WHAT WE DID IN 2022

This has been a busy year for The 25% ME Group, with participation in a range of initiatives. Here - in no particular order - is a quick round up of work we have undertaken on behalf of members.

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Social Care Resources

The charity put up a new webpage on social care. This can be found at the 'Resources' section of our website or by following this link: https://25megroup.org/social-care. Three resources from the 25% ME Group feature here:

Key Messages for Home Care Workers - practical tips for caring for clients with severe or very severe ME, on a single sheet; for home care workers, also suitable for personal assistants and residential care home staff.

NICE NG 206: Social Care - Core guidance relevant to social care from the 2021 NICE Guideline on ME/CFS; includes features of severe and very severe ME affecting care needs, approach to care assessment and delivery to help ensure access, rationale for flexible approach - avoiding sensory overload and consequent deterioration.

Improving Social Care for Severe and Very Severe ME - sets out the particular needs of people with severe ME, addresses training requirements across the sector and describes how to improve access and delivery of support - a five page document, new for 2022.

We hope these resources will assist the sector to implement NG 206, which states: "Health and social care providers should ensure that all staff delivering care to people with ME/CFS receive training relevant to their role..." (recommendation 1.16.1). That this implies *retraining* is apparent from the guideline implementation statement of May 2022, which states: "*Providers and other organisations should update their training for health and social care staff."*

https://tinyurl.com/3fpn6wzd

Webinar The new webpage was planned to coincide with a March 17th webinar on social care presented by Dr Nina Muirhead as part of the **'Learn about ME'** project. The webinar is linked from our social care webpage, or go directly to https://www.youtube.com/watch?v=63MXLuJML1c

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'NICE' work - guideline resource implementation implications

Following publication of a NICE guideline an assessment of the implications for NHS workforce and resources is prepared. In spring we prepared feedback on a draft Guideline Resource Implementation Panel (GRIP) statement relating to last October's ME/CFS guideline. We were asked by NICE to channel this *via* Forward-ME, which shortened the timeframe for reviewing the draft and putting together our feedback, however we worked as best to make a positive contribution.

The final Resource Implication Statement from NICEcan be found here: **https://tinyurl.com/3fpn6wzd**.

It concludes that due to variation across organisations and services, the size of the resource impact from implementing the updated guideline will need to be determined at a local level as it will depend on current local practice. The statement also lists sixteen areas that are considered to have implications for practice and *"will need to be considered by local commissioners and providers of health, education and social care to comply with the recommendations in the guideline."* These include: education and awareness; availability of experts in secondary care to provide guidance to primary care; access to social care support; specialist dietetic support; and regular reviews.

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Advance Care Planning

We were reminded of the need for future planning for long term severe and very severe ME patients who are being looked after by carers who are ageing after a communication was received by Forward ME from a concerned parent whose adult daughter has been very ill since childhood.

Following this, Helen Baxter did a brief presentation for Forward ME including a case study which highlighted the need for advance care planning.

This is an important issue, as is advance planning for hospital admission or other scenarios which may emerge at short notice and require swift and effective action - for example, a personal assistant who knows your care needs well becomes ill or leaves post.

Cross-Government Delivery Plan

On ME Awareness Day, 12th May, Secretary of State for Health Sajid Javid announced the development of a cross-Government delivery plan on ME/CFS for England, *"aligning with other devolved nations as appropriate."* He continued:

> *At the heart of the delivery plan will be two core principles. Firstly, that we do not know enough about ME/CFS, which must change if we are to improve experiences and outcomes. Secondly, we must trust and listen to those with lived experience of ME/CFS.*
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> (For more of Sajid Javid's statement, see page 9 of the summer newsletter, QUARTERly 53)

This announcement did not come entirely out of the blue as we had received a communication back in March from the Community Health Care Team at the Department of Health and Social Care (DHSC) *"regarding work we are currently undertaking on ME/CFS".* The message said: *"We are keen to meet with key stakeholders to understand their views on developing future work on ME/CFS."* In response, Helen Brownlie and Tony Crouch met with representatives of the DHSC team (on line) in April. As they were seeking relevant information, Helen and Cath put their heads together to identify resources that might inform the plan and submitted a range of items, particularly on social care, to the DHSC Team.

Work stepped up a gear following the ministerial announcement with the identification establishment three working groups, reporting to a 'Task and Finish' Group. The working groups are on:

RESEARCH - Helen Baxter is serving on this group, in view of her involvement in the recent research priority setting partnership and her publications.

ATTITUDES AND EDUCATION - medical adviser Dr William Weir is on this group; members may be interested to know that it is co-chaired by Dr Nina Muirhead.

LIVING WITH ME - our social work advisor Tony Crouch is serving on this group and has attended all meetings; medical adviser Dr Nigel Speight has joined the group more recently.

The Living with ME Group decided that it would be helpful to hold workshops around five themes:

- adult social care
- welfare, employment, adult education and training
- quality of life
- health services
- children and young people.

This had the effect of widening involvement and feedback opportunities and thus began a rollercoaster of new situations, new technologies, new terminology, tight deadlines and change models for our volunteers to get their heads around.

Tony attended all workshops with the exception of the one on welfare, which was attended by Helen Brownlie. Helen also attended the quality of life and health workshops and Cath was at adult social care. Medical adviser Dr Nigel Speight attended the workshops on children and young people and on health.

All workshop meetings were held online and in addition to verbal discussion used an online 'Post-It note' system, named Miro boards. The DHSC then circulated all contributions and invited comment. Submitting material and responding to the comments has been a major task. We have written in detail about some subjects e.g. benefits, quality of life and health, where we have been particularly strong on the need for medically-led clinics. In advance of the workshop on adult social care, we submitted a series of case studies.

Presenting member experiences in the form of anonymised case studies is a task that Cath and Helen had been trying to achieve since the APPG focussed on social care in 2016. Hitherto we had been thwarted due to pressure of work and our own changing health status. Thanks to Helen Baxter and Miriam Wood (of ME Support in Glamorgan) who helped with this task.

At time of writing a draft delivery plan is being written by the DHSC team. It is anticipated that the next stage will be a wider engagement process on this draft plan, which is due imminently.

This was a good opportunity for us to put forward the issues that concern people who are severely or very severely affected and their carers. While we cannot know what the outcome will be, we remain optimistic that the delivery plan will attempt to address some of the key issues and assist with the implementation of NICE guideline recommendations. Looking ahead, the challenge could be to have NHS England and other operational services to act. Come what may, this has enabled us to place high quality information resources on ME within government departments which we hope will continue to inform staff over time despite the frequent changes of minsters and prime ministers during 2022! (Sajid Javid himself resigned on July 5th).

How you can help……

How you can help
- a request for feedback -

We request members provide us with accounts of experiences of social and medical care. Difficult experiences are helpful for case studies to present to authorities, whilst accounts of good care can assist in the development of training packages for provider organisations as they can act as a model of care.

Accounts of how things should be done from professionals providing your care can also be helpful, so if you have home care / personal assistant / health care assistant staff or agencies who would be willing to write up their experiences please encourage them to do so.

We are particularly interested in whether people with severe ME are being put forward for reablement, rehabilitation or social prescribing, or where ME has became severe after attempting such approaches. Also of great interest are your experiences of 'ME/CFS Specialist services' on the NHS.

Your experiences of accessing - or attempting to access - healthcare for other reasons is also of interest (for example, elective surgery). Are adjustments being made to help facilitate this? In social care, if you require a special diet and/or food cooked from scratch, how have you fared?

If you or your staff have difficulty writing an account please contact us for help.

Publications, Conferences, Campaigns

'*Ensuring the Voice of the Very Severely Affected ME/CFS Patient Is Heard in Research'* by Helen Baxter was published in July. The paper provides a model to help ensure that those who are most severely affected can give their views, facilitating their participation in research. Helen presented on this at this summer's IACFS/ME conference. Her commitment to this also led to her assisting on the DecodeME Project (see page 9), where she is providing support by telephone to participants who need assistance to complete the questionnaire.

Helen was also involved in an exercise to identify views on research priorities, advocated for a person with severe ME at the related workshops, and was a co-author on the paper reporting findings.

Flowing from last year's publication of *'Life Threatening Malnutrition in Very Severe ME',* Helen did a related presentation for Malnutrition Awareness Week 'Sharing Practice Day' this October.

Helen used the opportunity provided by the Sharing Practice Day to launch our *'End Malnutrition in ME'* campaign. This initiative was instigated by Yvonne Foss on behalf of The 25% ME Group and is hosted on Twitter (follow us at @MalnutritionME). We are delighted to have another volunteer on board in the shape of Yvonne and asked her to say a bit about herself and what got her interested in this.

Service Redesign: Suffolk & North East Essex

The 25% ME Group is participating in work related to the development and implementation of a new ME/CFS service in Suffolk and North East Essex. The development of the service redesign has been driven by Suffolk Youth and Parent Support Group and is led at professional level by Alexis Johnys on behalf of the Suffolk and NE Essex Integrated Care System. It includes social care as well as NHS services. To scope the pathway further they are engaging with system partners and patient representatives and setting up a steering group. Tony Crouch is the 25% ME Group representative.

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'Learn about ME' Project

We continue to work as a partner on the 'Learn about ME' project promoting Dr Nina Muirhead's CPD accredited on-line learning module. This project is funded through the Scottish Government 'Neurological care and support: framework for action 2020-2025' and is into its third year, with funding until the end of September 2023.

The 'Learn about ME' project was represented at the Voluntary Health Scotland conference in October and we made contributions to the promotional and educational materials developed by the project for this event.

Three further podcasts have been produced this year, on medical education, nursing and social care, respectively - as well as the social care webinar, referred to at the start of this article. All podcasts can be viewed from this page: https://www.buzzsprout.com/1717775

As we go to press the CPD module itself is about to be relaunched in an updated version - see opposite.

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NHS Scotland misinformation corrected

Earlier this year we succeeded in having NHS Inform - Scotland's national health information service - take down a page with outdated coverage, including on graded exercise, which had been permitted to remain live on-line long after the new guideline from NICE expressly forbade such an approach. A fresh webpage was later posted, see: **https://tinyurl.com/4hsupa32**

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Health Department Liaison Scotland

2022 has seen ongoing if sporadic liaison as part of a stakeholder group convened by the Clinical Priorities Team, which has oversight of policy on ME in Scotland.

Relatedly, Blake Stevenson management consultants were commissioned to gather views on the 2021 NICE guideline and actions thought to be required to implement this guideline in Scotland. Dr
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Speight and Helen Brownlie have represented the 25% ME Group in this process.

The resulting report was published on 5th July:

https://tinyurl.com/tyuducfb

or

https://www.gov.scot/isbn/9781804354872 (takes you to the above webpage). A number of recommendations emerged, including that the 2010 Scottish Good Practice Statement (SGPS) be updated "to reflect the changes within the guideline". This intention was discussed at the most recent stakeholder meeting with the Clinical Priorities Team, held on 14th July. ME organisations have not been given opportunity to be involved in the updating of the SGPS. We understand that the outcome is expected imminently.

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NEWS: Learning module from Dr Muirhead, v2 now available

Dr Nina Muirhead's CPD accredited on-line learning module, launched in spring of 2020, has been reviewed and updated to take account of:

- the latest published papers
- coverage on NG206 from NICE
- parallels between ME/CFS and 'long COVID'.

The web address for the module remains:

www.studyprn.com/p/chronic-fatigue-syndrome

NEWS: Priority Setting Partnership

Many of you participated in the James Lind alliance (JLA) priority setting partnership (PSP) surveys which set out to explore research priorities from a patient/ carer/ clinician perspective. Together with three workshops, this has resulted in the identification of the 'Top Ten Plus' areas of research. The top three priorities were understanding the biological mechanism of post-exertional malaise, repurposing existing drugs and the development of a diagnostic test (http://psp-me.co.uk/explore-the-top-10/).

Results have been published in an article titled: *'Research priorities for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): the results of a James Lind alliance priority setting exercise.'* (available at:

https://tinyurl.com/4s3wwx8n
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