

Meeting of the APPG on Hospice and End of Life Care

10 May 2023

Attendees:

Parliamentarians:

- Alex Cunningham MP, Labour MP for Stockton North
- Baroness Finlay of Llandaff, Crossbench Peer
- Lord Balfe, Conservative Peer
- Peter Gibson MP, Conservative MP for Darlington
- Sally-Ann Hart MP, Conservative MP for Hastings and Rye
- Sir Peter Bottomley MP, Conservative MP for Worthing West
- Steve McCabe MP, Labour MP for Birmingham, Selly Oak
- Tom Pursglove MP, Conservative MP for Corby and Minister of State at the Department for Work and Pensions

External stakeholders:

- Dominic Carter, Head of Policy, Advocacy and Research, Hospice UK
- Dr Emily Pikett, Head Clinician, Department for Work and Pensions
- Katie Reade, Policy and Advocacy Manager, Hospice UK
- Maggie Doherty, Director of The Art of Dying Well, St Mary's University, Twickenham
- Member of the Minister's team, Department for Work and Pensions
- Paul Fraser, Head of Workplace Support, Hospice UK
- Professor Karen Sanders, Professor of Politics and Communications and Head of School of Business, St Mary's University, Twickenham
- Rachel Freeman, Age UK
- Rachel Warren, Senior Policy and Research Manager, Marie Curie
- Sarah West, Director of Campaigns and Communications, Hospice UK
- Sophie Meagher, Policy and Public Affairs Officer, Sue Ryder
- Trisha Thompson, Head of Programmes & Grants, Carers Trust

Summary of the session:

- Peter Gibson MP welcomed the attendees to the meeting and thanked them for coming.
- Peter Gibson Chaired the Annual General Meeting for the APPG. The attendees approved the Income and Expenditure Statement and elected the following Officers:
 - o Baroness Finlay of Llandaff as Co-Chair
 - o Peter Gibson MP as Co-Chair and registered contact
 - o Sally-Ann Hart MP as an Officer
 - o Sir Peter Bottomley MP as an Officer
 - o Patricia Gibson MP, Scottish National Party MP for North Ayrshire and Arran, as an Officer (elected in absentia)
 - o Jessica Morden MP, Labour MP for Newport East, as an Officer (elected in absentia)
 - o Mary Kelly Foy MP, Labour MP for the City of Durham, as an Officer (elected in absentia)
 - o Lord Sentamu, Crossbench Peer, as an Officer (elected in absentia)
- Baroness Finlay announced the beginning of the panel discussion around support for people with a terminal illness, caring responsibilities or experiencing bereavement in the workplace.

- Baroness Finlay said the APPG will be taking evidence as part of Dying Matters Awareness Week and because the recent APPG inquiry made the group aware of the lack of support for unpaid carers and the bereaved. She introduced Paul Fraser, Head of Workplace Support at Hospice UK to speak about the organisation's Compassionate Employers Programme. Paul Fraser said that:
 - Every day, more than 600 people quit work to look after older and disabled relatives.
 - 57% of employees will have experienced a bereavement in the last five years. Despite this, fewer than one in five managers feel very confident supporting someone they manage with a bereavement.
 - Three quarters of 18-34 year olds say that they would consider leaving their job if they didn't get proper support when bereaved at work. Expectations have changed and organisations are finding it hard to retain people.
 - Hospice UK used to be approached with numerous requests from organisations for ad hoc advice on supporting staff with grief and caring responsibilities. Hospice UK found Assistance Programmes were often poor or the grief was too complex to be managed by them. There could be a carers network but the Chair would be burnt out from supporting their colleagues.
 - It became unsustainable to respond to all the ad hoc requests and instead Hospice UK decided to look at supporting organisations more holistically, including looking at organisational policies.
 - Hospice UK identified that it needed to work on organisational culture and address support in the workplace in a more holistic way, looking at HR competence, peer support, line management support and policies.
- Baroness Finlay introduced Sally-Ann Hart, MP for Hastings and Rye and an Officer of the APPG on Hospice and End of Life Care, to speak about her personal experience of caring for a loved one and being bereaved at work. Sally-Ann Hart said she:
 - Returned to work after taking time away to care for her children. Not long after she learned that her father and his partner had been diagnosed with a terminal illness.
 - Arranged for her father to live with her and her family and became his carer.
 - Doesn't know how people manage a situation like this without additional support as she had paid help and still found it hugely difficult to work and care for her father.
 - Was only permitted three days of bereavement leave and asked people at work not to be sympathetic as it made it easier to cope if they weren't.
 - Has had two staff members become bereaved unexpectedly and, because of her own experience, told them to take as much paid leave as they needed. One came back after three weeks and the other did not come back. Sally-Ann did not care about them being back, she cared about them being able to heal.
 - Said there needs to be a system where everyone knows where they stand and employers are compassionate and understanding.
 - Said we need to think about the help people receive, which needs to include flexible and paid leave. Some employers are compassionate, others are not and many organisations could do much better.
 - Believes in statutory paid leave for people whose loved one dies of a terminal illness.
- Baroness Finlay introduced Tom Pursglove MP, Minister for Disabled People, Health and Work to speak about the special rules for those at the end of their lives accessing benefits. The Minister said:
 - Thanks to Hospice UK, Baroness Finlay and Peter Gibson MP for all they are doing.

- That families shouldn't have to be worried about finances when managing terminal illness and there needed to be a better basis for people to access financial support.
- The five key health and disability benefits can now be accessed six months earlier (when people have an estimated 12 months to live) to increase flexibility for people at the end of life. This definition aligns with the NHS definition of end of life.
- People near the end of life can access streamlined and fast-tracked support.
- These changes have gone live and now DWP needs everyone's help to get the message out. Clinicians need to think about financial needs as well as the other holistic needs of their end of life care patients. They can complete an SR1 form.
- If people near the end of their life want to work, they can be supported through work coaching and job centres. For some, working may be the right thing.
- People in their last year of life shouldn't be worried about finances. It is an earth shattering time and there needs to be a safety net for families.
- Many thanks to Amber Rudd, Justin Tomlinson, Chloe Smith who put in lots of work before he joined the department and for the many people who advocated for these changes. Thank you also to Emily for delivering the changes.
- Dr Emily Pikett, Head Clinician at the Department for Work and Pensions said she is trying to bring what she can from Dying Matters into the DWP.
- Baroness Finlay said that the problem with the previous DS1500 form was that saying someone had six months to live felt like you were only giving them six months. It is much easier to tell someone that you estimate they have one year to live and plan for the future. She also said that the stressors are always in the social domain.
- Lord Balfe:
 - Said David Cameron sent him to work with the Trade Union Movement and Baroness Stedman-Scott helped with the TUC 'Dying to Work' campaign and was a driving force for changes in regulations.
 - Asked whether Dying to Work should be put in touch with Dying Matters and Compassionate Employers.
 - Said his daughter and daughter in law work in HR and say there is no 'training module' on this issue. He asked if anything can be done to support people with a terminal illness who want to work.
 - Offered his help and support and said the GMB is run by professional officers rather than anyone who works in hospice care.
- Paul Fraser said he is always looking to form new partnerships and Lord Balfe agreed to put him in touch with the Dying to Work campaign. Lord Balfe said the Conservative party never signed the pledge but were close to doing so.
- Baroness Finlay said she was supporting a parliamentarian yesterday who was in tears trying to put together their speaking notes and arrange a funeral. She said she always hears about a crisis after the event and wonders why someone doesn't phone her. There is so much to arrange after a bereavement.
- Lord Balfe said the Lords do this very badly. There is an aged population but no pastoral care and support. He has raised this with three different speakers who have all said there are no resources. Peter Gibson said the Commons isn't much better.
- Baroness Finlay said there is a Chaplain in the Commons but it is about the culture and not being ashamed to speak.
- Sally-Ann Hart said she has heard that 15-20 people need to slip from a vote a week because of a bereavement or caring responsibilities. Parliamentarians have no time to find support.

- Paul Fraser said employers are responsible and Compassionate Employers has a hub for members, which includes practical tips, guidance and support.
- Peter Gibson asked about the size of employers that become Compassionate Employers. He said he also had a staff affected by bereavement and told them to come back whenever they were ready, however, they came back too early. He said tiny employers can be flexible but not SMEs.
- Paul Fraser said lots of Compassionate Employers are larger organisations but the principles of compassion and flexibility are universal. The economic impact of employees going off on long-term sick or resigning can be worse than permitting flexible leave.
- Baroness Finlay said productivity is much worse when people are not supported. She said a card or a cup of tea can make all the difference. Once she was on the woolsack and her brother had a cardiac arrest, the Lord Speaker covered for her and was supportive. Another person gave her a pot of homemade jam. She also said that sometimes children are told off at school for misbehaving when the teacher doesn't know this is because of a bereavement.
- Maggie Doherty said that the Art of Dying Well partnered with Child Bereavement UK to train educators in this.
- Karen Sanders said that St Mary's University could use Compassionate Employer's policies and train business students in this. The University had a great event when it launched the Centre for the Art of Dying Well which resulted in frank and free conversations in the workplace.
- Rachel Warren mentioned Marie Curie's role on the Steering Group of the UK Commission on Bereavement and its piloting of training modules for the workplace in Suffolk. She said there needs to be minimum standards, two weeks of statutory bereavement leave for close relationships and guidance for businesses of different sizes. She also said that the What Work Fund is doing a review of the experiences of people with a terminal illness at work.
- Baroness Finlay invited the Minister to make some closing remarks. He said:
 - o Some of these issues relate to DHSC, some DBT and others DWP.
 - o From his perspective, there is the awareness piece, partnership working across the country, good quality occupational health, the need to improve access to accredited advice for businesses, supporting people into roles and linking people to work.
 - o End of life should be a consideration in everything that the DWP does.
 - o He is keen to work together.
- Baroness Finlay said that SRI is here to stay and the Royal Colleges should publicise it. The other group is HR professionals.
- Peter Gibson thanked everyone and closed the meeting .

Agreed Actions from the meeting:

- o Baroness Finlay, Peter Gibson and Lord Balfe to approach the Speakers in the House of Lords and the House of Commons to advocate for improvements to the support for MPs and Peers impacted by grief and caring responsibilities.
- o Lord Balfe to connect Paul Fraser with the Dying to Work Campaign.
- o Any stakeholders to reach out to the Minister if they have ideas about how he can help.
- o Stakeholders to help promote the changes to the special rules for terminal illness and look at how they can help improve workplace support.