

**The All-Party Parliamentary Group on Hospice and End of Life Care
Annual General Meeting
20th May 2026 – 2.30pm – 3.30pm**

Attendees:

Parliamentarians

Alistair Strathern MP
Angus Macdonald MP
Anna Dixon MP (Co-Chair)
Baroness Cass
Baroness Foster of Aghadrumsee
Baroness Healy of Primrose Hill
Baroness O'Loan
Baron Taylor of Holbeach
Harpreet Uppal MP
Kim Leadbeater MP
Lewis Atkinson MP
Munira Wilson
Paula Barker MP (External Chair)
Paul Holmes MP (Officer)
Rachael Maskell MP

External stakeholders

Amy Cotter, Dementia UK
Andy Pike, Dementia UK
Katie Reade, Hospice UK (Secretariat)
Gemma Palmer, Marie Curie (Secretariat)
Sophie Meager, Sue Ryder (Secretariat)

Minutes:

- 1) The group held its Annual General Meeting and elected the following Officers:
 - Anna Dixon MP, Co-Chair of the APPG
 - Baroness Finlay of Llandaff, Co-Chair of the APPG
 - Luke Taylor MP, Officer of the APPG
 - Paul Holmes MP, Officer of the APPG

- 2) There was a brief discussion about the focus of the APPG. Attendees raised:
 - The representation of children's hospices. Hospice UK's representative mentioned the APPG for Children Who Need Palliative Care and spoke about their close working with Together for Short Lives and transitional care programme.
 - Whether the APPG is UK or England-specific. It was agreed that the APPG would zoom out and look at UK-wide issues but also examine England specific policy, such as the Modern Service Frameworks.
 - The importance of examining whether the Health Bill impacts the accountability to deliver palliative care and end of life care that meets population need.
 - The positive news of the Single Patient Record but concerns about whether patients will be concerned about sharing their data and whether this record will be available across all providers, including social care and hospices.
 - Concerns around fair funding for hospices and the progress on this as well as the wait for the Government's response to the Public Accounts Committee report on the financial sustainability of adult hospices in England. It was suggested the APPG invite representatives from the Treasury to come and talk to the APPG.

- 3) Representatives from Dementia UK presented findings from their new report [A better death: fixing palliative and end of life care for dementia](#). Attendees:

- Asked where responsibility for Advance Care Planning (ACP) sits. Dementia UK representatives said making plans should be the responsibility of everyone involved in a patient's care and everyone working in healthcare should feel confident to have these conversations. It was noted that the Palliative Care Commission did work around ACP.
 - Raised the low awareness of dementia as a leading cause of death and asked about severity of dementia. Dementia UK representatives noted that there is mild, severe and moderate dementia but that these levels from say different stages of cancer.
 - Noted that many may have dementia and another condition, this means they more have complex wishes and needs. Dementia UK representatives said the research found a high level of co-morbidity.
 - Raised the importance of training and education in dementia and palliative and end of life care for the wider health and care workforce, in addition to specialist support.
 - Raised instances of care homes not taking patients with dementia and limited hospice capacity. Dementia UK colleagues said many people with dementia are at home and die in hospital. Families and carers need support and there are stories of people getting family members sectioned for respite.
 - Asked what content on dementia is included in nursing education. Dementia UK colleagues said dementia is a component of training but not enough specialist nurses are trained.
 - Raised that comorbidity with dementia can hasten death, especially when people don't get the right interventions.
- 4) Attendees discussed the Government's upcoming Modern Service Frameworks on palliative care and end of life care and dementia and frailty:
- Parliamentarians asked external stakeholders how they can support this process and for an update from their perspective. It was agreed that there is still time for parliamentarians to input into the process. The opportunity of health and social care oral questions was also raised.
 - Representatives from Hospice UK and Marie Curie raised concerns around timing, accountability and resourcing. Fixing palliative and end of life care will require investment and a proper strategic shift in local commissioning.
 - Parliamentarians expressed concern about the lack of funding committed to delivering the MSF as well as whether the MSF will significantly tackle inequity in access and quality of care.
 - The group discussed the significant spend on people with a life-limiting condition in hospital settings, when they could be better cared for in the community at lower cost. Attendees highlighted [research](#) on the financial savings associated with specialist palliative care and how hospices locally say there is enough money, but it is being spent in wrong places.
 - The representative from Marie Curie also mentioned the interim MSF report, expected in Spring. They also mentioned Marie Curie's proposal for a transformation fund for palliative and end of life care.
 - Parliamentarians raised the impact of visa issues on availability of workforce in the community and the importance of care homes in providing end of life care.
 - Parliamentarians said there is the opportunity to work cross party through the APPG. It was agreed that the APPG will write to the Minister about the MSF and include reference to health inequalities, funding, accountability, timing and dementia care. The group also said it would consider whether there is an opportunity to submit amendments to the Health Bill or oral/written questions.