



# **The new NICE guideline and the future of ME medical care**

Virtual Meeting Minutes

24 November 2021, 2 – 3 pm

## **Attendees**

### Parliamentarians

Carol Monaghan MP  
Baroness Scott of Needham Market  
Lord Lipsey  
Baroness Finlay of Llandaff  
Baroness Meacher of Spitalfields  
Christian Wakeford MP (representative)  
Marion Fellows MP (representative)  
Olivia Blake MP (representative)  
Hywel Williams MP (representative)  
Dr James Davies MP (representative)  
Pete Wishart MP (representative)

### Speakers

Dr Paul Chrisp, Director of the NICE Centre for Guidelines  
Dr Peter Barry, Consultant Clinical Advisor, NICE centre for guidelines, and Chair of the NICE ME/CFS Guideline Committee  
Sonya Chowdhury, Chief Executive of Action for ME

### Guests

Dr Charles Shepherd, medical adviser, ME Association  
Andrew Morris, Chair, Forward ME  
Neil Drake, External Communications Officer, NICE

## **Apologies**

Layla Moran MP  
Baroness Masham of Ilton  
Kerry McCarthy MP  
Margaret Ferrier MP  
Mary Glendon MP  
Lord Dubs  
Lord Wigley of Caernarfon  
Baroness Nicholson of Winterbourne  
Baroness Watkins of Tavistock

## 1. Welcome

Carol Monaghan MP, Chair of the ME APPG, welcomed all attendees and introduced the topic (the new NICE guideline and the future of ME medical care) and guest speakers.

Carol Monaghan MP mentioned the sad death of Maeve O'Neill to ME, the daughter of Sean O'Neill, a Chief reporter at the Times who has worked extensively on highlighting the issues facing the ME community. The APPG agreed that the Chair should send a letter of condolence to Sean.

Carol Monaghan MP then explained the meeting purpose which was to give Parliamentarians the opportunity to learn about ME and the new and long-awaited guideline and the impact this will have on clinical services.

## 2. Update

Andrew Morris, Chair Forward ME

- Andrew updated the APPG on the role of Forward ME: a sector-wide alliance of ME charities. He the formal retirement of the Countess of Mar from Forward ME. The Countess of Mar served as Founding Chair of the group, and she was instrumental in amplifying the patient voice in order to see the NICE guideline revised. Andrew has now taken over as Chair of the group and he has set up a steering group for direction-setting according to three key aims: (1) to encourage research which enhances understanding of ME (2) to ensure that support and care is based on best practice (3) to advocate for people with ME and educate the medical profession and wider society on the impact of ME.

## 3. Q&A Discussion

The three speakers (Dr Paul Chrisp, Dr Peter Barry and Sonya Chowdhury) briefly summarised their involvement in the NICE ME guideline development process. Questions were directed to each as appropriate to their expertise.

The following topics were covered:

- The delay to the release of the new guideline due to the discontent of some royal colleges.
- The importance of educating the medical profession.
- The meeting with the Secretary of State for Health and Social Care on ME research priorities attended by Sonya Chowdhury.
- The issues associated with the term “exercise” and the “deconditioning” narrative used by some medical professionals to describe people with ME.
- The importance of patients staying within their energy envelope.
- The challenges associated with the implementation of the new guideline as it is not mandatory.
- The role of NICE in encouraging guideline implementation.

#### **4. AOB and Close**

Carol Monaghan MP thanked the speakers for their insightful comments and suggestions. She mentioned that the report of the APPG on ME is due to be published in early next year. She additionally mentioned that there is the potential for the APPG to collaborate in the near future with the APPG on Coronavirus in relation to the overlaps between Long Covid and ME.