**Policy Group Meeting Agenda**

**2 November 2022**

**11.00am**

**Attendees**

Keith Park - MS Society, Chair

Guest speaker: Mark Hazelwood – Scottish Partnership for Palliative Care

Mary Ramsey - Scottish Tremor Society

Thomas Mulvey - MS Society

Shirley Young - MND Scotland

Leigh-Ann Little - The Oxygen Works

Sophie - Sue Ryder

Tanith Muller - Parkinsons

Stehanie Fraser - Cerebral Palsy

Anna Telfer - Epilepsy Scotland

Laura Pulteney - MS Trust

Jane Haley - MND Scotland

Leanne Creighton - Sue Ryder

Ewan Dale - ME Association

Olivia Bird - My Name'5 Doddie

Ron Culley - Quarriers

Alice Struthers – NAoS

Lorna McGee - NAoS

**Apologies:**

Avril McClean – Action for ME

David Mulligan – Funding Neuro

Shirley Maxwell – Epilepsy Connections

Pamela Binny – ME Action

Helen Gibson – ME Action

Carol Cochrane – Brainstrust Scotland

Colin Robertson – Headway Dundee & Angus

George Allan – Scottish Post-Polio Network

Katie Rigg – MSA Trust

Jackie Munro – MD UK

AGENDA ITEMS

1. Chair’s welcome

Our Chair for the meeting, Keith Park, Policy, (Public Affairs and Campaigns Manager for the MS Society Scotland) welcomed attendees and asked everyone to briefly introduce themselves.

1. Action points from previous meetings – follow up

We are pleased to report that there are no outstanding actions from the policy group.

1. Introduction to our guest speaker

Keith Park introduced Mark Hazelwood from the Scottish Partnership for Palliative Care (SPPC) to the group. Mark talked through his [presentation](https://docs.google.com/presentation/d/1Mm52I2LLaH16ZqgVzzEaPCnufhtNX7T7/edit#slide=id.p1) ‘Assisted Dying: How potential legislation may interact with/impact the practice and provision of palliative care’.

This is in reference to Liam McArthur’s [Assisted Dying bill proposal](https://www.assisteddying.scot/) which was lodged with Scottish Parliament at the end of September 2022 having garnered cross party support. The draft bill is expected to be published in early 2023 along with supporting documentation including the financial memorandum.

Following this there was a Q&A

Q1: Do MSPs have a good understanding of what assisted dying is?

There is not a consistent level of understanding of what palliative care and assisted dying is amongst MSPs. 50,000 people need palliative care each year in Scotland and the numbers of those who could use assisted dying would be much smaller, so it is frustrating that so much time is spent on assisted dying when much more needs to be done to address the deficits in palliative care.

The SPPC is sending out invitations to MSPs for seminars on assisted dying to talk through some of the terminology and statistics. The emphasis is to improve understanding around what palliative care is and what good palliative care should look like. SPPN is not judging whether assisted dying is good or bad but is advocating for improved palliative care. It is expected to go to a free (conscience) vote although MSPs are likely to mirror the views of the general public.

Q2. There are many examples of people being discharged from hospital back home, with weeks to live and with inadequate social and palliative care provision, which can be hard to access.

The palliative care framework is not robust enough but assisted dying as an option is not a sticker to put on top. One narrative is that in other jurisdictions which have introduced assisted dying, that additional funding is also funnelled to palliative care provision. However, this is not a logical follow and there is no evidence to suggest that this would also happen in Scotland. We will read the financial memorandum carefully when it is published (early 2023).

Q3. Conversations about safeguards are critical, but what about groups who are currently discriminated against in this bill, for instance people with learning disabilities. They should be allowed to access assisted dying like the rest of the population.

In the bill proposal, there are recommendations around capacity but nothing specifically around learning disability. We need to keep an eye on this and raise it with MSPs in due course.

Q4. One concern about assisted dying is that people may feel pressured into ending their lives early, to avoid being a burden on their families.

If assisted dying were an option, this would be a very individual choice. However, in reality, it would be hard to assess if people were making a free choice. A question for legislators is how we will assess people to see if they are eligible to make this choice and how to screen others out. If people are screened out on their initial application (for instance due to depression), would they be able to make a successful case for assisted dying further down the line? From a human rights point of view it is incredibly complex to protect some of the population from being pressured into assisted dying and to let others who may be in the same circumstances, access it.

1. Children and Young People issues

The Neurological Alliance of Scotland until fairly recently ran a children and young people’s special interest group (CYPSIG) attended by charities who work in paediatric neurology. However, this group no longer meets and so CYP issues have now been absorbed into the main policy group. This is therefore the space for any NAoS member to raise any CYP issues going forward.

Q1. Will the NCS include children’s services? The implications of including children’s services is huge, with the likelihood that we end up with the wrong bill.

There is not enough information currently to know what’s happening with children’s services.

The idea of extending the NCS to include children’s services was proposed by the SG in August 2021. The SG “wants to broaden its responsibilities to include social work, children’s services, community justice and alcohol and drug services. Under the proposals the responsibility for provision would switch from local areas to the NCS, delivered through Community Health and Social Care Boards.”[[1]](#footnote-1)

Social care minister Kevin Stewart said: “I believe that it is right for this consultation to look beyond simply the creation of a national service for adult social care. The ambition of this government is to go much further, and to create a comprehensive community health and social care service that supports people of all ages. We are also committed to ensuring there is strong local accountability in the system."

[COSLA](https://www.cosla.gov.uk/news/2021/inclusion-of-childrens-services-in-national-care-service) has taken the position that including children’s services would be [very concerning](https://www.cosla.gov.uk/news/2021/inclusion-of-childrens-services-in-national-care-service) particularly because no-one knows what the proposed changes would actually mean for children and young people, and it goes beyond the scope of a review on adult social care.

1. Horizon Scanning (consultation responses, Parliamentary activity of interest etc)

Thomas Mulvey (MS Society Scotland) updated the group on the Parliamentary work that NAoS has been engaged in:

 - June 2022 launch of our [1 in 6 report](https://www.scottishneurological.org.uk/files/one-in-six-findings-from-my-neuro-survey-in-scotland-final.pdf) to the joint epilepsy and MS CPG

- Sept 2022 – presentation of report and discussion with the clerks to the Health and Sports Committee

- October 2022 – presentation of report and discussion with the Labour health team in Scottish Parliament

- November 2022 – presentation of report and discussion with the Conservative health team in Scottish Parliament

1. A.O.B

We are keeping an eye out for the publication of the rare disease framework.

29 November the European Parliament is hosting a conference addressing gender related issues and bias in the treatment of neurological conditions. [Click here to register.](https://docs.google.com/forms/d/e/1FAIpQLSfaSzjzAZZ5Or67YgqkkW4PZTusIyumAg5lxpXPloqOh8Wa0g/viewform)

1. Next meeting date: 11 January, 11 – 12pm

We are delighted to have secured Jeremy Balfour MSP as a guest who will update us on progress with his Disability Commissioner Private Members Bill. If you would like to Chair this meeting, please contact Alice

1. https://www.cypnow.co.uk/news/article/scottish-government-proposes-centralisation-of-children-s-services [↑](#footnote-ref-1)