# Members meeting minutes

# 24 July 2024, 10.30-12.12

## Attendance

Morna Simpkins, Chair

Mary Troup, Orthostatic Tremor

Kripen Dhrona, British Polio Fellowship

Andrew Lindsay, Epilepsy Scotland

Stephanie Fraser, Cerebral Palsy Scotland

Emily Holmes, Neuro Hebrides

Rachael Edwards, Epilepsy Connections

Vicki Cahill, Alzheimer Scotland

Mary Ramsay, Essential Tremor

Colette McDiarmid, MND Scotland

Charlotte Encombe, Compass

Farhar Khan, Muscular Dystrophy

George Reid, Scottish Post Polio Network

Lawrence Cowan, Spina Bifida Hydrocephalus Scotland

Liam Mac Lua-Hodgson, Brain Tumour Action

James Jopling, Parkinson’s Scotland

Mark Jackson, PSP Association

Alistair Haw, Scottish Huntington’s Association

Ewan Dale, ME Association

Gillian Robinson, Compass

Pamela Binny, ME Action

Claire Winchester, MS Trust

Tanith Muller, Parkinson’s Scotland

Keith Park, MS Society

Claire Stevens

Alice Struthers, NAoS

Hester Lee, NAoS

## Apologies

Jenn Hall, Alzheimer Scotland

Vic Baxter, Scottish Post Polio Network

Andy Barrick, MSA Trust

Carol Cochrane, brainstrust

## Chair’s welcome and NAC update

Morna Simpkins, chair, announced she is leaving MS Society and therefore standing down as chair of the NAoS.

Morna gave update from NACNC May meeting:

* progress update on framework and what has been achieved
* Nurse census currently underway, will be presented on at the Service Improvement Forum which Morna will attend- update to follow at next members meeting
* Presentation from regional neuro leads on self evaluation, NAoS can arrange for members to see this update if they wish
* Discussion on framework ending in 2025- committee wants to support all projects that are in progress to be delivered through to completion. Strong position from the third sector that once the framework finishes there should be a continued focus on neurological services and supporting work.

Next NACNC meeting is in August

## Policy Group update

**NAoS draft response to Assisted Dying for Terminally Ill Adults (Scotland) Bill**

Hester gave overview of NAoS r[esponse to Assisted Dying Bill Consultation](https://www.scottishneurological.org.uk/file-download/25/the-neurological-alliance-of-scotland-assisted-dying-bill-consultation-response.pdf) and posed questions to members for their feedback.

Discussion from members:

To question regarding evidence of DNR orders, Stephanie Fraser noted that Cerebral Palsy Scotland were made aware of people with CP having do not resuscitate orders issued during covid.

Comment from Kripen Dhrona, British Polio Fellowship that involvement of mental health professionals in the assessment process is a must but there also should be mechanisms in place to support the professionals involved.

Discussion around length of time people should know the practitioner involved in assessment. Some members see merit in involving professionals which patients have longstanding relationships with, however note that many people don’t see the same GP twice in a row so mandating this would be hard. Some members agree that suggesting a time frame of two years is too long. Some conditions will get a diagnosis quite late and will only live for 18 months e.g MND. Also need to consider where the two year suggestion has come from, is it an artificially created time period?

With regard to age limit, some members agree that should the Bill pass, assisted dying should be available to everyone regardless of age but there must be stronger safeguards in place such as further consultation and input from family members.

Discussion around appropriateness of definition of ‘terminally ill’ used in the Bill. Query from Mark Jackson, PSPA, as to whether it is appropriate to use a definition that was used for the benefit act 2019. The definition was drafted to be significantly more expansive in the context of the disability support so as to help enable people to access financial support. The case could be made that assisted dying is very different and perhaps there should be a more narrow definition.

Role of assessment from medical practitioners in assessing capacity and coercion – clinicians may feel it is quite outwith their expertise and feel uncomfortable with making this assessment. Maybe in NAoS’ response there should be an acknowledgment that this may present a challenge for clinicians and suggestion that assessment of capacity and coercion should be done by a professional with experience in this area such as a psychologist or psychotherapist.

Charlotte Encombe, Compass, notes that NAoS should look to other counties to see what examples have been set where assisted dying is legal.

Comment on patient access: co-ordinated support is a post code lottery. Not having access to adequate services and support can lead people to feeling very desperate. This is a set of circumstances which could be alleviated by filling gaps in service provision where they’re lacking. This could be part of the independent assessment- asking the question: do you feel you are getting the care you need to lead a full integrated life? This could then be something to pressure local service commissions to improve.

Comment from Mary Ramsey, Essential Tremor, that there should be protections in place for the practitioners as well as the patients.

Members agree the suggested recommendations on speech and language and mental health professional involvement is appropriate.

Question regarding whether members think the vote is likely to pass. Suggestion that there is more support for the Bill in Parliament than has been disclosed. However, the threshold for passing is so high it seems unlikely.

Members given overview of next steps and timescale: Hester will send out second draft in following week; members asked to get any comments or reflections on the response to Hester by the 9th August. If members feel there is need for another meeting Hester can arrange a second call to have further discussion. Submission on 16 August.

**Adult Disability Payment update with Keith Park (Policy, Public Affairs and Campaigns Manager at the MS Society)**

Keith gave an overview of Adult Disability Payment- replacement of PIIP. Rolled out two years ago across Scotland; adopted same eligibility criteria as PIIP but made some changes around process of applying and how the applications are processed. Taken away need for appointments to be reviewed.

When Scottish government rolled it out, they promised to have an independent review of ADP within the first year. As part of this process, they have undertaken a consultation on the mobility component which has already taken place.

Chair of the independent review is Edel Harris, there is also a stakeholder advisory group which Keith is part of. Call for evidence and consultation is currently live- closing date 23 August. Contingencies in place that they may extend the deadline if not enough people have responded. Review is 18 months, interim report will be published In Oct/Nov this year.

Meeting for NAoS members to meet with Edel Harris is currently being arranged for members to share their views.

Questions from members:

Who is managing the assessment process?

Social security Scotland is the organisation that has been set up to carry out assessments and make decisions.

## My Neuro Survey update

Alice gave overview of the My Neuro Survey and update on launch. [See slides here](https://www.scottishneurological.org.uk/file-download/35/pes-presentation-to-mm-july-24-2024.pptx).

Engagement pack, unique URL and QR codes have been sent to members.

Survey open from 22 July – 15 November.

Kripen Dhrona, BPF, noted how important the survey was for British Polio Fellowship in collecting data for fundraising and data collection.

Any member who gets 21 or more responses from their unique URL will get a custom report of their audience responses, broken down by health board.

We’re hoping to get 10% of representation across the UK.

NAoS will invite health boards to come and assess the data with us before drafting the report to identify some of the key themes emerging.

## Members check in

Proposal to reduce the members meeting to four in order to increase capacity of members and NAoS freelancers.

Chair also raised question for smaller organisations of how best can NAoS serve you when capacity is a challenge?

General agreement from members that they’re supportive of reducing meetings. Some smaller members find it hard to attend every meeting.

James Jopling, Parkinson’s Scotland noted, it’s not about reducing engagement from NAoS or members, but there are various subgroups which are more focused and deliver a huge amount of work. NAoS need to publicise these smaller groups so people can have more targeted discussions.

Two new sub groups will be set up – Holyrood election and BAW. Let Hester know if members want to be part of these groups.

Suggestion from Kripen Dhrona, BPF, that members should call out to the wider membership for help and engage with each other- ask the larger charities if they have resources or skills that they could share with smaller charities. NAoS’ role could be in facilitating relationship building between charities.

## AOB

Announcement of four trustee vacancies and one co-option. James Jopling, Parkinson’s Scotland, gave short overview of trustee role and his experience being a trustee; why he thinks it is valuable and encouraging those who don’t have previous experience being a trustee, have lived experience of a neurological condition, or are part of a member led organisation particularly to come forward.

Ewan Dale, ME Association, new network being developed by NHS Ayrshire and Arran on supporting people with a neurological condition to live well at home.

The next NAoS meeting will be our AGM on Wednesday 25 September 2024, 10:30-12:30, a hybrid event held at the Alzheimer Scotland National Office, 160 Dundee St, Edinburgh, EH11 1DQ.