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[LocalME] ME in Westminster

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[Debates]

Appropriate ME Treatment

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Mr Deputy Speaker (Sir Lindsay Hoyle)

I call Carol Monaghan to move the motion. She has up to 15 minutes. Given that so many Members wish to speak, I shall be very grateful if they do all that they can to help each other.

Carol Monaghan (Glasgow North West) (SNP)

This debate is long overdue and much anticipated, and I thank the Members who have remained in the House on a Thursday afternoon to contribute to it.

There have been previous debates on ME, including one called by the then Member of Parliament for Great Yarmouth, Anthony Wright. That debate took place 20 years ago, and in 20 years little has changed for those living with ME. There is currently no cure, and many with the condition experience inadequate care and support. An estimated quarter of a million people in the UK suffer from it, and we are letting those people down. Many adults with ME cannot maintain employment or relationships, while children frequently fall behind at school. The ignorance surrounding the condition makes it harder for people to access benefits, and assessors from the Department for Work and Pensions often decide

that sufferers are fit for work.

ME has specific characteristics—severe fatigue, debilitating muscle and joint pain, and extreme sensitivity to light and sound—but an important marker for the condition is that mental and physical activities can make the symptoms more acute. Some people with severe ME spend their days in darkened rooms, unable even to watch TV or listen to music. Touch is intolerable. Many are tube fed. For these individuals, ME is a life sentence, but it is a life spent existing, not living.

Mr Jim Cunningham (Coventry South) (Lab)

Will the hon. Lady give way?

Carol Monaghan

Very briefly.

Mr Cunningham

I fully support the motion, because it alludes to some of the complaints that ME sufferers have brought to my surgeries. This is a timely debate, and what the hon. Lady has said so far is quite right.

Carol Monaghan

I thank the hon. Gentleman.

This condition is largely unknown, because those affected are often hidden away. I commend the ME community for lobbying so successfully to ensure so many Members are here this afternoon. Ultimately, what that community wants is better treatment and care for people with ME.

Paula Sherriff (Dewsbury) (Lab)

Will the hon. Lady give way, on that point?

Carol Monaghan

Again, very briefly.

Paula Sherriff

I congratulate the hon. Lady on her sterling work on this issue. It is my privilege to represent Lucy, a lovely teenage girl in my constituency who has ME. Her parents have requested me to ask the House to ensure that biomedical research shapes all aspects of support-in which case it must be funded-and to reiterate that ME is a physiological condition, although it is often treated as a psychological condition. Lucy was asked if she needed to get around. She was told to just get up and walk, but she needs a wheelchair. Much more awareness is needed generally.

Carol Monaghan

Yes, ME receives far less research funding than other similarly prevalent conditions. That, I fear, reflects the attitude of some in the medical community who consider it to be behavioural rather than a pathological condition.

Mr Robert Goodwill (Scarborough and Whitby) (Con)

Will the hon. Lady give way?

Carol Monaghan

I shall have to keep going. I apologise, but a great many Members want to speak.

The psychological view of ME led to the controversial and now debunked PACE trial-PACE is 'Pacing, graded Activity, and Cognitive behaviour therapy; a randomised Evaluation'. The researchers reported that with cognitive behavioural therapy and graded exercise therapy-in which patients were encouraged to attempt increasing levels of exercise-approximately 60% of patients 'improved' and 22% 'recovered'. The treatments were labelled safe. Patient groups, however, were saying the opposite. Many who were able to walk when they embarked on a course of graded exercise dropped out of the treatment in wheelchairs or bedbound. Furthermore, patients were pressurised to describe improvements that they did not feel. As the trial progressed and the results did not meet the authors' expectations, they simply lowered the threshold to define improvement. In some cases, those whose condition had deteriorated were classed as 'recovered'. That is simply not good science.

The recommendation of graded exercise has caused untold physical damage to thousands of people. In fact, a 2018 survey found that 89% of ME

sufferers experienced worsened symptoms after increasing activity. If graded exercise were a drug, it would have lost its licence.

The blatant ongoing refusal to accept ME as physiological doubtless explains the lack of proper research. Of course it is the Medical Research Council that allocates funds, but the Government can demonstrate their true commitment to improving the lives of ME sufferers. The Scottish Government have committed 90,000 pounds for a PhD scholarship to support research into the causes, diagnosis and treatment of ME, and I would ask that the UK Government follow this lead.

During the debate in June, the Minister for public health, the hon. Member for Winchester (Steve Brine), who is in his place, said that 2.62 million pounds had been spent on ME research since 2011. Let me be very clear: this money was spent on behavioural studies. We need money to be spent on biomedical research, and we are looking for a solid commitment from the Minister.

Until we have developed effective treatments, however, we must ensure suitable care plans are in place to respond to patients' varying needs. Many US agencies are now removing their recommendations for graded exercise. However the National Institute for Health and Care Excellence guidelines continue to advocate this, despite patient surveys consistently indicating its harm. The risks are not acknowledged in the guidelines, undermining patients' ability to give informed consent, and some patients are being threatened with being sectioned if they do not commit to a programme of graded exercise.

Mr Goodwill

Will the hon. Lady give way?

Carol Monaghan

Very briefly.

Mr Goodwill

Many consider the NICE guidelines to be completely inappropriate. Does the hon. Lady agree that the timescale for that review, which will end in 2020, is far too long for these patients?

Carol Monaghan

Actually, NICE has taken a very positive step in reviewing the guidelines-it is listening to the community-but until they are published in 2020, we need NICE to make a public statement about the potential harm of graded exercise; patients must be made aware of the risk. It is a big ask to request that the Minister talks to NICE and encourages it to make that statement, so that this information can be added to the current guidelines while we are waiting for updated guidelines in 2020.

Care programmes for people vary greatly. Some with ME describe medical professionals who are sympathetic, but others talk of being disbelieved and forced down treatment paths to which they have not consented. Coverage of ME in many medical textbooks remains potentially misleading and inadequate, even non-existent. Health professionals must be equipped with clear guidance on diagnosing ME early and accurately, and with appropriate basic management advice.

At the end of last June's debate, the Minister for public health resolved that 'as a result of the debate I will redouble my efforts to' raise awareness among medical professionals concerning ME, and said that 'as part of my role as Minister for primary care, all GPs certainly should be aware of ME'. - [Official Report, 21 June 2018; Vol. 643, c. 229WH.]

That was a welcome statement; I would now like to understand what concrete steps have been taken since that promise was made. Furthermore, I would ask the Minister to ensure that ME clinics and treatment centres are aware of the risks of graded exercise and are not forcing this on patients.

Some of the worst cases we hear about are children with ME. ME affects an estimated 25,000 children in the UK. Many experience significant distress when disbelieved by medical and teaching staff, often when these professionals do not understand how ME affects the child's ability to attend school.

Dr Matthew Offord (Hendon) (Con)

Is the hon. Lady aware that one in five families looking after children with ME have been referred to child protection services?

Carol Monaghan

Yes. The statistics are terrible, but I want to describe one such case, which is really quite harrowing. It involves a girl, B, whose name cannot be disclosed. B became ill at the age of eight. A diagnosis of probable ME was made, but it was suggested that the underlying issues were psychological. To show willing, her parents took her to a child psychiatrist, who then involved social services. B's parents were warned that if they did not fully comply, child protection proceedings would be initiated. Social services specified graded exercise, despite being warned of the dangers. As a result, B deteriorated rapidly until she became wheelchair-bound. Under threat of court action, B's parents were then forced to take her to a children's hospital, having been warned that they were 'not under arrest just yet.'

B's parents found what they presumed to be a safer option in an ME unit run by a consultant who appeared to view ME as an organic illness, but this was disastrous. B arrived wheelchair-bound but still able to sit upright and read and write, but under the activity programme, she deteriorated. Her mother was banned from visiting, but other parents in the unit observed B unattended in the wheelchair, in constant pain, unable to sit upright, with her head hanging down the side and crying in distress. This treatment continued for five months. Her parents were threatened that if B did not progress, she would be transferred to a psychiatric unit or placed in foster care. Desperate, they turned to Dr Nigel Speight and the Young ME Sufferers Trust. B was finally allowed home, and her name was eventually removed from the at-risk register. However, by the age of 15, she was bedridden, paralysed, unable to feed or wash herself and utterly dependent on carers. Doctors, psychiatrists and social services all failed her when she was eight. As the hon. Member for Hendon (Dr Offord) suggested, this is the case for one in five families living with a child with ME.

A firm diagnosis of ME protects the child from these proceedings, but unfortunately, paediatricians are often reluctant to give this, simply because they do not understand the condition. This leaves the child open to social service intervention. Often, paediatricians phone a so-called expert on ME, who immediately prescribes graded exercise, without even seeing the child in person. I say to the Minister that this is a national disgrace and it needs urgent action. Children who are already blighted by ME must not be subjected to this trauma. I ask him to consider this issue with the utmost seriousness, and to give the House an assurance that parents will not be prosecuted simply for caring for a sick child.

ME has been disregarded for far too long, and it can be fatal. In the UK, there have been two patients, Sophia Mirza and Merryn Crofts, whose deaths have been attributed by coroners to ME. However, the actual number of deaths due to ME may be much higher, and we cannot wait for more. The ME community have waited decades for their voices to be not only heard but believed. The Government have the power to make radical changes, and I invite the Minister to meet groups of patients who would welcome the opportunity to describe their experience. Little progress has been made in the 20 years since the 1999 debate. Surely, Minister, in the 21st century we can do better for those suffering from this devastating illness.

[Several hon. Members rose]

Mr Deputy Speaker (Sir Lindsay Hoyle)

Order. If each hon. Member can stick to four minutes, we will get everyone in, and everyone will get equal time.

Sir David Amess (Southend West) (Con)

I congratulate the hon. Member for Glasgow North West (Carol Monaghan), along with the hon. Member for Ceredigion (Ben Lake) and my right hon. Friend the Member for Loughborough (Nicky Morgan), on initiating this debate. I first heard ME being mentioned in the Chamber in the 1980s by, I think, the late Richard Holt on these Benches and Jimmy Hood on the Labour Benches. I could not pronounce the long title of the condition, but they could. As the hon. Member for Glasgow North West has said, it is disappointing that not much progress has been made, all these years later.

Like so many other Members, I am here today to speak on behalf of constituents with ME who want their voices to be heard. I am thinking of last week's Westminster Hall debate on fibromyalgia, which is another of those problems that is not spoken about much. ME is also an invisible illness, and many people suffer in silence, so I will be using this opportunity to speak on behalf of my 500 constituents in Southend West who suffer from the illness. I would like to share with the House the words of one of them, Isabel Butler, whose moving story tells of the devastating impact of the condition, and the desperate need for the Government to take action. She says: 'I was a trainee teacher and raising my young son, having just graduated with a first class honours

degree when I was struck down suddenly with this horrific illness in 2003. I battled on in pain, and despite repeated visits to my GP was simply fobbed off with antidepressants. I was not depressed, I wanted to do things but for every exertion I was overcome with pain that left me bedbound for days. Despite my best efforts and determination, I was too unwell to continue my job and pursue the career I had also dreamt of. The worst of it is, I went undiagnosed for seven long years. People don't believe you when you tell them that you are ill, so you keep quiet, even when I had been admitted to hospital, as medics can often turn on you in contempt at the mention of ME.'

Justine Greening (Putney) (Con)

My hon. Friend is setting out a shocking case, and I am sure that we will hear many others like it today. The key to this has to be research, so that we can start to understand this terrible disease and then be able to build proper treatments that actually have a chance of working.

Sir David Amess

I am taken by the fact that we have two former Secretaries of State sitting together—my right hon. Friend the Member for Putney (Justine Greening) and my right hon. Friend the Member for Loughborough (Nicky Morgan)—and I certainly listen well to their advice. I absolutely agree with what my right hon. Friend says.

My constituent goes on to say: 'I do not understand why we are not being believed. I had a promising life, two beautiful boys and a career I loved. I didn't choose to be this ill with no hope of any treatment, compassion or cure.'

The overwhelming experience of sufferers is a struggle to be believed. There is a lack of understanding among the public, policy makers and, most worrying of all, the medical profession.

Dr Julian Lewis (New Forest East) (Con)

My constituent Rachael King told me that one area in which there has been understanding is in schools, saying that Noadswood School and Brockenhurst College in my constituency are very understanding indeed. However, she says that her 15-year-old daughter Larissa is one of the luckier ones in that respect, because so many people are not believed, as we have heard today. If they were not depressed by the condition,



they will be depressed as a consequence. However, ME is not depression; it is a serious illness in its own right.

Sir David Amess

I hope that the good practice in the schools in my right hon. Friend's constituency will be shared throughout the country.

Sufferers are too often left in agony for years, undiagnosed and untreated. GPs are failing to recognise or even believe the severity of symptoms that can devastate patients' lives. I urge the Government, as the hon. Member for Glasgow North West did, to work with the medical profession to ensure that all GPs have the understanding to diagnose, treat and manage ME with compassion.

However, a lack of awareness among GPs is a symptom of how little we understand the condition medically. There is no known cause, reason or cure, and there is a worrying lack of investment in biomedical research for ME in this country. Without that research, we simply will not be able to improve diagnosis or treatment for patients. I join Members across this House in calling on the Minister to consider properly funding the biomedical research that ME desperately needs.

Finally, as the National Institute for Health and Care Excellence guidelines are under review-I was on the Health Committee for 10 years and remember the arguments-we should now take this opportunity to start listening to patients. The controversy of the PACE trial arose from a failure to listen to sufferers and to believe their experiences. For the NICE guidelines to be successful and transform sufferers' lives, we need to listen to patients. I sincerely hope that this debate will not just be mere words and that it will lead to some well overdue action. In signing off her letter, my constituent Isabel said: 'After 20 years of pain, thank you for listening.'

Now that this House has listened, I hope that we can have some action.

Mr Adrian Bailey (West Bromwich West) (Lab/Co-op)

I thank and congratulate the hon. Member for Glasgow North West (Carol Monaghan) on her commendable perseverance in pursuing this matter. Like others, I have been approached by constituents to discuss ME, which caused me to dredge my memory and recall individuals whom I have known personally who have suffered from this illness. From my conversations

with sufferers, I know that they have been confronted with a range of problems that still exist for others today. Those problems include: a lack of understanding and support in the workplace and in schools, which can mean a loss of job opportunities or problems for the parents of young pupils; inadequate understanding by clinicians; delays in diagnosis and, indeed, inappropriate treatments and tests; incomprehension and insensitivity by the DUP for recipients of benefits, which can lead to a loss of benefits. [Interruption.] Sorry, I mean the DWP. A Freudian slip. I do not blame the hon. Member for Strangford (Jim Shannon) for that particular problem.

The loss of those benefits can lead to a loss of income, leading to life challenges over and above the problems such people confront because of their illness. Over and above all that, there is the stigma of mental or psychological problems, which can reinforce the sense of social isolation. It is amazing that, despite the debates we have had on this subject and despite our world-class NHS and top-class medical research, these problems have not been addressed.

Like many people, I have personal examples from those who have had their life devastated by this illness. Lucy, a vivacious young political activist I know, was heading for an early parliamentary career before she was struck down. She found that she could manage to work only 10 hours a week, and describes how every speech and every meeting is absolutely devastating to her body. She describes it as remaining awake while her body sleeps. She went to the doctor, and even different doctors within the same medical practice gave different diagnoses, which demonstrates the unbelievable lack of comprehension of this illness.

I would have liked to give many more examples, but I finish by saying that, in summing up last June's Westminster Hall debate, the Minister spoke about channelling research, but the problem is that it seems to be going towards psychological research, rather than neurological research. He also said that the NICE draft consultation will be ready in 2020. Why the wait, given our knowledge of the scale of these problems? He said that he would follow up with the DWP on the problems there, and I hope he can report on that.

Nicky Morgan (Loughborough) (Con)

It was a pleasure to apply for this debate with the hon. Members for Glasgow North West (Carol Monaghan) and for Ceredigion (Ben Lake) and others. [Interruption.] How could I possibly forget the hon. Member for

Ealing North (Stephen Pound)?

Like other Members, I will speak about my own constituents' experiences. As we have already heard, so many Members are here on a Thursday afternoon to talk on behalf of their constituents. We held out for a debate on the Floor of the House, and we are debating not a 'take note' motion but a substantive motion. This House debates many contentious issues, passions can run high and there can be many points of order, but hopefully we will see the House of Commons at its finest this afternoon as we do our job of bringing to the attention both of Ministers and of the wider public an issue of real importance that devastates the lives of our constituents and their families.

We have already heard about the issues of funding for biomedical research, and it is clear that, given the prevalence of the condition, there must now be an increase in funding not only to help advance our understanding of its underlying biology but to develop new diagnostic tests and better, more targeted treatments. The problems and dangers of graded exercise therapy and CBT have already been powerfully set out. My constituents have also called for NICE to take their concerns into account and to remove those treatments from its guidelines. We have heard the call for NICE to issue an immediate public statement on the harm that may be caused by the current guidelines for the period they remain active.

It is right that we want GPs and health professionals to know more.

Paula Sherriff

My constituent has to travel 40-odd miles to Manchester for treatment. With a condition such as ME, that is particularly distressing. Does the right hon. Lady agree that we need many more specialists throughout the country?

Nicky Morgan

I agree with the hon. Lady. We all know that resources may be constrained, but we want our constituents to be able to see specialists who really know about a condition. One of the most powerful things that we have heard is that not only are sufferers fighting a condition that makes them feel terrible, but they are not believed when they say what they are going through. That must compound the difficulties of the condition. Having a GP who not only believes them, but wants to help and

understand, would make a huge difference. The same is true of other health professionals.

We have talked about children being affected. One of my constituents wrote to me to say that she had had ME since 2013, and had been left housebound. She added: 'As if having this illness wasn't devastating enough, in 2016, my then 10 year old son became unwell and never got better, he has also been diagnosed with ME.'

We have heard today about the potential involvement of child protection services. In addition, some schools can deal with the condition, but some schools will struggle. I was contacted only this week, as the debate was being advertised, by another constituent. She talked about her daughter, Elisha, who is now 11 years old and has had ME for four years. Elisha has been discharged from the community paediatrician, physiotherapist and occupational therapist and left with no support or medical help, because there is no funding for paediatric ME care in Leicester or Leicestershire. She has missed most of her schooling in the last four years. Clearly, with children as well as with adults, people must be believed and the condition must be investigated. It is a considerable source of stress for parents and carers, but of course it has a negative effect on the child's personal development and future life chances.

I have family experience of ME, but I want to pay tribute to the constituent who first brought the matter to my attention, Sarah Reed. Some Members, particularly Opposition Members, will know her as the wife of the former Labour MP, Andy Reed, who was my predecessor in Loughborough. Sarah has been a tireless campaigner for ME Action and for sufferers.

There are 250,000 - a quarter of a million - sufferers of ME, or chronic fatigue syndrome, in the UK. With any other condition, we would not allow a situation in which people continue to struggle to have their voice heard, and the NICE guidance takes so long to be delivered. There are many examples, and it is time for the Government to respond.

Mrs Emma Lewell-Buck (South Shields) (Lab)

I thank all the hon. Members who secured this debate. In preparing to speak, I have become more and more angry about the injustice and pain heaped on those who suffer from ME. They live in a country where their illness is at best belittled and at worst ignored. Their illness is

sneered at thanks to the development, in the medical field and in the press, of a culture of believing that it is just people being lazy or women being hysterical.

The effects of the condition can be totally debilitating. Any other illness with such life-limiting effects would not have psychological and behavioural treatments as the go-to options. This is not a psychosomatic or psychosocial issue, and a better response is needed. Graded exercise therapy must be suspended and CBT therapy should be an option, add-on or complement to other treatments, not the treatment.

There is a growing consensus about the use of pacing for managing ME. Sadly, current NICE guidelines state that there is insufficient research evidence about the benefits or harm of pacing. That is why more funding for research is vital. We need a commitment from the Minister to increase the sparse funding for ME research, which at present stands at a paltry 1 pound for every sufferer.

The now widely discredited PACE trial had far-reaching implications. Not only did it add to the existing myths around ME, but it led to alterations in the application of benefits and eligibility for social care.

For someone who knows how unwell they are, there must be nothing worse than being told that it is all in their head and being sneered at by the very professions and organisations that should be supporting them. The constant quest to be believed and the desperation of just wanting some answers was summed up powerfully by my constituent, Barbara Kell. She described the endless rolling of eyes by some GPs and the frustration of others who wanted to help her but knew they would be hauled up in front of the General Medical Council if they did. Barbara told me that she is living 'half a life', and that she grieves for her past. She said she is missing out on so much, including time with her grandchildren-I can testify to the House that they are gorgeous little girls. Like thousands of others, Barbara wants and deserves to live in a country where the Government properly fund research; where treatment helps and does not hinder; where support from the state does not come at the cost of dignity; and where people actually listen to her. Right now, that is not the case.

Barbara told me that every time she went for blood tests, which were of course the wrong ones, and the results came back, she was actually hoping it was something like cancer, just so that she could put a name

to the intense pain that she was feeling, get the right treatment, and know whether she was going to live or die. For the sake of my constituent Barbara and the 250,000 others affected, I hope that the Minister is really listening to what is being said today and is ready to give some justice and comfort to those who have been ignored for decades.

Kevin Foster (Torbay) (Con)

It is a pleasure to be called to speak in this debate, and particularly to follow the hon. Member for South Shields (Mrs Lewell-Buck) and her comments. I thank the constituents who contacted me ahead of the debate not only to encourage me to attend but to make clear their concerns about this issue. Several Members have picked up a point on which I shall reflect as well: ME can have such an impact on someone's life, but at the same time they sometimes have to battle for recognition that that is what is affecting them. Of course, there is no specific test for the condition, which leads on to the fact that there is no specific cure for it. As we heard in the previous speech, that can lead to scepticism rather than someone being supported.

As several Members have already said, this condition has a 3.3 billion pounds impact per year, in terms of healthcare costs, the related welfare payments, productivity losses and unpaid informal care, as well as, of course, the wider lost opportunity because those who suffer from this condition are not able to live life to the full or as they would wish. It will be interesting to hear from the Minister about the review of the NICE guidelines. For the reasons that other Members have already gone into, it is welcome that we know what is being looked at, but it would be particularly welcome to hear whether we might be able to bring forward some updated guidelines earlier than the stated timeline of 2020. It would be interesting to hear the Minister say that when he responds to the debate.

As has also been touched on already, when one considers the impact of ME, it is quite remarkable to see how little is spent on research. I think something like only 0.02% of all active grants given by UK mainstream funding agencies goes towards research in this area. Clearly, without research, there will not be the hope of improved treatment or of a test being developed so that people can move away from scepticism and get support from their medical practitioners. Ultimately, we will hopefully find a cure, or a treatment that at least mitigates some of ME's effects.

Members have already touched on the fact that there is clearly an issue in relation to how those living with this condition are assessed for welfare benefits, particularly because they might be assessed on a good day, which does not then reflect their overall condition. When he sums up, it would be interesting to hear the Minister reflect on some of the conversations that the Department of Health and Social Care is having with the Department for Work and Pensions, although I accept that he is unlikely to get a particularly long time to sum up, given the short length of the debate.

I welcome the opportunity today to highlight this issue on the Floor of the House, and I congratulate the hon. Member for Glasgow North West (Carol Monaghan) and the other Members who applied on securing this debate and enabling us to raise our concerns on a cross-party basis. As has been touched on, 250,000 people live with this condition in the UK. It needs research, support and a change of culture, so that sufferers feel supported and believed and can have some hope of living the sort of normal life that we all expect and deserve.

[Several hon. Members rose]

Madam Deputy Speaker (Dame Eleanor Laing)

I am terribly sorry but it is obvious that a lot of people wish to speak. We have very little time, and I am sure the House wishes the Minister to have time to answer the many important points raised, so I must reduce the time limit to three minutes.

Dr David Drew (Stroud) (Lab/Co-op)

I shall be brief, Madam Deputy Speaker.

I congratulate the hon. Member for Glasgow North West (Carol Monaghan) on securing this debate through the Backbench Business Committee. I shall try not to go over ground already covered, but I must pay due regard to my constituent Dr Charles Shepherd, who continues to advise the ME Association and has come forward with many suggestions that it has followed.

On medical education, there is evidence of some progress, which is very pleasing. GPs are the gatekeepers and need to recognise ME at an early stage so they can help their patients. It is heartrending to read what

constituents have written to me, particularly the parents of younger children suffering dramatically from this dreadful condition. The PACE trial and the need for a rewrite of the NICE guidelines have been touched on already. It is important that NICE bring that forward. It would be interesting to know why the Government have cut the money for biomedical research and the National Institutes of Health. If that money could be put back in, that would be one bit of good news the Minister could give us. My hon. Friend the Member for West Bromwich West (Mr Bailey) touched on the role of the Department for Work and Pensions. It is important that this condition be recognised and that sufferers get early support. On the work of clinical commissioning groups, the NHS has to do more and spend its own local resources.

To finish, I want to touch on the overlap with B12 deficiency, which has not been mentioned yet. Autoimmune metaplastic atrophic gastritis, previously known as pernicious anaemia, is often confused with ME. It is very important that we encourage local health bodies to rewrite the rules for that condition as well to ensure that people are correctly diagnosed. It is very unhelpful when people's conditions are not properly recognised as it can result in a downward spiral of psychological problems. It is about time we spent the necessary resources on this condition and gave the necessary help to sufferers.

Stephen Kerr (Stirling) (Con)

I could easily say amen and sit down, but I would like to compliment the hon. Member for Glasgow North West (Carol Monaghan) on her speech.

I hope this debate and the passionate interest of colleagues from the across the House bring some encouragement to those suffering from this condition that they are not forgotten. Louise McAllan from Riverside got in touch with me last June. She tells me that ME led her to medically retire in her early 30s, that she has been too sick to leave her bed for months at a time, that she is unable to tolerate light or sound, that she cannot meet her friends and that she suffers intolerable pain. She was told by a neurologist in a major hospital that there was no such thing as ME, and she was told when she got a diagnosis that at least she did not have anything serious.

Catherine Schmitz from Stirling got in touch last May to tell me her story. For her, it is a dreadful illness that has left her signed off work for 22 years. She has balance and vision problems and sensitivity to light and noise. To get a diagnosis, she was passed around hospital



departments that could look only at their own specialist areas.

Cathy Dickson from Torbrex got in touch in November 2017. Her case and the dangerous advice that she was given saw her become more ill because of doctors who had no knowledge of ME. She continues to fight for the support that she needs and deserves.

Pam Sullivan from Bridge of Allan also suffers from ME, which has left her with crippling fatigue, exhaustion, viral symptoms, muscle pain, and impaired cognitive function. Without her loving family, she would have no support at all.

I know the Minister is both compassionate and dedicated, so I hope that he will respond to the demands that we are hearing today in this debate. Treatments that harm patients should be discontinued with immediate effect. Does he appreciate the fact that ME patients cannot wait for NICE guidelines to be reviewed? I very much hope that he will agree that it is simply not acceptable that seriously ill people should be left feeling that, somehow, they are to blame for not getting better, and that if only they had a better attitude and a different mindset, they would recover.

What more will be done to provide updated professional training for GPs and other healthcare professionals properly to recognise the symptoms of ME? What more can the Department for Work and Pensions do to see that ME patients are treated fairly and that the process to which they are subject does not worsen their illness-especially in respect of how assessments are conducted? Will the Minister please reassure the House that substantially more resources will be dedicated to biomedical research so that we can understand ME and begin to reach for solutions? Minister, people need help.

Kelvin Hopkins (Luton North) (Ind)

First, may I add my support to the motion as set out on the Order Paper and congratulate the hon. Member for Glasgow North West (Carol Monaghan) on leading the way in securing this debate and also on her excellent speech.

I spoke in a previous Westminster Hall debate and later put down written questions on ME on the basis suggested by Dr Ian Gibson, whom longer-standing Members may remember as the Labour Member for Norwich and a distinguished medical scientist in his own right. Ian was incensed

by the use of graded exercise therapy. He said that it was less than useless and actually damaging to sufferers as well as causing them pain and raising false optimism that such therapies would work. Given that ME causes extreme fatigue, suggesting more exercise seems to me about as sensible as asking frostbite sufferers to walk about in snow. The other suggested treatment, cognitive behavioural therapy, helped to underpin the myth that ME is a psychological problem, not a physical condition. Neither of those supposed therapies should have been given credence and efforts should have been focused long ago on discovering the real causes of ME and on undertaking proper and thorough research to develop effective treatments.

I first became aware of ME more than 25 years ago when two of my young relatives were found to be suffering from the condition. The fact that I was not aware of ME until then is itself extraordinary given that some 25,000 children are estimated to be suffering from the condition. That is more than 38 children, on average, for every one of our constituencies.

I later became informed of sufferers in my own constituency and recall one man in particular who suffered constant pain and had to lie in a darkened room because he could not bear the light. Such symptoms are well known, but, of course, like so many illnesses, the severity of symptoms can vary greatly. MS, for example, can advance rapidly, or can remain fairly mild and stable for many years. Such variations do not invalidate the condition.

I have mentioned children with ME, but if all adults were included, the figure reaches 250,000, or nearly 400 per constituency; it really is that serious. The impact on the lives of those constituents is enormous, but the cost to society and to the economy is over 3.3 billion pounds a year-an enormous sum. Therefore, finding causes and discovering effective treatments are vital. Funding research must be a priority, first, to reduce the level of suffering, but also to reduce the wider social and economic costs. Research into ME represents just 0.02% of all grants given to funding agencies-just one 500th of the total, a pathetic amount.

In conclusion, I hope that we are now putting behind us all the myths and misdiagnoses related to ME. It is a physical condition and it is causing untold suffering. Recent research has looked very promising, and has pointed to possible causes of ME. One factor in particular has recently received publicity-the overactive immune system in many

sufferers. It seems that we are starting to move in the right direction. We must congratulate the scientific and medical researchers who have done, and who are doing, so much valuable work towards finding solutions to the scourge of ME and alleviating the suffering that it causes.

I hope that Ministers and other hon. Members will take note of the reports in 'Breakthrough', the journal of ME research...

Madam Deputy Speaker (Dame Eleanor Laing)

Order. I call Mr Stephen Pound.

Stephen Pound (Ealing North) (Lab)

May I say that north-west London salutes north-west Glasgow? I was honoured and proud-not that I had much choice in the matter-to support the hon. Member for Glasgow North West (Carol Monaghan) when she applied for the debate. Her influence clearly spreads much further than Whiteinch, because only last week the Scottish Government launched their national action plan on neurological conditions. Action for ME was not particularly delighted with the plan, but one of the good things to come out of it is the allocation of 90,000 pounds to fund a PhD study on the impact of ME. If that funding was increased proportionately for the whole country, it would be well over 1 million pounds. That is something we certainly look forward to.

We have talked about the individual circumstances of many of our constituents. I want to mention one area that has not yet been mentioned: the provision and allocation of social housing. People with myalgic encephalomyelitis and chronic fatigue syndrome often have very specific housing needs. I think of my constituent Pamela Badhan-she is admirably represented by Councillor Deirdre Costigan-who finds it intensely difficult to live where she is at present because of her condition. The thing about ME is that, even if someone with the condition sleeps all night, they are still exhausted the next day, because the exhaustion is endemic; it cannot be sated by sleep. That is how terrifying the condition is.

I will not go into the details of the research today, but we do need to have the biomedical research. We have moved a little further forward since the dark days of the stiff upper lip, when people were told to take one round turn and two half hitches and then pull themselves together. We have to change attitudes, and that cannot be dictated-we

have not had a dictator in this country since Oliver Cromwell. We cannot say what a people will do. What we can do is raise this issue, calmly, objectively and using all the pragmatic skills and data available to us.

I want to say to all those people out there who are suffering from ME; all those people suffering from chronic fatigue syndrome; all those people who have been ignored, belittled and, in many cases, insulted: 'This House recognises the reality of your condition. This House will not sit idly by while you suffer. This House will not ignore you. This House will devote its intelligence and resources to research and ultimately resolve and cure this terrible condition, because we respect you, we understand you and we give credit and credibility to what so many people have for far too long denied.' ME sufferers the world over must know that this House and this nation are finally speaking for them.

Karen Lee (Lincoln) (Lab)

How do I follow that? I congratulate the hon. Member for Glasgow North West (Carol Monaghan) on securing this important debate. Last year I was invited by a group of ME patients in Lincoln to a screening of 'Unrest', Jennifer Brea's deeply moving and personal documentary. The film really opened my eyes to the bravery and resilience that people living with ME display on a daily basis. Over the past week, many constituents have contacted my office to encourage me to attend this debate. Hearing at first hand from people in Lincoln about the complex difficulties that people with ME encounter really underlined for me the need to provide more support at national and local level.

ME is a disease that poses unique difficulties for those who suffer from it. We are all aware of its fluctuating and sometimes invisible symptoms, which have fuelled an unjust and debilitating stigma around the disease. That stigma is institutionalised in the fabric of ME medical research, healthcare provision and our welfare system. When it comes to treatment, most people do not have access to adequate care and support, and there is an almost total lack of appropriate secondary services. Many primary care professionals receive minimal training on ME-I did not get a lot of training on this when I was a nurse-and are therefore occasionally prone to holding stigmatising and misinformed opinions about the illness. It is clear that more training is required, not only for healthcare professionals but for welfare assessors. Welfare assessors frequently have insufficient understanding of ME and therefore often fail to assess claimants accurately. I heard that a lot at the

film screening.

It is completely unacceptable that people suffering from ME are, through no fault of their own, even more harshly exposed to the cruelties of Tory welfare cuts and the disastrous roll-out of universal credit. This Government must consider properly funding research into ME to better understand the condition. It is crucial that we all work towards eradicating the stigma of ME and improve routes to diagnosis, care and treatment. It is also crucial that all Members across this House recognise that that can only be achieved with adequate resources. I hope that today the Minister will give us a real commitment to do this, and not just warm but empty words.

Ben Lake (Ceredigion) (PC)

I join others in congratulating the hon. Member for Glasgow North West (Carol Monaghan) not only on securing this important debate but on her tireless work, with others, to raise awareness of the difficulties that individuals with ME endure; on relentlessly challenging authorities to improve the way in which they support sufferers; and on giving a voice to those who all too often feel abandoned and alone.

As we know, ME is a chronic, multi-system disease that impacts approximately a quarter of a million people across the UK. To put that number into context, ME affects more people than the terrible Parkinson's disease and multiple sclerosis combined. It is estimated, as has been mentioned, that it has an economic cost of some 3.3 billion pounds. One would imagine that those considerations alone were sufficient to ensure adequate funding for biomedical research into ME and clinical care for those suffering from the disease, and yet ME research represents just 0.02% of all active grants given by UK mainstream funding agencies. It really does beggar belief that research into an affliction that leaves 25% of sufferers housebound or bedbound, and from which 95% of people do not recover, receives so little funding. This underinvestment needs to be addressed urgently, and I hope that the Minister can help in this regard. I also support a review of NICE guidelines on the treatments prescribed for ME and hope that that can be implemented as soon as possible. If positive changes are adopted, I hope, of course, that they are, in turn, implemented by the Welsh Government so that ME sufferers in Wales can benefit.

It is near impossible for those of us fortunate enough to not suffer from ME to truly comprehend its real, tangible impact, so I would like

to conclude with the words of two individuals who have contacted me to share their experiences of the disease. John Peters suffers from ME and was first struck down in the 1980s. The impact on his life has been total, as he so painfully put it to me: 'I have missed the whole spectrum of life: the big things such as family, a career; holidays, celebrations, the 'hooks' of someone's years; but also the minor events-that night out with a friend, the moment on a mountain, the lazy morning in bed with someone, that fantastic book, the sharing of a joke.'

Saran, a teenager from Ceredigion, has suffered from ME for over a decade and is now mostly housebound after receiving a formal diagnosis only last year. She told me: 'I have no idea what a life without chronic pain is, I don't know what it's like to be able to tolerate noisy bright spaces, what it's like to remember the conversations I've had with those I love...I have slowly watched my life disappear over many years, and now I'm entirely dependent on my parents, have no job, A levels, or hope for the future.'

I sincerely hope that this debate succeeds in its objectives, for we simply cannot wait any longer. John and Saran deserve some hope for the future.

Liz Twist (Blaydon) (Lab)

I thank the many constituents who have contacted me about their experiences, asking me to take part in this debate. In particular, I thank Pauline Donaldson of the Tyne and Wear ME/CFS support group, who plays a really important part in making sure that I and other Members from Tyne and Wear are aware of the very real problems faced by people who have this debilitating condition.

It is six months since we last debated this issue in Westminster Hall. That is six months more that people with ME have been waiting to see real progress on finding effective biomedical research into ME to work towards finding effective treatments for their condition, and six months more to suffer from the effects of ME. They are weary and impatient, and angry that treatments like CBT and graded exercise-psychological treatments-are still being put forward as the most common treatment for what is a physical condition. I am glad to take this opportunity to speak on their behalf.

Those people are looking for four things, the first of which is funding

for biomedical research. I was shocked to hear that patients and families are helping to fund research themselves. It is really important that we find a way of having that biomedical research done through public funds.

Secondly, many people with ME and their supporters have demanded that the use of CBT and graded exercise therapy be stopped. I will come on to talk about my constituent's experience of that. Thirdly, they want to see more training for GPs in recognising the signs and symptoms of ME. Invest in ME Research is doing much and has information packs, but it does not have the funds to extend that medical training everywhere. Fourthly, they would like to see an end to families with children with ME being subject to child protection procedures.

To finish, I want to talk about my constituent Angus, who was a senior lecturer in business at a north-east university. He says: 'In 2012, every aspect of my life changed when I was struck down with ME aged 47'..

He lost his job. He says that he was never a 'couch potato'-in fact, just the opposite-and still loves active pursuits, but can no longer do any of them. He says: 'Climbing the stairs in the house seems more exhausting than any mountain I've climbed in the past.'

He underwent CBT and GET and found that it made him not better but so much worse that it was a relapse. I wish I had the time to read his evidence. It is crucial that we address this problem and give our constituents with ME the treatment they deserve.

[Several hon. Members rose]

Madam Deputy Speaker (Dame Eleanor Laing)

Order. I have to reduce the time limit to two minutes, or else every Member will not get a chance to speak.

Nick Thomas-Symonds (Torfaen) (Lab)

I pay tribute to the hon. Member for Glasgow North West (Carol Monaghan) for securing the debate. The Welsh Association of ME and CFS Support confirms that 12,600 families in Wales are affected by this condition. Even with those numbers, awareness of fluctuating conditions such as these is crucial in society generally and in the Department for Work and Pensions.

It is true that ME receives far less funding than neurological conditions of similar prevalence. That must change, and the funding must also be appropriately targeted. If the World Health Organisation classifies ME as a neurological condition, clearly investment in biomedical research is required, whereas thus far funding has been concentrated on psychological and behavioural studies.

In the short time I have, I would like to pay tribute to two constituents who have contacted me. First, Sarah Oakwell spoke movingly about her symptoms and the need to develop new initiatives and additional forms of individualised treatment. She spoke of the need for new therapeutic strategies and multi-centre interventions, given the fluctuating nature of the condition. She also spoke of the need for more Government-funded research and said: 'We will wait as we do now in the hope that today will be the day you listen, take note and do something to help us all.'

I would also like to pay tribute to my constituent Reg Hann, who contacted me about his grandson and made these moving comments: 'I have had a close relationship with him all his life. Now he is too ill to travel to visit me. Too ill to speak on the phone... He is 18 at the beginning of February and will be unable to celebrate such an important birthday. I will be 95 the week after. My best present would be if he is well enough to visit me.'

What Reg and Sarah need is action. I hope they get the action that they deserve.

Liz McInnes (Heywood and Middleton) (Lab)

I thank the hon. Member for Glasgow North West (Carol Monaghan) for securing this important debate. I spoke in the debate last year about Merryn Crofts, who is one of just two people in the UK to have myalgic encephalomyelitis recorded as the cause of death. She was my constituent and lived in Norden, in the Rochdale area of my constituency.

Merryn suffered so badly from pain that she could not get out of bed. Her GP had worked in a hospice for 10 years, looking after cancer patients, and said that in that job, she could not always take away pain but could manage it. The GP said that Merryn's pain was unmanageable. Although Merryn was on diamorphine and ketamine, she was still in pain. Any kind of stimulus—even just a nurse walking into the room—was an



exertion for Merryn.

Merryn's mother was very critical of the PACE guidance given by NICE and attributes the worsening of Merryn's condition to it. She tells me that Merryn thought she could push through the condition and keep going, although her family wanted her to slow down. Sadly, it was only when the family contacted a private medical practitioner that Merryn was given the advice to slow down and rest. The specific advice given was, 'Whatever you feel you can do, only do 50% of it.' Merryn's mother feels strongly that, had Merryn been given that advice when her condition started, she might not have gone on to develop severe ME, and she strongly urges that the NICE guidelines be reviewed. Merryn's mother told me: 'If the PACE trial were a drug, it would have been banned by now.'

I have also been contacted by other constituents who have urged me to take part in this debate. One of them is Rebecca Pritchard, who points out that it would not be difficult to increase funding for research, given that very little funding for ME has been given so far. She highlights the work done by Invest in ME Research, based in Norwich, and points out the huge funds that have been crowdfunded by patients and their families.

Patricia Gibson (North Ayrshire and Arran) (SNP)

I have a very short time, but I hope this debate will raise awareness of this condition. It is still an illness that people very often do not know much about, despite the fact that 250,000 people in the UK are affected by it, with about 20,000 of those living in Scotland. Despite all this, there are still no effective treatments for this life-changing, life-stealing and cruel condition. We need our frontline GPs to have proper training so they feel equipped to diagnose and are more confident in the treatment of this condition.

Although recent investment by the Scottish Government is very welcome, it is nothing more than a start for this very long-neglected and misunderstood condition. I am keen to hear what action the UK Government will take to increase awareness and understanding of this condition, and to help us understand the causes of the illness, so that we can improve its diagnosis and treatment.

Having listened to speeches from across the House, I have no doubt that we need a concerted effort right across the UK to tackle this illness. I

very much look forward to hearing the response from the Minister. Before I sit down, I want to extend my thanks to my hon. Friend the Member for Glasgow North West (Carol Monaghan) for bringing forward this debate, and for all the work she has invested in bringing the subject to the House and raising Members' awareness of it.

Darren Jones (Bristol North West) (Lab)

Given the very short period available, I will not be able to do justice to Karen, Carolyn, Nathalie, Anna, Emma or many of my other constituents by telling their stories today. Like my hon. Friend the Member for Ealing North (Stephen Pound), I tell my constituents and all those watching, 'The House has heard you and your stories, and understands your plight.' The will of the House will make that very clear to those on the Government Front Bench.

It is clear from the stories we have heard today what a devastating and complex disease this is. When I was a young undergraduate in human bioscience, studying immunology, I heard this referred to in the labs as 'Multiple Excuses', and that was not so long ago. There is clear evidence that much more work is needed on the biomedical and biological processes behind this complex and devastating disease.

I am a member of the Science and Technology Committee, and we have recently completed an inquiry into research integrity. We have some concerns about reporting and transparency, especially in clinical trials. This goes to the concerns of many ME sufferers about what research is being done and how it is being done. Further to our Select Committee inquiry, I hope that the Minister will say what he will do to provide transparency in prospective registration, to deal with positive bias in journals—researchers are incentivised to find positive answers, as opposed to proving negatives, which is sometimes just as important—and perhaps to change the culture of that environment.

Lastly, on the delivery of care, about which we have heard from many hon. Members, the research must be recognised in the NICE guidelines, which lead to the delivery of care for many sufferers—children and adults—and to some of these heartbreaking situations. In my final 10 seconds, I pay tribute to the hon. Member for Glasgow North West (Carol Monaghan), a colleague on the Science and Technology Committee. I was pleased to support her application for this debate, and I hope the Government will respond in the significant way that is needed.

Mohammad Yasin (Bedford) (Lab)

I am grateful to the hon. Member for Glasgow North West (Carol Monaghan) for securing this very important debate. I have received a number of requests from my constituents to attend this debate to highlight this devastating condition.

Sufferers of ME are often stigmatised and marginalised, as their conditions are not fully recognised by the Government or the medical profession. A number of my constituents suffer from ME. At least two have been bedridden for 30 years because of their condition, and their story is not uncommon. Some 250,000 people suffer from ME, with 25% of individuals house or bed-bound. Children as young as five can develop the condition, and it is the most common cause of long-term school sickness absences.

A Westminster Hall debate last February raised issues about the PACE trial, which has influenced the NHS treatment of ME. A report had recommended CBT and GET as effective treatments. More recent research has disproved that study, which shows that CBT is not effective, and that GET can worsen individual symptoms, as has been the case for some of my constituents. However, those are the only treatments available on the NHS, which means that individuals and their families must endure treatment that not only fails to improve them, but can worsen their condition.

I therefore support suspending CBT and GET treatments in the NHS, as well as updated training for GPs and medical professionals, to alleviate the unnecessary hardship to which individuals with ME are currently subjected. ME has been overlooked for too long. We must fund and support research properly, and work to ensure that those who suffer from ME are listened to, diagnosed, and treated in the best possible way.

Jim Shannon (Strangford) (DUP)

I congratulate the hon. Member for Glasgow North West (Carol Monaghan) on securing this debate. She has been a champion for those who suffer from ME. We thank her for all her efforts, and are here to support her.

I have had the pleasure of meeting a lady in my constituency who is attempting to cope with her illness. She is also a champion for raising awareness and changing how those who suffer from ME are dealt with—I say 'suffer', because the lady I met certainly suffers. It is estimated that

ME affects some 25,000 children in the UK, and it is said to be the leading cause of long-term school sickness absence in the UK. Given the stigma that people with ME face, families will continue to meet accusations of misconduct and withholding support. What is being done to help those 25,000 children?

We urgently need to update the training of GPs and medical professionals, so that they are equipped with clear guidance for a diagnosis of ME, and can give advice and guidance on appropriate management to reflect international consensus on best practice. In addition, all commissioning bodies must ensure that medical, welfare and care services are accessible to people with ME, including home visits for those severely affected.

As the hon. Member for Glasgow North West said, not much has changed. I still have constituents with ME who are turned down for the personal independence payment, even though they are unable to leave the house for 29 days in a month. People are removed from employment and support allowance and told to go to job interviews, even if they cannot manage to stand in the shower, let alone leave the house or get a job. It is time to move past the idea that if something cannot be tested it cannot be helped.

This debilitating illness takes its toll on men, women and children throughout the United Kingdom of Great Britain and Northern Ireland, and we simply must do better by them. I would appreciate a response from the Minister on whether there are any plans to do better. If such plans are not in place, when will they be introduced? The 400 sufferers of ME in my constituency request such plans—indeed, they demand them.

Dr Philippa Whitford (Central Ayrshire) (SNP)

I thank my constituents who have written to me to share their experiences, both as patients and parents. I also have a close friend who has battled this condition for 18 years. I know that many sufferers find it dismissive to refer to the condition as chronic fatigue syndrome because it sounds so trivial. At very least it should be chronic exhaustion syndrome, because that is what it is—absolute exhaustion. ME affects a quarter of a million people, 10% of whom are children and young people. A quarter of those are so severely affected that they are either housebound or bedbound.

The basic problem is that we do not know the cause of ME. It often seems

to start post-viral; I, no doubt like many others here, have had post-viral syndrome, and it can often take weeks or even months to recover from. What is it about ME sufferers that makes the condition become long-term and chronic? That is the crux of the matter. We need biomedical research to consider whether it is an autoimmune cause, a genetic weakness, or a neurological problem. Is it metabolic? There is some interest in whether the mitochondria-the little power packs in the cells-are at fault. Such things need to be considered, and at the moment the only real funding of research is by ME charities.

The UK has not funded any biomedical research since 2012. That makes diagnosis problematic because it is based only on symptoms. We do not have a test because we do not know the cause or what to test for. Naturally enough, I will stick up for doctors and say, 'That makes it kinda hard for them.' It becomes a diagnosis of elimination-when they do not find the other obvious causes, the symptoms are put down to ME.

Following on from that, there is simply no treatment. There is no cure because we do not know the cause. There are no drugs coming down the pipeline, no procedures. That means that we are dependent purely on management and support. As has been said, CBT is not a cure or a treatment. It may help some people cope with the depression and mental health issues that come from being so disabled, but it does not tackle the underlying ME.

As has been said, graded exercise can actually make things much worse. The suggestion that it might work was based, as has been said, on the flawed PACE trial published in *The Lancet* in 2011. I think it is quite sinister that some of the funding for that trial was from the Department for Work and Pensions; that added to the implication of malingering, despite the fact that 90% of sufferers were working before they were diagnosed. That figure drops to 35% afterwards. It was an unblinded study, because it is not possible to hide from people what treatment they are getting. That means that all other aspects should be very strict, yet CBT and GET were promoted to patients as something that would help them. The researchers did not analyse their planned outcomes, which is critical in research. They lowered their defined targets simply because the treatment was failing, and used subjective rather than objective measures. Re-analysis of the PACE study has shown minimal benefit to these treatments; indeed, as my hon. Friend the Member for Glasgow North West (Carol Monaghan) said, some people got worse but still had their treatment classified as a success.

The only thing that has been shown to make a difference to some patients is what is called adaptive pacing-listening to one's body, balancing activity with rest, and planning one's day, or one's weekend activities with the family.

The United States Centres for Disease Control and Prevention removed the recommendations of CBT and GET, but as has been said, they have still been NICE recommendations since 2007, and although they are under review, with the results due to come out in 2020-too far away-the NICE website still promotes CBT and GET. There should be a red warning, saying, 'Don't follow this. We are looking into it.'

Most of all, we need research to define the underlying cause of this condition, and to develop treatments. We have heard about the 300,000 pounds of funding that the Scottish Government have given to Action for ME to develop peer support projects, but research needs to be on a bigger scale, considering the 3.3 billion pounds economic impact. The US has moved to biomedical research and, as has been said, the UK is still totally focused on psychological research.

In the meantime, until we have answers, the DWP needs to recognise the impact and the disability of ME. GPs, NHS staff and care staff need to provide support, including emotional support, to help manage the condition, and all of us need to recognise the impact of the condition and reduce the stigma that simply adds insult to injury.

Mrs Sharon Hodgson (Washington and Sunderland West) (Lab)

I start by thanking the hon. Members for Glasgow North West (Carol Monaghan) and for Cheltenham (Alex Chalk) and the right hon. Member for Loughborough (Nicky Morgan) for securing this important debate. I thank all hon. Members who spoke; it was great that so many did so. Due to time, I shall not list them all.

I thank the charities - MEAction, Action for ME, the ME Association, the M.E. Trust and ME North East - and all the patients who have been in touch with me to share their thoughts, feelings and experiences of living with ME. The ME Association estimates that approximately 250,000 people in Britain are affected by ME; we have heard plenty of moving stories about those individuals today. However, an article published in the British Medical Journal in July 2018 reported that 90% of cases are thought to go undiagnosed, and that people with ME are substantially undercounted, underdiagnosed and undertreated. As we have heard, patients are often passed from pillar to post with dismissals and

misdiagnoses, and sometimes left waiting over a year for a diagnosis. I am sure the Minister does not need me to tell him that that does not meet NICE guidelines of diagnosis within four months of the onset of symptoms. The Government should therefore do more, and considering that they are not doing much for patients with ME at the moment, I do not think that that is too much to ask.

The Government do not fund research and clinical care for people with ME at the rate they do for other serious prevalent diseases. As we have heard, the average spent on research for a person living with ME is just 1 pound a year. According to Action for ME, that represents just 0.02% of all active grants given by the mainstream UK funding agencies. I am therefore concerned that the Government recently confirmed in a written answer that ME research funding is lower now than it was even in 2013-14.

Current treatments of graded exercise therapy and cognitive behaviour therapy have been found to be harmful to patients with ME, and continue the narrative of disbelief and neglect of them, which we have heard about from a number of hon. Members. NICE has already recognised that its guidelines are outdated, and that patients do not receive the full picture on recommended treatments. NICE is updating its clinical guidance on the diagnosis and management of ME, but that is not expected to be published until October 2020. Patients and their families have already waited long enough, so will the Minister work with patients, charities, researchers and NICE to ensure that treatment and care for ME is appropriate?

We have heard today why funding for biomedical research into ME is so desperately needed. According to MEAction, the only year in which the Medical Research Council invested any meaningful sum in biomedical research was 2012, when 1.5 million pounds of funds were ring-fenced. However, no funds have been allocated for biomedical ME research since then.

In the Westminster Hall debate in June last year, I called on the Government to consider funding research, because it is long overdue. Will the Minister commit to doing that today, or will the Government continue to leave it up to the charity sector to do so? Projects such as Invest in ME Research, which has four PhD students researching ME, have been financially supported by patients and their families via crowdfunding in excess of 870,000 pounds. That is fantastic, but it should not be left to patients to crowdfund research. More funding for

research will enhance healthcare professionals and clinicians' understanding of ME, which will improve the patient experience and debunk the myths of ME being a primarily psychological condition, as we have heard about today. Clinicians must have access to up-to-date research and information so that they can give patients the best possible care and advice.

In some areas, however, that is not the case, as Jennifer Elliot, the CEO of ME North East, has brought to my attention. Jennifer told me of the diminished services available to patients with ME in the north-east region. There are no services at all for young people with ME in the entire north-east. Adult services in Sunderland are closed to patients altogether, and have been for some months, with no date for them to be reinstated. For 20 years, ME North East has been doing all it can to help and support ME patients but, with a severe lack of funding, it is now at crisis point. I am sure that other regions have similar stories, as we have heard today, so will the Minister please consider the loss of services in his response? Will he ensure that the services are reinstated and supported financially by the Government?

Finally, we must ensure that the stigma of ME is tackled. Funding and research will help, but it cannot be right that, as found last year, more than one in five families caring for a child with ME have been referred for child protection proceedings due to school absences and a lack of understanding by the school, as we have heard. I am pleased that the vast majority of those accusations are dismissed in less than a year, but the added stress and burden to families with children suffering with ME can be overwhelming. We therefore need more funding for research, so that we can understand, care for and treat ME, and break down the stigma.

The Parliamentary Under-Secretary of State for Health and Social Care  
(Steve Brine)

The two-minute limit produced an impressive result, showing what can be done in the Chamber, but let me issue a plea to the Backbench Business Committee. I know it is unusual for Ministers to make comments like this, but I reckon that sometimes doing less and doing it better is preferable to trying to squeeze two really important debates into a very short space of time. Perhaps the Committee will listen to my plea.

I thank those who have contributed to the debate, including my hon. Friend the Member for Southend West (Sir David Amess), the hon. Member



for West Bromwich West (Mr Bailey), my right hon. Friend the Member for Loughborough (Nicky Morgan), the hon. Member for South Shields (Mrs Lewell-Buck), my hon. Friend the Member for Torbay (Kevin Foster), the hon. Member for Stroud (Dr Drew), my hon. Friend the Member for Stirling (Stephen Kerr), the hon. Member for Luton North (Kelvin Hopkins), the hon. Member for Ealing North (Stephen Pound), who spoke in his usual style, the hon. Member for Lincoln (Karen Lee), the hon. Member for Ceredigion (Ben Lake), the hon. Member for Blaydon (Liz Twist), the hon. Member for Torfaen (Nick Thomas-Symonds), the hon. Member for Heywood and Middleton (Liz McInnes), whom I have heard mention her constituent before, the hon. Member for North Ayrshire and Arran (Patricia Gibson), the hon. Member for Bristol North West (Darren Jones), who I thought gave the best speech-the prize goes to him-and the hon. Member for Bedford (Mohammad Yasin).

I also, of course, thank the hon. Member for Glasgow North West (Carol Monaghan) for introducing the debate. I think I am right in saying that this is the third debate on this subject that she has tabled and been granted in the last 12 months. I applaud her dedication, and her passion for ensuring that awareness of ME is kept very high. I echo the thanks given by the hon. Member for Washington and Sunderland West (Mrs Hodgson) to all the charities that are working in this space, and I welcome the ladies from the Millions Missing campaign who are in the Public Gallery. I thank them for coming to listen to our debate; I am sorry that it has been so rushed.

The Government do not for one minute underestimate ME. As we heard from the hon. Member for Central Ayrshire (Dr Whitford), the truth is that we do not understand the underlying causes, and there is no single diagnostic test to identify it. Although some patients-very few-improve and recover, there is currently no cure. We know that the condition has a devastating impact, and we have heard some stories about that today. It has a complex range of symptoms which cause great difficulties for physicians, including disabling fatigue, a flu-like malaise and neurological problems. We have also heard about the effect on families, friends, carers, schools and housing.

No one mentioned the powerful film 'Unrest' today, so let me mention it briefly in passing. It won an award at the Sundance film festival a couple of years ago. That was a powerful presentation, if ever I saw one, of the impact that ME can have on people's lives. I will not say any more about it, because last time I did so someone accused me of doing a film review instead of responding to the debate-which I think

was slightly harsh, but that is what social media does for you. I thought that the hon. Member for Ceredigion, who is still in the Chamber, put it very well: although we give constituents' stories in this place, we cannot for one minute begin to understand what it must be like to suffer from this condition. Those who have seen the film will know that it literally puts people flat on their backs, sometimes for years.

We have heard a lot about the medical profession today, and I think—the hon. Member for Central Ayrshire touched on this—that the profession has had a bad rap, some of it deserved. As we have heard, the difficulties in diagnosis mean that patients with ME often experience great delays in receiving the treatment and support that they require. Recognising the need for GPs to be aware of the condition, the Royal College of General Practitioners includes it as a vital area of clinical knowledge that GPs should have as part of their qualifying exams, featuring it in the guidance for the applied knowledge test, which is a key part of those exams.

The RCGP has also produced an online course on ME for GPs. It highlights many of the common misconceptions, and considers the challenges for primary care professionals that surround this complex condition. Nevertheless, once they are qualified, clinicians are responsible for ensuring that their own clinical knowledge remains up to date—it is not for Ministers to go on educating GPs; that is one of the jobs of the RCGP - and for their ongoing learning. I made clear in the last debate, and I will make clear again, that that activity should continue, and should take into account new research and developments in guidance such as that produced and updated by the National Institute for Health and Care Excellence.

My hon. Friend the Member for Southend West said that people felt that they had been fobbed off. They should never be fobbed off by the medical profession, and I should be very concerned to hear of any examples of that.

Mr Bailey

Will the Minister give way?

Steve Brine

No, I will not, because everyone had a chance to speak and wanted the

Minister to respond.

As I have said, I think that GPs have had a hard rap this afternoon. Before the debate I spoke to Helen Stokes-Lampard, who chairs the RCGP, because I anticipated that that would happen. I asked her whether she would be willing to come to the House if I were to facilitate a roundtable-perhaps involving the all-party parliamentary group on myalgic encephalomyelitis, which we hope will be reconstituted, but certainly involving the sponsors of today's debate. She is very willing to do that, and I think it would be a positive development. If the hon. Member for Glasgow North West would like to be part of that, perhaps we can get in touch and make it happen. The door will be open.

The NICE guidance is clear on a number of important points. There is no one form of treatment to suit every patient; that is self-evident. The needs and preferences of patients should absolutely be taken into account. Doctors should explain that no single strategy will be successful for all patients, which is a hallmark of this condition. In common with people receiving any NHS care, ME patients have the absolute right to refuse or withdraw from any part of their treatment; nobody is making this happen. Those with severe symptoms may require access to a wider range of support, managed by a specialist.

NICE guidance supports commissioners to plan, fund and deliver ME services. As we have heard in this debate, and in others secured by the hon. Member for Glasgow North West, the use of CBT and GET in treating ME has long been controversial for patient groups, charities and some clinicians, who are very divided on this condition-understatement of the afternoon, perhaps. That began with the publication of the NICE guidance in 2007, and continued with the PACE trial. However, as Members clearly, from what I have heard this afternoon, know, NICE is updating the ME guidance and will examine the concerns about the PACE trial and whether there are implications for its current recommendations.

The updated guidance is due, but sadly not until October next year, and until then the existing guidance will remain current. I will look into the request made by the hon. Lady and others for an early statement from NICE, but NICE is an internationally respected independent organisation; if we did not have NICE, we would have to invent it. The time allotted for the development of the new guidance will allow all the evidence to be considered and all the voices to be heard, and I am determined to make sure that happens.

I think every single speaker - I have a list here of who spoke and what they said-mentioned research. As set out in previous debates, the Government invest 1.7 billion pounds a year in health research via the National Institute for Health Research and the MRC through UK Research and Innovation. Together, the NIHR and MRC welcome high-quality applications for research into all aspects of ME, which would absolutely include biomedical research. The MRC has had a cross-board highlight notice on ME open since 2003, updated in 2011, inviting innovative research proposals, alongside a bespoke funding call in that year.

ME research remains an area of very high strategic importance for the MRC. I do not have time to go into all the money granted. Members have said this afternoon, 'We must surely fund more research,' but Ministers do not sit in the Department of Health and Social Care and decide on what to do research. One of the great legacies of the late Baroness Jowell was that she understood in brain tumour research that we need to stimulate that research community to come forward with the best research proposals that then can be successful in bidding for funding. The truth is-sometimes it is a hard and inconvenient truth to hear-there have not been good enough research proposals in the ME space, partly because of the stigma-a point raised very well by the hon. Member for Lincoln; she looks delighted that I have mentioned her-and partly because of the division in the medical community. We need people to come forward with good research proposals in this space; that can only be advantageous.

I want to give the hon. Member for Glasgow North West a chance to conclude, but I thank her for raising the issue again on behalf of those affected, including many of my constituents who have contacted me asking if I would be able to attend today's debate; I was able to say, 'Yeah, there's a fairly good chance that I will pop in.' One of the Whips present on the Treasury Bench, my hon. Friend the Member for Bury St Edmunds (Jo Churchill), asked me to mention her constituent, Rosalind Amor, who has been in touch with her many times on this subject.

The Government fully recognise the strength of feeling on this issue, as we do for all those living with conditions and disorders which research is unable yet to help us fully understand. That is why we remain fully committed to delivering significant investment in our research programmes and infrastructure, but we need people to come forward with quality proposals.

Carol Monaghan

I thank all Members who have stayed behind once again on a Thursday afternoon, particularly the Members who sponsored the debate, and especially the right hon. Member for Loughborough (Nicky Morgan) and the hon. Member for Ceredigion (Ben Lake). I also thank the ME community for their lobbying and presence here today in the Gallery, and the Backbench Business Committee for granting the debate. We had some very clear asks for the Minister, which he has responded to in part. On the question of medical research, I am sure that many researchers will have heard what he said. However, it is notable that although there is some excellent biomedical research going on just now, it is being funded by charities, and not by the Government. The Government need to take this seriously.

Question put and agreed to.

Resolved,

That this House calls on the Government to provide increased funding for biomedical research for the diagnosis and treatment of ME; supports the suspension of Graded Exercise Therapy and Cognitive Behaviour Therapy as means of treatment; supports updated training of GPs and medical professionals to ensure that they are equipped with clear guidance on the diagnosis of ME and appropriate management advice to reflect international consensus on best practice; and is concerned about the current trends of subjecting ME families to unjustified child protection procedures.

Karen Lee

On a point of order, Madam Deputy Speaker. I did actually mention the film 'Unrest', and I am sure that Hansard will bear me out on that. My constituents would never forgive me if I did not point that out.

Madam Deputy Speaker (Dame Eleanor Laing)

The hon. Lady clearly appreciates that that is not a point of order, but she has corrected the record and, as she says, I am sure that Hansard will bear her out.

Just before we adjourn the House, I am afraid that once again I have to inform the House of a further correction to the number of votes for Members for English constituencies in the Division on Lords amendment 36 to the Tenant Fees Bill yesterday. There was a technical hitch at that time, and the figures were announced as: Ayes 261, Noes 194. The figures

should have been: Ayes 263, Noes 194. The result is unaffected, but the record has been put straight.

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