

Update on progress for the eight Principles

Since the publication of the UK Commission on Bereavement's report (October 2022) and vision for change, steering group members have been working to progress the Commission's recommendations.

Significant progress has been made towards the recommendations over the last two years, including:

- The Department for Education in England has consulted on proposals to include grief education on the school curriculum;
- The eligibility criteria for social security benefits for parents of bereaved children have been extended. Families who were living together but not married can now access these benefits;
- The UK Government is introducing a new right to bereavement leave for employees bereaved of a close relative;
- The Northern Ireland Bereavement Network has been consulting on a new Bereavement Charter:
- The Welsh Government is developing a bereavement care pathway for children and young people:
- UKCB steering group partners have requested that the National Institute for Clinical Excellence produce a clinical guideline on bereavement;
- The National Institute for Health Research has commissioned a major new study into equitable bereavement support for people of all ethnicities;
- The UK Government is introducing the facility for people to register a death online; and
- New national Bereavement Support Service Standards have been published.

UKCB steering group members and others are continuing to campaign for change. Current priorities include:

- Improvements to the ways that major companies treat their bereaved customers;
- Greater security for bereaved people who rent their home;
- Uprating of benefits for bereaved families so that they keep up with inflation; and
- Sustainable funding for specialist bereavement support organisations

Below is a short summary of key updates and progress for each of the eight Principles

Progress to date - December 2024

Principle 1: I am supported by my family, my friends and the communities around me

In order to increase understanding and normalise conversations about death, dying and bereavement, governments in each UK nation must commit 6p per person to help develop, resource and evaluate cross-sector, collaborative initiatives.

The UK Commission on Covid Commemoration's final report, published in September 2023, included a recommendation on supporting an annual <u>Day of Reflection</u>, to remember those who died and were bereaved during the pandemic. We are still awaiting the Government's response to the report.

All schools and other education settings must be required to provide age-appropriate opportunities for children and young people to learn about coping with death and bereavement as part of life.

- Following submissions by UKCB steering group partners, the Department for Education included new content on grief education in its <u>proposed revisions to the Health and Relationships curriculum</u> issued under the previous government in May 2024. The new government launched a Curriculum and Assessment Review, which steering group partners submitted evidence to, highlighting the need for grief education.
- In December 2024 a Petition Debate was <u>debated</u> in Parliament calling for content on death, dying and bereavement to be added to the national curriculum.
- In Northern Ireland Marie Curie launched a report in November 2024 titled <u>Compassionate</u>
 School Communities: Embedding a Culture and Practice of Grief Education and Bereavement
 Support in Educational Settings. This report- the culmination of over three years of work
 aimed at raising awareness of childhood grief and bereavement gathered evidence to
 support and strengthen school-based loss and bereavement information and support for
 pupils. Encouragingly, the report and its recommendations have also been endorsed by the
 Education Minister.

Principle 2: I am sensitively supported by my school, college or workplace during my bereavement

New legislation must require that all employers have a bereavement policy. Relevant government departments should publish guidance on minimum standards and best practice for large, medium-sized and small employers

While there are a number of initiatives in this space, there is still a lack of coordination and leadership to capitalise on these individual initiatives, and no statutory requirement to have a policy in place. In Great Britain, the Employment Rights Bill provides an opportunity – steering group members are asking parliamentarians to introduce an amendment requiring employers to have a bereavement policy.

Statutory bereavement leave and pay entitlement of 2 weeks must be extended to encompass all close relationships

The UK Government is introducing a day one right to be reavement leave for employers through the Employment Rights Bill. This will bring in the right to one week's leave for employees be reaved of a

close relative. Steering group partners have held initial meetings with the Department for Business and Trade and briefed in to Second Reading of the Bill. Partners will continue to campaign on the duration and structure of bereavement leave, the definition of 'close relationship', and the need for bereavement leave to be paid.

The Bill covers Great Britain. The Good Jobs reform agenda announced in Northern Ireland in July 2024 does not include bereavement leave.

All education establishments (early years, schools and further and higher education) must be required to have a bereavement policy including staff training, and a process for supporting a bereaved child or young person and their family

While there are pockets of excellent practice, the lack of guidance and leadership from governments means there is great inconsistency between (and within) schools and other education establishments. A <u>petition</u> asking the government to create a registry of bereaved children so that the scale of the issue can be revealed, and these children and their families can be offered support proactively, was debated in Parliament in December 2024.

Principle 3: I am well supported before and during the death, and feel confident that the person who died received appropriate and compassionate care

Professional bodies and employers of anyone whose role brings them into contact with bereaved people must ensure they have bereavement training that is culturally-informed, and contextually tailored, including training on complex and traumatic grief, at an appropriate level

Many organisations provide high quality bereavement awareness training but this does not routinely form part of initial training programmes or inductions. Significant further work is needed to embed bereavement training across sectors and at appropriate levels.

In Wales, the National Bereavement Steering Group (NBSG) have provided funding for bereavement awareness training courses for a variety of organisations. The NBSG encourages all employers to ensure that all staff who come into contact with bereaved people have access to the appropriate training to undertake this work compassionately.

Each UK Government must ensure that there is sustainable funding and effective delivery of palliative care services

Sustainable funding for palliative care remains a critical ongoing challenge. Steering group partners raised issues of funding for palliative care through the course of the 2024 General Election campaign and have continued to work to ensure that this is recognised as a key issue by the new government.

To ensure an integrated approach to delivery of care before, during and after a death, governments across the UK must ensure that palliative and end of life care strategies are effectively linked to be reavement support strategies.

In England, the Health and Care Act 2022 placed a new duty on Integrated Care Boards (ICBs)
to commission palliative care services, and the subsequent statutory guidance elaborated
that this includes commissioning a sufficiency of bereavement support services. However, in
practice steering group partners are not seeing bereavement being prioritised at systems
level.

- In Scotland, bereavement has been reflected in the draft Scottish Palliative Care Strategy after several meetings to ensure bereavement was prioritised.
- In Northern Ireland, Marie Curie continues to engage with elected representatives and commissioners on the need for a new palliative and end of life care strategy to address current and future need.
- In Wales, bereavement is now embedded within the NHS Wales Executive's Palliative and End of Life Care programme.

Principle 4: The things I must do after a death are simple and straightforward

Governments across the UK must legislate so that people can choose whether to register a death in person or online.

Relevant clauses on the establishment of an online register were included in the Data Protection and Digital Information Bill introduced in the previous Parliament, but this bill did not pass into law before the general election. The new UK Government has announced a Digital Information and Smart Data Bill which covers the same ground as the previous legislation, enabling the move from a paper-based system to an electronic register.

Governments across the UK must conduct a review of the flow of information from death registration to relevant public bodies and industry, including the feasibility of extending the remit of Tell Us Once

Steering group partners have held conversations with the Department for Work and Pensions around reviewing the function and coverage of the Tell Us Once (TUO) service. Partners continue to press for a review of TUO.

Government departments and regulators must ensure bereaved customers are treated fairly and sensitively by working with relevant industry groups to develop minimum standards for death administration processes

Marie Curie has launched a campaign 'Make Sadmin Simple'. More than 30,000 people have signed the public petition calling on banks, telecoms companies and utilities to improve how they support terminally ill and bereaved customers. Meetings have been held with companies and an industry roundtable was recently convened.

Principle 5: I am compassionately and helpfully supported by those whose job brings them into contact with me through all stages of my bereavement

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Principle 6: I have access to an affordable and meaningful funeral

The Competition and Markets Authority must carry out its proposed further market investigation into the funeral industry now the exceptional circumstances of the pandemic are passed

The Competition and Markets Authority invited views on the funeral market in August 2024 to enable it to consider next steps, including whether or not to consult on a market investigation reference. We await their response.

New regulations must be created setting out minimum standards for public health funerals

It is a statutory requirement for local authorities to carry out a burial or cremation, but not all local authorities offer dignity around this option or sensitive customer service for bereaved people.

Quaker Social Action published *A patchwork of provision: council funerals across the UK* in July 2024, based on a survey of 102 councils and phone calls to 54 councils with volunteers taking on the role of the friend of a bereaved person who needed to organise a funeral. The report shows that a compassionate, simple and equitable process is far from guaranteed in some parts of the country.

Funeral Expenses Payment must be extended to currently excluded groups including students

No progress has been made on extensions to currently excluded groups.

Down to Earth at Quaker Social Action have launched a new <u>eligibility checker</u> that guides people through the complex criteria for the Funeral Expenses Payment. The hope is that the tool will help potentially vulnerable, recently bereaved people to avoid funeral related debt.

Out of hours systems must be in place in every local authority to enable rapid processing of death paperwork and registrations so that quick burials can take place for people whose religion requires it

Steering group partners will be monitoring the implications of the introduction of the Medical Examiners Scheme in England and Wales, which became statutory for all deaths in September 2024. The scheme has processes in place to ensure the urgent release of bodies for burial or cremation where that is required. In 2023, Medical examiner offices in England reported that when urgent release of the body was requested, this was achieved 89% of the time.

Principle 7: I feel secure in my home and have the right financial support

Bereavement Statutory Payment must be extended to cohabiting partners

Following a decade-long, sector-wide <u>campaign</u>, the eligibility rules for Bereavement Support Payment across the UK were changed in February 2023 and surviving members of a cohabiting couple with children can now make a claim for support of almost £10,000.

Bereavement Support Payment extended to those whose partner was unable to make sufficient NI contributions due to sickness or disability

The recent changes to the eligibility criteria for cohabiting parents do not change the eligibility criteria that relate to NI contributions. However, there is a separate campaign to extend eligibility to people whose partner was not able to make NI contributions because of illness or disability

throughout their working life. This campaign has been successful in the Court of Appeal in Northern Ireland and in Great Britain but the previous government signalled its intent to appeal this decision. The Childhood Bereavement Network and WAY Widowed and Young are making representations to the new government to reconsider the eligibility criteria.

Funeral Expenses Payment and Bereavement Statutory Payment extended to those with No Recourse to Public Funds

There has been no progress on this issue

Funeral Expenses Payment extended to students

There has been no progress on this issue

Governments across the four UK nations must work to increase uptake of Pension credit

UKCB steering group member Independent Age has conducted long term activity to highlight low Pension Credit uptake and push governments and others to act.

Following the government's announcement in July 2024 to introduce means-testing for Winter Fuel Payment, there have been a range of measures aimed at increased Pension Credit take up, including a week of Action in September 2024.

Financial support following a bereavement must be extended beyond current time limits:

Benefits for carers extended to 6 months after death (up from 2 months)

In April 2023, following a consultation on the new Scottish Carer's Assistance, the Scottish Government published a commitment to extending Carer Support Payments from 8 to 12 weeks when a cared for person dies.

Bereavement Support Payment extended to 6 years / completion of 1 year of secondary education for the youngest child (up from 18 months)

This issue was taken up by the Liberal Democrats as a major plank of their manifesto commitments in the run-up to the General Election. The Child Bereavement Network and WAY Widowed and Young are meeting with parliamentarians to continue to press for change.

All benefits for bereaved people must be up-rated annually in line with inflation in all four nations.

While Guardian's Allowance and Pension Credit were uprated in April 2023, the main benefit for working age bereaved people - Bereavement Support Payment - has been frozen since it was introduced in April 2017, meaning it has lost value over time. The Childhood Bereavement Network continues to draw attention to this in representations to DWP.

Funeral Expenses Payment has also not been increased since 2020. Quaker Social Action organised a sector letter to the Pension Minister asking for the capped element to be increased in line with inflation to account for the rising cost of funerals, but this was refused.

Legislation must require that landlords give at least 6 months' notice for an eviction after a bereavement.

Marie Curie has further explored the links between housing insecurity and bereavement through the commissioning of new polling data which revealed that around one in ten bereaved renters are forced to move home as a direct result of being bereaved.

The previous UK government introduced a Renters' Reform Bill. Marie Curie briefed in probing amendments calling for the removal of death of a tenant as a ground for eviction, with the support of the Labour party in opposition. This bill did not pass into law before the general election, but the new government has introduced a very similar Renters' Rights Bill. Disappointingly it makes no proposal to remove or substantively amend ground 7 (death of a tenant) as a grounds for possession. Marie Curie has raised their concerns, briefing into the bill at second reading and will continue to push for the bill to be amended to ensure that bereaved renters are protected.

In Wales, the Renting Homes law has given more rights to tenants, including enhanced succession rights. The new law enables both a priority and reserve person to succeed an occupation contract if the contract holder dies, allowing two successions to take place. A new succession right for carers has also been introduced. In addition, there is greater security for people who live in the private rented sector, to whom landlords must give at least 6 months' 'no fault' notice.

In Scotland Marie Curie has used the <u>"Dying in the Margins"</u> research to introduce MSPs and Government to the relationship between insecure housing and bereavement. This work was also cited in October 2024 by the Scottish Parliament's Local Government, Housing and Planning Committee which has recommended that the Scottish Government considers our proposals to protect bereaved tenants from eviction.

Principle 8: I can easily find and access the right emotional bereavement support for my circumstances

Bereavement services and support (including that provided by communities and faith groups) must sign up to an agreed set of standards, including ensuring they meet the diverse needs of the communities they serve.

The National Bereavement Alliance has comprehensively refreshed the <u>Bereavement Support</u> <u>Service Standards</u> with an audit that services can undertake to consider the quality of their work.

NICE and SIGN must develop guidelines for the delivery of bereavement support at all levels, including for complex and traumatic grief, such as facilitating access to appropriate mental health services when necessary

UKCB steering partners have submitted a paper to inform a discussion with NICE about prioritising this work and are awaiting a decision from NICE about whether this has been prioritised. Similar representations have been made to SIGN.

Integrated Care Systems across England must support partnerships of bereavement services, mental health and other relevant services to address levels of need and ensure compassionate and appropriate referrals between services

The National Bereavement Alliance guidance to support Integrated Care Systems and place-based partnerships to commission compassionate community bereavement support across all types of death and relationships continues to be used by commissioners but in a piecemeal way. The NBA would welcome support from NHSE&I to cascade this guidance to all ICBs.

In order that everyone has access to good and appropriate bereavement support, governments in each UK nation must invest 79p annually per person in the population for transforming bereavement services over the next 5 years, with a particular focus on better supporting Black, Asian and ethnic minority communities, and others who are currently poorly served.

The government has reviewed the relevant pages of gov.uk, improving clarity about how to seek support for those that need it.

In response to the challenges that people identified in understanding what bereavement support is out there and might help them, the Marie Curie Palliative Care Research Centre, Cardiff has collaborated with national partners to produce a new resource, the <u>Grief Support Guide</u>, based on research conducted during the Covid-19 pandemic and published on the National Bereavement Alliance website. The Guide, which has been viewed almost 7,000 times since September 2023, is available in ten languages and has been widely adopted, including in the RCGP's End of Life Tool Kit and Macmillan's e-learning resources, and by the Medical Examiners Wales, the Cremation Society and the Palliative and End of Life Care Programme Board (Wales). The Guide is updated annually and Version 2 is due to be released shortly.

Disappointingly, no progress has been made on securing national funding for the bereavement support. Anecdotally, the National Bereavement Alliance and Childhood Bereavement Network are hearing about significant funding pressures from their members, especially now that funding linked to the pandemic has largely ended.

The Welsh Government introduced a new funding stream for bereavement support services in 2021. It committed £3 million over three years, and an additional £420k for bereavement coordination posts at each of the health boards. An extension to the Bereavement Support Grant of £927k for 2024/25 has been provided, and a further BSG scheme worth £927k pa has been launched for 2025/28. Welsh Government also currently provides a minimum of 21% of hospices total funding in Wales and all hospices deliver aspects of bereavement support as part of their overall service provision.

Ends