

APPG on Hospice and End of Life Care Annual Activity Report 2024-6

Overview by the APPG Co-Chairs

Over the last year, the APPG on Hospice and End of Life Care has focused our work on an inquiry into the financial impact of a terminal illness, with the aim to produce a report containing policy recommendations for the government to improve the financial security of people at the end of life.

To do this, the APPG held three evidence sessions to hear in person from people with lived and professional experience of the financial impact of a terminal diagnosis. We heard from policy experts, hospice workers and people with lived experience about the financial difficulties that people with terminal illness often face, including with additional energy costs, loss of income (sometimes of both the terminally ill person and a loved one who gives up work to care for them), travel costs to hospital appointments, and more.

Alongside our evidence sessions, we also ran a call for evidence that was publicised throughout the sector. We received some really insightful submissions from organisations across the healthy policy sector, and all evidence we received, both written and oral, contributed to the findings and recommendations of the report.

We hope the government will use this report as impetus to improve the financial support system that is available to people at the end of life.

Publications

APPG report on the financial impact of a terminal diagnosis – September 2025

The APPG ran an inquiry into the financial costs of a terminal illness and found that it often leads to dramatic income loss, especially for working-age people and their families, who may also see carers forced to reduce paid employment.

The extra costs of terminal illness—such as increased energy bills, specialist food, travel to appointments, and social care—can amount to tens of thousands of pounds.

Unfortunately, current government support is insufficient and complex, with terminally ill people receiving significantly less than those above pension age and facing gaps in benefit provision.

The APPG has produced several recommendations for the government to consider to improve the financial support available to people with a terminal illness. [Read the full report here.](#)

Meetings Held

19th November 2024: AGM

- Attendees elected Officers.

Wednesday 26th March 2025: Inquiry launch and first evidence session

- Heard from Chair Paulette Hamilton MP about the inquiry launch
- Then heard evidence from three panel guests:
 - **Sandra Cayzer**, a Welfare Adviser at the Heart of Kent Hospice, and the Welfare Benefits Lead for the Association of Palliative Care Social Workers (APCSW);
 - **Katie Reade**, the Head of Policy and Public Affairs at Hospice UK, presented the findings of their report "It's a nightmare scenario" - death, dying and financial hardship';
 - **Jamie Thunder**, Senior Policy Manager for Financial Security at Marie Curie about their report, published in November last year 'Dying in Poverty 2024'.
- Attendees included:
 - Lewis Atkinson MP
 - Alison Bennett MP
 - Rachael Maskell MP
 - Sarah Russell MP
 - Representative from the Department of Health and Social Care
 - 2 members of staff from the Commission on Palliative Care

Wednesday 14th May 2025: Second evidence session

- Heard evidence relating to inquiry from four panel guests:
 - **Peter**, a Marie Curie storyteller who was diagnosed with leukaemia in November 2021, then spoke about his difficult financial situation since his diagnosis;
 - **Simon**, Head of Wellbeing and Community Support at Sue Ryder for the region of Berkshire West and South Oxfordshire, spoke about the role of local charities which specialise in helping terminally ill people to navigate the benefits system;
 - **Gill and Sarah**, from Hospice of the Valleys who provide hospice at home support Blaenau Gwent in the South Wales Valleys, spoke to the issues of financial hardship faced by people in their area.
- Attendees included:
 - Josh Fenton-Glynn MP
 - Sarah Hall MP
 - Joy Morrissey MP
 - Tessa Munt MP
 - Luke Taylor MP
 - Harpreet Uppal MP
 - Representative from the Department of Health and Social Care

Wednesday 2nd July 2025: Third evidence session

- Heard evidence relating to the inquiry from three panel guests:
 - **Kim Brockhurst** spoke about her experience caring for her partners' elderly parents, who have been diagnosed with Parkinson's and Alzheimer's;
 - **Rekha Vijayshankar** who spoke to her experience as a care giver for her husband, before she retrained as a palliative care nurse where she has now worked for several years, and spoke to the APPG about her

research into the palliative and end of life care pathway amongst racialised minority ethnic communities;

- **Beka Avery**, Head of Wellbeing and Community Support for East of England at Sue Ryder, spoke to the various challenges faced by people with caring responsibilities for people at the end of life.
- Attendees included:
 - Alison Bennett MP
 - Brian Mathew MP
 - Josh Newbury MP
 - Luke Taylor MP

Tuesday 9th September 2025: Report launch

- Heard from Co-Chair Paulette Hamilton MP about the findings of the report, as well as the policy recommendations put forward by the APPG to address the issues raised in the report.
- Heard from Kim Brockhurst who attended the previous evidence session in July, as well as Mark Hughes, a constituent of a Member of the APPG, who shared his experience of campaigning whilst living with terminal bone cancer to improve the process of signing up for benefits after receiving a diagnosis of a terminal condition, about their thoughts and views on the report.
- Attendees included:
 - Bayo Alaba MP
 - Ayoub Khan MP
 - Seamus Logan MP
 - Josh Newbury MP
- MPs in attendance were asked whether they would be willing to sign a letter to the Minister of Social Security and Disability Rt Hon Sir Stephen Timms MP sharing the findings of the APPG, which was sent round in the follow up email.

Wednesday 11th March 2026: Meeting on national accountability for equitable provision of care

- Discussed the lack of accountability in the commissioning of palliative care and end of life care, including hospice services.
- Joined by Anushka, who shared her personal experience of the importance of hospice care. Anushka and her two sons were supported by Community Hospice in South East London when Anushka's husband Mike died at home in 2024.
- Attendees included:
 - Lord Brennan
 - Baroness Hollins
 - Antonia Bance MP
 - Alison Bennett MP
 - Rachael Maskell MP
 - Martin Vickers MP
 - Luke Taylor MP
 - Lord Shinkwin
 - Lord Taylor of Holbeach
 - Lord Austin
 - Anna Dixon MP

APPG on Hospice and End of Life Care Income and Expenditure Statement

Name of APPG	APPG on Hospice and End of Life Care
Period covered by this statement	19 th November 2024 – 18 th March 2026

£

A. Balance brought forward from previous year:

0

B. Income received during the year:

i. Membership subscriptions (parliamentarians)

0

ii. Monetary donations (including external subscriptions and sponsorship)

0

iii. Trading income

0

iv. Interest received

0

v. Other (please explain)

0

TOTAL income

0

C. Expenditure during the year:

i. Employment costs (salaries, NI, pensions costs)

0

ii. Costs of contractors and freelance staff

0

iii. Visits and events (UK)

0

iv. Visits and events (abroad)

0

v. Cost of generating income

0

vi. Office and communications costs

0

vii. Other (please explain)

0

TOTAL expenditure

0

D. Balance carried forward (A+ total B-total C)

0

E. Value of benefits in kind received from each source during the reporting year (in bands of up to £1,500; £1,501-£3,000; £3,001 to £4,500; £4,501 to £6,000 etc)

Please itemise according to the source and band

Hospice UK, Marie Curie and Sue Ryder provide joint secretariat for the APPG. Over the course of the year they have organised 6 events in Parliament (The IGM, 3 evidence sessions, 1 report launch and 1 additional meeting focused on equitable provision of care). For each of these events the Secretariat have utilised staff time this equates to:

Marie Curie
£3,001 to £4,500

Hospice UK
Up to £1,500

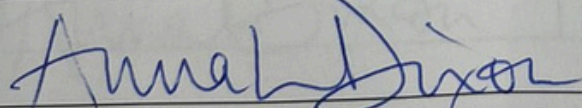
Sue Ryder
Up to £1,500

Other costs:
£178.75 paid by Hospice UK for lived experience speaker travel costs

£119.20 paid by Sue Ryder for lived experience speaker travel costs

£540 Report design paid by Marie Curie

£365 Report printing paid by Marie Curie



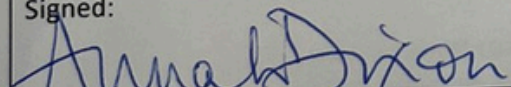
Signed by Chair of Group:

Date: 20/5/26

Due Diligence Checklist

13. To support APPG Officers to conduct reasonable due diligence checks, the table below summarises the advice above and can be used as a checklist.

14. This checklist may be used as the due diligence statement required to be published at an AGM by APPGs that have met the threshold to have an external chair.

Name of APPG: APPG on Hospice and End of Life Care	
Secretariat Assurance Statement	
All members of the secretariat are fully identified.	Yes
I [APPG Officer undertaking due diligence] understand who else the secretariat members work for and their external responsibilities.	Yes
I know whether the secretariat members are paid or remunerated, and if so, by whom.	Yes
They have confirmed they are not part of, working for or funded by a foreign government.	Yes
Where a group, charity, company, etc, is providing or finding the secretariat, I know how that entity is funded.	Yes
The group, charity or organisation has stated it is not funded, directly or indirectly, by a foreign government.	Yes
Online Research	
Individual, group or company providing secretariat has a publicly available online presence.	Yes
Individual, group or company appears elsewhere online (e.g. news articles, blogs) linked to a foreign government.	Yes
Online presence does not confirm or infer a link to a foreign government, now or in the past.	Yes
If appropriate, Companies House checks have been conducted and results considered.	N/A
Signed: 	Role of Member in the APPG