recognises Myalgic Encephalomyelitis as a neurological condition. We are therefore interested in biomedical research and treatments and do not seek to promote 'biopsychosocial', psychological or psychiatric approaches to dealing with M.E. The

WHO does not have a classification for 'myalgic encephalopathy' and we do not promote this name as an alternative for Myalgic Encephalomyelitis.

We do not accept Chronic Fatigue Syndrome as being another name for M.E., nor do we agree that M.E. is an illness 'characterised by fatigue'. While we recognise that any severe long term illness can induce fatigue as well as anxiety, despair or even depression in patients, in line with the experience of hundreds, if not thousands, of patients we do not accept that cognitive behavioural therapy (CBT) or graded exercise therapy (GET) - or equivalent 'treatments' under other names - actually address the illness itself.

Our Aims and Objectives:

To provide information and support to people with M.E., their carers, families and friends.

To raise awareness of M.E. locally within the media, health care organisations and the general public.

To campaign for more recognition, research and better care and benefits for people with M.E.

{2} 'There is a place beyond anger:

<snip>

3. when I wrote to my local group, ME Support Norfolk, and asked them to tell me exactly what they are doing for the severely affected and they responded:

"This question cannot be answered directly, since "the severely affected" is an abstract concept."

There is a place beyond anger alright, one where people put selected out-of-context quotes like this on the internet!

Greg did not write to "M.E. Support-Norfolk" with his question, but to one of our committee members. The above quoted answer to that question came from me, which I then had to elaborate in a follow-up e-mail, since Greg, in his response to me, had clearly misunderstood what I meant:

"Yes, I realise that by "the severely affected" you mean "severe M.E. sufferers". I wasn't trying to be facetious (if that's what you thought), only pointing out that your question was too abstract to be answered in a direct way: we do what we can for individuals, with their individual needs.

"As for the general picture, we follow our constitution's Aims and Objectives, which are 'to provide information and support to people with M.E., their carers, families and friends; to raise awareness of M.E. locally within the media, health care organisations and the general public; and to campaign for more recognition, research and better care and benefits for people with M.E.'

"I can't go into many specifics here because I can't remember them all and I would need to go through all our committee minutes, correspondence and back issues of MEMO (our newsletter) to compile a comprehensive list.

"Off the top of my head I can refer to the talks by Dr Carruthers and Prof Hooper we sponsored in 2005, along with the DVDs produced from those talks and distributed to health centres and surgeries throughout Norfolk; the various speakers (eg Betty Dowsett, Jane Colby, Nigel Speight) we have had following our AGMs over the years; leafletting campaigns we have conducted, usually in M.E. Awareness Week; putting our literature in hospitals and surgeries; informing the county's MPs; lobbying various departments within the health service, including the PCT; issuing press releases and writing to the media; and challenging the DWP, NICE etc.

"I don't know that we've done anything specifically for the severely affected as such, any more than we've done anything specifically for the mildly or moderately affected. We just do what we can, when we can, on behalf of M.E. sufferers generally. Of course, in day-to-day individual practical terms, that means for our members, since we are obviously not in contact with non-members so don't know what their specific needs are.

"I was helpless, bedridden and almost praying for death in the first few months of becoming ill. Thankfully, I improved gradually for a year or so (and honestly believed at the time that I was 'recovering' and would soon be back teaching). However, since first reaching a peak back in 1995 I have slowly but steadily declined and live with the realistic possibility that I will regress back to that earlier hell. If things continue as they are, it is only a matter of time before I am unable to continue producing MEMO, serve on our committee or do anything at all on behalf of myself or other sufferers. In the meantime I (as do the other members of the MES-N committee and individual members of our group who are able and motivated enough) keep at it, and it consumes the major part of my life.

"Best wishes to Linda, with whom I fully empathise."

Since Greg's response to that e-mail was, "Thanks John. Very best wishes," I was absolutely shocked to read his "ME - there is a place beyond anger" posting, especially when he lumps together "MES-N", the psychiatric lobby and AfME:

"What hope is there of getting proper medical tests and treatment or validation for this severely disabling, multi-dysfunctional, neurological disease, when these are the attitudes and views of the people who represent ME to the world?"

Greg should hang his head in shame. (Or at least join one of the Norfolk support groups, if he thinks he can do any better).

John Sayer
(Chair, "M.E. Support-Norfolk")