

Report on progress against the recommendations, December 2024

Executive summary

This paper reports on progress against the recommendations made in the UK Commission on Bereavement report <u>Bereavement is Everyone's Business</u>, published in October 2022.

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

Progress is rated separately for each of the four nations, against each of the eight principles for change. Where powers over policy matters are reserved to the UK Parliament, this is noted with an 'R'.

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

1.1. 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 - similar to public health campaigns reducing mental health stigma such as *Time to Change* and *See Me*. These must reflect the needs of all communities in the UK, prioritising under-served population groups. This funding should supplement funding for the transformation of bereavement services set out in the recommendation below and have a particular focus on community-based informal support, and communication campaigns. These initiatives will be led by networks of charities, academics,

community-based organisations, faith groups, compassionate communities and health and social care providers, co-produced with people with lived experience.

England	Northern	Scotland	Wales	
	Ireland			

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

Despite the lack of wider funding, a number of initiatives are underway locally and nationally to raise awareness of the importance of supporting grieving people and to increase understanding and normalise conversations about death, dying and bereavement. The National Bereavement Alliance continues to coordinate meetings between the organisers of relevant awareness weeks and campaigns in this space, including Dving Matters Week, Demystifying Death Week (Scotland), National Grief Awareness Week, Children's Grief Awareness Week and the Good Grief Festival, to support collaboration and align messages.

Key initiatives include Marie Curie's National Day of Reflection, Cruse Bereavement Support's Connecting Communities project and Sue Ryder's Grief Kind campaign. Sue Ryder continues with their programme to launch Grief Spaces across England. The Good Grief Trust are launching a new map of bereavement cafes as part of National Grief Awareness Week this December. The stakeholders behind these initiatives are ready to work with UK governments and each other to create the necessary sea change in public attitudes and knowledge, but commitment and investment at a governmental level is essential. Of note, investing in these community-level activities is likely to save costs in the long run by reducing demand on bereavement services and preventing the known long-term social, physical and psychological sequelae of unmet bereavement support needs.

In Wales, Compassionate Cymru is a national movement aiming to help people access information, care and support in a compassionate way within their communities, supporting those at the end of life and people who are bereaved, lonely and isolated. Their collaboration with the Good Grief Connects Project has focused on strengthening community networks and support for bereaved people in Wales. Similar community outreach projects led by CRUSE and Marie Curie & Diverse Cymru have also been funded by the new Bereavement Support Grant, and government funding has recently been provided to Age Cymru to establish a Secretariat function for the Compassionate Cymru network as part of the Healthy Ageing Programme.

Furthermore, the National Bereavement Steering Group is working closely with the Advance & Future Care Planning group to help facilitate conversations about death, dying and bereavement. In addition, a Future Care Planning Task and Finish Group has been established to take a 'One Wales Approach' to: defining Future Care Planning in Wales; communicating the intent with the public through 'Big Conversation' events; exploring and agreeing how health care professionals can best ensure that the person's FCP (including their end of life wishes, DNACPR etc) are shared and made accessible across the system to support timely an effective decision making; considering

the training and education of the health and social care workforce; and reviewing systems and processes that enable Future Care Planning.

The Northern Ireland Bereavement Network is delivering a programme of activity to better support its bereaved population through four main workstreams. A new website for both public and professional audiences — Bereaved NI - has been built and launched. Scoping work has been undertaken on a new Bereavement Charter, with a specific working group established to support the development of a children and young people specific Charter. Further training has been developed for professionals, and a bereavement strategy is planned but awaiting ministerial sign off.

1.2. 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.



The Childhood Bereavement Network (CBN) is coordinating regular meetings of key stakeholders around the topic of grief education. Following submissions by this group, the Department for Education included new content on grief education in its proposed revisions to the Health and Relationships curricula issued under the previous government. The group and some of its members responded positively to the consultation. The General Election paused this process and CBN wrote to the new Schools Minister to urge her to push through with these changes - she replied saying that consultation responses would be considered as part of the wider Curriculum and Assessment Review currently underway. The group has made a further submission to this Review. The Petitions Committee has honoured a commitment to consider John Adams' petition for grief education made under the previous administration, and this will be debated on 2 December.

In Northern Ireland Marie Curie launched a report in November 2024 titled <u>Compassionate School Communities: Embedding a Culture and Practice of Grief Education and Bereavement Support in Educational Settings</u>. 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. Five key recommendations were included, including one specific to grief education (*'ensure the education curriculum offers a range of opportunities for pupils to discuss bereavement and grief'*). The recommendations in the report have received wide-ranging support from young people, parents / carers, teachers, teaching unions, and health practitioners working in and with schools. Encouragingly, the report and its recommendations have also been endorsed by the Education Minister.

In Scotland, the <u>report</u> of the June 2023 Bereavement Summit recommended calling explicitly for grief and bereavement to be included in the Curriculum for Excellence. A <u>paper</u> has explored current and potential coverage across the curriculum.

In Wales, representatives from educational establishments are engaged in the development of a Children and Young People's Bereavement Pathway. The Office of the Children's Commissioner for Wales and child bereavement charities are also involved. As part of the implementation of the Pathway, colleagues will indicate the wider need to increase death literacy and coping strategies for

bereaved children and young people to be incorporated as part of the guidance. Local Health Board Bereavement Co-ordinators are already encouraged to reach out to schools and colleges to talk about coping with death and bereavement.

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

2.1. 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. These should include specific guidance on support for those who experience death and bereavement in the course of their work, and should be written in consultation with all relevant stakeholders in the public, private and third sectors.

England	Northern	Scotland	Wales	
	Ireland			

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 and we will ask parliamentarians to introduce an amendment requiring employers to have a policy.

In Wales, the Health & Safety Executive state that employers have a legal responsibility to help their employees. The Stevenson / Farmer review of mental health and employers was commissioned by HM Government in January 2017 to independently review the role employers can play to better support individuals with mental health conditions in the workplace. It proposes a set of mental health core standards for organisations, including support for those distressed as a result of major life events, including bereavement. Discussions are also taking place with The Wales TUC to understand more about workplace bereavement policies.

2.2. 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 bereavement leave for employers through the Employment Rights Bill. This will bring in the right to one week's leave for employees bereaved 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. We are coordinating our efforts and 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 and the importance of employers having a bereavement policy.

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

2.3. 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> has been set up 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, and this will be debated on 2 December.

The Compassionate Schools report, launched by Marie Curie in Northern Ireland, contains a recommendation for every school to have a bereavement policy, teachers given a range of opportunities to access training and a Department of Education led policy and practice framework to support schools.

In Wales, the role and remit of schools and other education establishments is being considered in the new child bereavement support pathway that is currently being developed and is due to go out for consultation imminently.

- 3. I am well supported before and during the death, and feel confident that the person who died received appropriate and compassionate care
 - 3.1. 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.

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

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Sustainable funding for palliative care remains a critical ongoing challenge. Marie Curie, Sue Ryder, Hospice UK, and the National Bereavement Alliance 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. The need for action on this was further increased by announcements in the budget around changes to employer National Insurance Contributions which will put further pressure on non-NHS providers of palliative care. Campaigning on this issue will continue in advance of the three year Comprehensive Spending Review expected in Spring 2025.

In Northern Ireland, Marie Curie continues to engage with elected representatives and commissioners on the need for a new PEoLC Strategy to address current and future need. There is now have a new Commissioner for PEoLC and the Health Committee has launched an inquiry into palliative and end of life care and hospice funding. The lack of a devolved government until February 2024 and a challenging budget situation has greatly impeded progress.

In Wales, Marie Curie are working with other providers of palliative and end of life care to ensure that the Welsh Government establishes a sustainable funding regime. Work is being undertaken by the National Programme Board for Palliative and End of Life Care to develop recommendations for the Welsh Government as part of its Phase 3 Funding Review to this effect. The Welsh Government currently invests over £13m per annum in palliative and end of life care, up from £10m last year, and is currently undertaking a funding review looking at the whole spectrum of end of life care services.

3.3. To ensure an integrated approach to delivery of care before, during and after a death, all UK Governments must ensure that palliative and end of life care strategies are effectively linked to bereavement 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. This is further elaborated in the Handbook of technical guidance for ICBs. However, in practice steering group partners are not seeing bereavement being prioritised at systems level (see NBA's analysis of Integrated Care Strategies at 8.3 below).

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 fully embedded within the NHS Wales Executive's Palliative and End of Life Care programme.

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

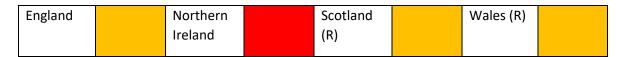
4.1. Governments across the UK must legislate so that people can choose whether to register a death in person or online



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.

In Northern Ireland, although people can contact the Registrar's Office via email, phone or in person, the process has not yet been streamlined to an online service. Marie Curie in Northern Ireland is continuing to lobby for the replication of the system established in England.

4.2. 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



Conversations were held last year with the Department for Work and Pensions around reviewing the function and coverage of the Tell Us Once (TUO) service. The previous UK government indicated there were no plans to explore extension into the private sector, which we believe is a missed opportunity – we will be calling on the new government to explore this.

Probing amendments were introduced into the Data Protection and Digital Information Bill calling for a comprehensive review of TUO in the last Parliament. We are seeking to amend the new Digital Information and Smart Data Bill accordingly.

TUO does not operate in Northern Ireland. A lighter touch service called the 'Bereavement Service' exists, but it only covers information sharing relating to benefits and is not as far reaching as TUO. Marie Curie has advocated for a TUO like service in Northern Ireland and the Executive does recognise the benefits. With support from Marie Curie, the Chair of the All-Party Group on Terminal Illness has recently written to the Minister of Finance and Communities at Stormont raising this issue. Marie Curie is also working closely with Advice NI to address the fact that Northern Ireland is the only part of the UK not covered by TUO. Marie Curie will also continue to campaign for this in collaboration with the NI Bereavement Network.

4.3 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 commissioned and conducted further research to advance understanding of death administration issues, in addition to launching a campaign 'Make Sadmin Simple'. More than 30,000 people have signed the public petition calling on banks, telecoms companies and energy providers to improve how they support terminally ill and bereaved customers. Meetings have been held with companies and an industry roundtable was recently convened. The campaign has attracted significant media coverage, including by Money Saving Expert as its 'Campaign of the week'.

In Scotland, the campaign has been of great interest to some MSPs and a motion has been drafted. And in Northern Ireland, Marie Curie is a member of the Utility Regulator's Consumer Protection Advisory Group. Marie Curie have this group on the campaign, and the Utility Regulator is interested in collaborating next year to inform planned work on supporting bereaved customers.

Furthermore, the National Bereavement Alliance and Childhood Bereavement Network have met with DWP and HMRC to discuss specific issues relating to communications and policy affecting bereaved people in the area of death administration.

- 5. I am compassionately and helpfully supported by those whose job brings them into contact with me through my bereavement
 - 5.1. 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.

See 3.1 above

6. I have access to an affordable and meaningful funeral

6.1. 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 <u>invited views</u> 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 are awaiting their response.

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



Council funerals or public health funerals are undertaken by local authorities when someone has died in their area and no one else is making funeral arrangements. It is a statutory requirement 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 <u>A patchwork of provision: council funerals across the UK</u> 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.

6.3. 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.

6.4. 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 (for example Jewish and Muslim communities).



We will be monitoring the implications of the introduction of the <u>Medical Examiners Scheme</u> in England and Wales, which became statutory for all deaths on 9 September. 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 <u>reported</u> that when urgent release of the body was requested, this was achieved 89% of the time.

In Wales, most local health board (LHB) Care After Death or Bereavement Services already have provision for the out of hours issue of medical certificate of cause of death for religious reasons. All

LHBs are reviewing the provision of bereavement services to ensure a standard baseline across Wales. This is being monitored as part of the ongoing review of LHB bereavement teams services and reported to the Welsh Government at six monthly intervals.

In Northern Ireland, burial/cremation and funerals generally happen within a short timeframe (usually 3-5 days), although this can be longer if the coroner is involved. Although out of hours systems are not in place, there is an accepted urgency to processing death paperwork to facilitate this. There are no formal expedited protocols in place to support the cultural rites of specific religious communities requiring burial as soon as possible after death.

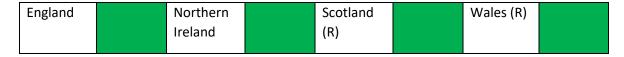
7. I feel secure in my home and have the right financial support

7.1. Overall work



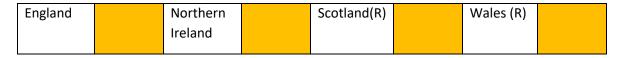
7.2. Entitlements to financial support following a bereavement must be extended to key groups including:

7.2.1. Bereavement Support Payment 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 on 9 February 2023 and surviving members of a cohabiting couple with children can now make a claim for support of almost £10,000.

7.2.2. BSP extended to those whose partner was unable to make sufficient National Insurance (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 drop this appeal.

7.2.3. FEP and HRBSP to No Recourse to Public Funds



No progress

7.2.4. Funeral Expenses Payment extended to students



No progress

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

England	Northern	Scotland	Wales	
	Ireland			

UKCB steering group member Independent Age has conducted long term activity to highlight low Pension Credit uptake and push governments and others to act. The DWP has carried out a Pension Credit Week of Action in 2023 and 2024, during which the DWP worked with charities and other partners to share information about eligibility for Pension Credit, although this year's had to be scaled back due to the general election. The DWP has carried out a project in which older people in receipt of Housing Benefit living in ten local authority areas in England were contacted by DWP and invited to apply for Pension Credit. Following the government's announcement in July 2024 about the means-testing of Winter Fuel Payment, there have been a range of measures aimed at increased Pension Credit takeup, including a week of Action in September 2024, and writing to around 120,000 Housing Benefit recipients about Pension Credit.

The Welsh Government has been running a 'Claim What's Yours' campaign to encourage individuals across Wales to claim their entitlements. This includes uptake of Pension Credit.

The Department for Communities in Northern Ireland run the 'Make the Call' service for people who feel they may be missing out on benefits, services or support they are entitled to. It is estimated that approximately 28% of those entitled to pension credit, comprising over 26,000 families, do not currently claim it. The department also funded research in 2021-22, which looked at the barriers and interventions to pension credit uptake in Northern Ireland. Marie Curie has also recently launched its latest report into Dying in Poverty and Marie Curie will be making the link to the Pension Credit issue in Northern Ireland- particularly pension credit being the gateway benefit for accessing the winter fuel payment.

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

7.4.1. 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.

There has been no progress on this in Northern Ireland.

Benefits are not devolved in Wales.

7.4.2. 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. CBN and WAY Widowed and Young are meeting with parliamentarians to continue to press for change.

7.4.3. Exemption from bedroom tax extended to a year (up from 3 months)



No progress.

In NI, time limited mitigations are currently in place which protects people from this tax.

7.5 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 <u>sector letter</u> 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.

7.6 Legislation must require that landlords give at least 6 months' notice for an eviction when an original tenant dies. This must apply to all tenancies in both the private and social rented sectors.

England	Northern	Scotland	Wales	
	Ireland			

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 NI, the social rented sector is more secure for tenants than the private rental sector. The Housing rental scheme and 'legal succession' laws mean that under certain circumstances a cotenant can remain in a property following the death of deceased tenant. The private rental sector is largely unregulated apart from legislation governing notice periods; notice periods are commensurate with the length of tenancy and are up to a maximum of 12 weeks for those living in a property for more than 10 years.

In Scotland Marie Curie has used the "Dying in the Margins" research to introduce MSPs and Government to the relationship between insecure housing and bereavement. The University of Glasgow will be exhibiting the research at a parliamentary reception next year – a further opportunity to spotlight issues around insecure housing. 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. Furthermore, there are also plans for two practice notes to be launched in 2025 in collaboration with MND Scotland. The first would be focused for the social housing sector to include: matching people to accessible housing; supporting timely adaptations installation in both existing and new housing stock; and supporting tenancy and succession rights. The second would be primarily focused for owner occupiers to support implementation of the Scheme of Assistance.

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

8.5 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.

All bereavement services in Wales are expected to abide by the new Framework, adopting the standards for commissioners and providers that are set out in Framework. The standards specify the need to address diversity and tackle inequity. Adherence to the standards is a condition of the new funding allocated.

The Northern Ireland Bereavement Network's programme of work includes a requirement to meet the needs of all communities and faith groups. Maire Curie sits on a Children and Young People's Bereavement Charter group which aims to establish specific standards for children and young people, relevant to a range of settings, that include health and social care services, schools and the wider community.

A bereavement subgroup of the Scottish Government's palliative care strategy has been established, and the National Care Service bill has been passed. We have concerns around the progress of the bill and its removal from this years' programme for government.

8.6 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. We await a decision from NICE about whether this has been prioritised. Similar representations have been made to SIGN.

Whilst HSC in NI can endorse NICE Guidelines, they predominantly are written for NHS in England and Wales.

The 'Dying in the margins' parliamentary exhibition and debate held in the Scottish Parliament highlighted issues around complicated grief.

8.7 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

England	Northern	n/a	Scotland	n/a	Wales	n/a
	Ireland					

The National Bereavement Alliance <u>guidance</u> 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.

- 8.8 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. As well as service delivery, it must cover:
 - improvement including training and tailoring of support
 - improvements in access assessment, signposting and referral mechanisms to mental health services for people affected by complex grief
 - local and national collaboration
 - research, data collection and evaluation
 - innovation in practice, including trialling new approaches to signposting support, and piloting the feasibility and effectiveness of offering bereavement support proactively to specific underserved and vulnerable groups.

Signposting to services

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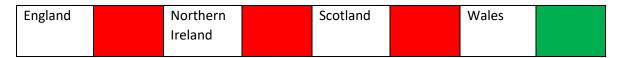
The government has reviewed the relevant pages of gov.uk, improving clarity about how to seek support for those that need it.

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 <u>research conducted during the Covid-19 pandemic</u> and published on the National Bereavement Alliance website. The Guide, which has been viewed almost 7,000 times since September 2024, 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.

In Wales the new Framework places a clear expectation on commissioners/health boards and services to engage in effective signposting to sources of support and the related pathway specification places a strong emphasis on local signposting and needs assessment of bereaved

individuals across the bereavement journey, as well as improving coordination and information sharing between local services. The progress of health boards in improving access to bereavement support is now being evaluated in the NHS performance framework.

Funding of services



Disappointingly, no progress has been made on securing national funding for the bereavement support outlined above. 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.

8.9 All public, private and third sector bodies supporting bereaved people must commit to tackling inequalities in access to emotional support following a bereavement and ensuring underserved communities, including Black, Asian and ethnic minority communities and groups whose grief is disenfranchised, are better supported.



The NIHR funded project *Equitable Bereavement Support for All* is exploring the experiences of bereaved people from racially minoritised communities, and the efforts of bereavement services to address practice. The research team recently presented to the bereavement lead at DHSC and further links are being made with the health inequalities team to maximise impact.

A number of specific projects are underway, including Cruse Bereavement Support and the Co-op's Connecting Communities Project. Cruse and Co-op are currently working in 12 geographical locations across England, Northern Ireland, Scotland and Wales, providing training and printed/online resources to local community groups and networks. An online training package has also been developed. The Ubele Initiative's work on support in diverse communities, including their Good Grief Connects project with the University of Bristol.

In Wales, the Bereavement workstream have developed and published a National Bereavement Pathway Model Specification and their first bereavement specific module on support following the sudden death of a child or young person aged 25 or under. There is a requirement for local health boards to ensure that bereavement support is available to all, including people with protected characteristics and those who find it difficult to access support due to language, ethnicity,

disability, sexual orientation. The NBSG Provider Forum has a sub-group specifically looking at issues relating to Black, Asian and Minority Ethnic Communities, chaired by the CEO of Diverse Cymru, who is also a member of the NBSG.

Addressing inequities was a core part of the funding criteria for the new Bereavement Support Grants, with several projects funded which focus on improving support for minoritised/underserved groups. All applicants to the new round of BSG allocations are required to commit to specific proposals to tackle inequalities and collaborate with other national and local bereavement providers, and health board bereavement leads, to ensure the equitable provision of bereavement support across the locality.

8.10 All UK Governments must commission further research to better understand the emotional support needs of people affected by bereavement with a particular focus on understanding how services can be improved for Black, Asian and ethnic minority communities and groups whose grief is disenfranchised. The voice of people affected by bereavement must be central to this research.



See 8.5

In Wales, research activity to understand the bereavement support needs and experiences of minority ethnic communities took place at a Good Grief Connects event in Cardiff last year cohosted by Compassionate Cymru. Learning from organisations working with these groups has also been shared at NBSG meetings and the provider forum. The Marie Curie Research Centre and Cardiff University are part of the NIHR research project described above (and part of the NBSG), enabling direct and rapid access to learning from this study. Furthermore, local health boards are required as part of their six-month update against the NHS Performance Framework's Policy Assurance Assessments to demonstrate their progress in implementing the Bereavement Framework and National Bereavement Pathway. This includes a requirement to provide adequate service provision for people with protected characteristics. The Welsh Government, as part of their response to these assessments, have asked for specific updates on local health board's assessment of the local population's bereavement needs, including the needs of those with protected characteristics.

9 Underpinning recommendations

- 9.5 To deliver all of the above recommendations, each UK Government must establish and deliver a cross-departmental strategy for bereavement that recognises support following bereavement as a human right. This must:
 - encompass all aspects of public policy affecting bereaved people
 - involve the voices of bereaved people

- draw on learning from the pandemic to set out how people (public, communities and workforce) will be supported in future mass bereavement events.
- set out the responsibilities of national and local government, health and care commissioners and other statutory bodies, and
- address inadequacies in support for Black, Asian and ethnic minority communities, and others who are particularly poorly served.

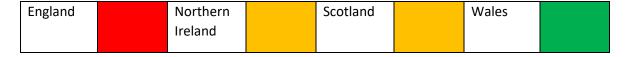


The UK Government has not committed to a cross-government strategy and this means that bereavement still does not attract the attention it deserves. While the cross-government bereavement working group, established in 2021, provides an important forum for the discussion of bereavement issues, there is a lack of concerted effort across government to address the changes that bereaved people called for in their evidence to the UK Commission on Bereavement.

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 and associated bereavement strategy to address current and future needs. The challenging budget situation is greatly impeding progress.

In Wales, the National Framework for the Delivery of Bereavement Care in Wales, was published in October 2021. It was subject to public consultation and reflects the views of bereaved people. The NBSG contains representation from Diverse Cymru, an organisation specifically established to champion the needs of Black Asian and Minority Ethnic communities across Wales. In addition, the Provider Forum and Bereavement Pathway groups include organisations working directly with Black Asian and Minority Ethnic Communities.

9.6 The Government and NHS England should each have a named lead for bereavement.



While HM Government has ministers with specific responsibility for bereavement (the Minister for Mental Health and Women's Health Strategy and the Minister for Work and Pensions), there is no parallel lead for bereavement in NHS England. Although individual National Clinical Directors and policy teams have shown leadership on specific aspects of bereavement support (including suicide postvention, and bereavement in the context of palliative care), there is a lack of joined up responsibility within NHS England, and this hampers change.

Although the Northern Ireland Bereavement Network is led by the Department of Health, there is no officially named lead for bereavement in Northern Ireland.

9.7 Other work raising general awareness of the recommendations

England	Northern	Scotland	Wales	
	Ireland			

UKCB steering group partners have presented the report findings at a variety of conferences and other events, including those organised by Bereavement Care (Harrow), Barts Health, the European Grief Conference, the Cremation & Burial Communication & Education Conference 2024, South West Academic Primary Care Conference 2024, European Association of Palliative Care 2024 and the Marie Curie Research Conference 2024.