

Commissioning for Compassionate Community Bereavement Support

How bereavement contributes to health outcomes frameworks

This document sets out how bereavement is relevant for outcomes frameworks that are used to prioritise work and track progress and trends across health and social care. These are the NHS Priorities and Operational Planning Guidance, the Public Health Outcomes Framework, and the Adult Social Care Outcomes Framework. It can be used to help raise the profile of bereavement in local areas, and to demonstrate how meeting bereaved people's needs can contribute to better outcomes locally.

The document forms part of a suite of resources for commissioners and providers of bereavement services. These resources are intended to build on the opportunities in the Health and Care Act 2022 and the UK Commission on Bereavement. These provide new structures and ways of working for local people, communities and services to collaborate to set out a vision for bereavement support in the local area, and to work together to make this vision a reality. Overall, these will help communities, providers and commissioners collaborate to ensure that the full range of bereavement support is in place and integrated, following expected and unexpected deaths across an Integrated Care System or place-based partnership.

The resources are available at <https://nationalbereavementalliance.org.uk/ourpublications/commissioning/>

NHS Priorities and Operational Planning Guidance 2023/24

<https://www.england.nhs.uk/publication/2023-24-priorities-and-operational-planning-guidance/>

The 2023/24 priorities and operational planning guidance reconfirms the ongoing need to recover NHS core services and improve productivity, making progress in delivering the key NHS Long Term Plan ambitions and continuing to transform the NHS for the future.

Recovering our core services and improving productivity	Primary care <ul style="list-style-type: none"> Make it easier for people to contact a GP practice, including by supporting general practice to ensure that everyone who needs an appointment with their GP practice gets one within two weeks and those who contact their practice urgently are assessed the same or next day according to clinical need Ensure people can more easily contact their GP practice Transfer lower acuity care away from both general practice and NHS 111 by increasing pharmacy participation in the Community Pharmacist Consultation Service. 	28% of respondents in an Australian survey of bereaved people had sought help from their community pharmacist and of these, 61% said this was helpful (Aoun et al 2018). No respondents to a parallel survey in Ireland had sought help from their pharmacist (Aoun et al 2020), suggesting this may be an under-used resource in England too
LTP and transformation	Mental health: Improve access to mental health support for children and young people in line with the national ambition for 345,000 additional individuals aged 0-25 accessing NHS funded services (compared to 2019)	While bereavement is not itself a mental health disorder, it does increase the risk of a range of poor mental health outcomes including anxiety, depression, PTSD and prolonged grief disorder. Normalising grief through community capacity building approaches can help people to realise that their responses are normal if overwhelming and to access the type of support that is right for them, helping to prevent difficulties from escalating.
	Mental health: Increase the number of adults and older adults accessing IAPT treatment	
	Mental health: Achieve a 5% year on year increase in the number of adults and older adults supported by community mental health services	
	Mental health: Improve access to perinatal mental health services	84% of English hospital trusts have signed up to the nine standards of the National Bereavement Care Pathway (NBCP) led by SANDS in collaboration with bereaved families, other charities and Royal Colleges. Across the 21 pilot sites, the NBCP has been found to improve the bereavement care received by parents after the loss of a baby, and to increase confidence and empower staff to provide consistently good bereavement care (Donaldson 2019).
	Prevention and health inequalities: Continue to address health inequalities and deliver on the Core20PLUS5 approach	Inequities persist in people's experiences of bereavement and access to support (Selman et al 2022) and this is associated with poorer outcomes in bereavement.

Public Health Outcomes Framework

<https://fingertips.phe.org.uk/profile/public-health-outcomes-framework>

The Public Health Outcomes Framework provides indicators that to understand trends in public health. Data for available indicators at England and local authority levels, are collated by the Office for Health Inequalities and Disparities. The indicators for which bereavement is relevant are outlined below.

A: Overarching indicators		
A01	Life expectancy and healthy life expectancy	Bereaved spouses lose on average 12% of residual life expectancy after conjugal bereavement. The death of a spouse affects the share of healthy years over the rest of life (residual lifetime), primarily because healthy years are replaced by years with chronic diseases (van den Bout et al 2011). A systematic review of the relationship between spousal bereavement and physical and physiological health problems found that the majority of included studies found a statistically significant and positive association between spousal bereavement and adverse physical and physiological health outcomes such as inflammation, cardiovascular risk, chronic pain, and mortality (Ennis and Majid 2021).
B: Wider determinants of health		
B01	Children in absolute/ relative low income families	The death of a partner is a route into, and exacerbator of poverty among families with dependent children, with three quarters seeing their equivalised household income falling (Corden et al 2008). Working age people with dependent children are particularly vulnerable to experiencing poverty in the last five years of their life and they are less likely to be able to absorb the income loss associated with a terminal diagnosis than other household types (Marie Curie 2022). In turn, poverty worsens the risk of bereavement. Berg et al (2015, Sweden) found that much of the association they found between parental death and lower grades and school failure was accounted for by family socioeconomic position and parents' psychosocial factors. 90% of widowed parents responding to a Childhood Bereavement Network survey said it was more difficult to put their children's needs first when their Bereavement Support Payment ended (CBN, 2019)
B03	Pupil absence	After accounting for demographics and for other traumatic experiences, sudden loss in childhood is significantly associated with lower academic achievement, lower self-rated concentration and learning ability, lower beliefs that teachers are fair, less school belongingness, and less liking of school relative to youth without a history of sudden loss (Oosterhof et al 2018).
B04	First time entrants to the youth justice system	Bereaved people are over-represented among children involved in a pattern of offending (Vaswani, 2008) and young people in custody (Finlay & Jones, 2000; Vaswani, 2014).
B05	16 and 17 year olds not in education, employment or training	Bereaved children and young people have been found to have lower educational aspirations and fewer plans for career development than their peers (Brent et al 2012, Dyregrov 2015). The death of a parent

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		reduces the probability of completing secondary school and university education, controlling for family socioeconomic status and psychiatric illness within the family (Hoeg et al 2018).
B08	People with a physical or mental long term health condition in employment (16 to 64)	Bereaved people were significantly less likely to be employed in the year of and 2 years after bereavement than non-bereaved matched controls (Stephen et al 2015).
B09	Sickness absence	At any time, one in 10 employees are thought to be affected by bereavement (McGuinness, 2009). Sickness absence attributable to bereavement is likely to be under reported, as it would likely be recorded as anxiety, depression or stress on a statement of fitness for work.
B13	Offending and re-offending	See B04
B15	Homelessness	People's accounts of the factors contributing to their route into homelessness frequently include bereavement (Mayock et al 2021, Song et al 2007, Ross-Houle et al 2017). Homeless people are more likely to die young, often from sudden and unnatural causes (Thomas 2012, ONS 2022) meaning that their peers are more likely to be bereaved.
B17	Fuel poverty	Even before the cost-of-living crisis, rates of household fuel poverty almost treble after one member of a couple dies and many people struggle for two years or more to manage fuel costs now they are heating their homes and cooking for one person instead of two (Corden et al 2010).
B18	Social isolation: percentage of adult social care users and adult carers who have as much social contact as they want	Many bereaved people report loneliness following the death, from the loss of the relationship with the person who died, from awkwardness with family members and friends and stigma following certain types of death, and the loss of the staff who supported them while caring for the dying person. Some carers' resources may have become so depleted during caregiving that they are unable to rekindle old relationships or make new ones (Burton et al, 2006). The NICE guideline on Older people: independence and mental well-being (NICE, 2015) identifies that older people bereaved of their partner are at increased risk of decline. Carers who have good social support while they are caring are more likely to do better when they are bereaved (Aneshensel 2004, Brazil et al 2002, Kurtz et al 1997, Tsai et al 2015, Kreicbergs et al 2007).
B19	Loneliness: Percentage of adults who feel lonely often or always or some of the time	Partner loss is consistently identified as a risk factor for loneliness in older adults (Dahlberg et al 2020). Loneliness is most prevalent in those who are widowed, followed by those who are divorced or unmarried (Lim et al 2020). Loneliness plays a key role in adaptation to bereavement (Fried et al 2015) and is linked to some extreme difficulties in adjusting to the loss of a close person (Vedder et al 2021), including suicidal ideation and suicide attempts (Pitman et al 2020). Feelings of loneliness in bereavement are not determined solely by the quality or quantity of social relationships (Utz et al 2014).
C: Health improvement		
C11	Hospital admissions caused by unintentional and deliberate injuries in children	Children and young people (particularly adolescent boys) experience more accidents in the year following a parent's death than their non-bereaved peers (Worden 1996) and this is associated with higher levels of conflict in the household and worse behaviour. They are also more likely to take risks

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		including not wearing a seat belt, being in a car driven by someone who had been drinking, carrying a weapon, and being in a physical fight in the last year (Muniz-Cohen et al, 2010, USA).
C12	Percentage of looked after children whose emotional wellbeing is a cause for concern	Bereaved children are likely to be overrepresented in the public care system, because many of the factors that contribute to a child becoming looked after also contribute to early mortality (drug and alcohol misuse, poor general health, serious mental health difficulties, domestic violence and involvement in crime). Some young people come into care specifically because there is no-one left to care for them after a death in the family (Penny, 2007).
C14	Emergency hospital admissions for Intentional Self-Harm	Bereavement is a common problem preceding deliberate self-harm in older adults (Hawton and Harris, 2006), and young people bereaved of a parent by cancer are twice as likely to self-harm as those who haven't been bereaved (Bylund-Grenklo et al, 2014). Young people bereaved of a parent are more likely to attempt suicide (Jakobsen and Christiansen, 2011).
C19	Successful completion of drug or alcohol treatment/ deaths from drug misuse	People whose parent died during their childhood are more likely to be hospitalised for drug or alcohol use than their non- bereaved peers (Wilcox et al, 2010), and young people bereaved suddenly of a parent are more likely to have a substance or alcohol abuse disorder (Brent et al, 2009).
C21	Admission episodes for alcohol-related conditions	See C21
C23	Percentage of cancers diagnosed at stage 1 and 2	Widows and widowers who receive fewer reminders to manage their health after the death have worse outcomes in bereavement, thought to be associated with a lessening in take up of preventative health care
C26	NHS Health Checks for eligible 40-74 year olds	
C28	Self-reported wellbeing (people with a low worthwhile, satisfaction and happiness score, high anxiety score	The death of a parent in childhood has a persistent, worsening effect on teenagers' emotional and social wellbeing, long after the death (Jones et al, 2013). They have lower self-efficacy and self-esteem (Worden, 1996). Bereaved children have lower life satisfaction, even if they are not showing emotional or behavioural difficulties (Parkes et al, 2014). Bereavement has a significant impact across many domains of adults' self reported wellbeing (Stroebe et al, 2007).
E: Healthcare and premature mortality		
E03	Under 75 mortality rate from all causes considered preventable	The death of a spouse is associated with increased risk of death from cardiovascular disease, coronary heart disease, stroke, all cancer, lung cancer, smoking-related cancer, and accidents or violence. The risk may be greater among those bereaved unexpectedly (Hart et al, 2007) and among men (van den Berg et al, 2008). A population-based national cohort study found mortality the year after spousal loss was 70% higher for men aged 65–69 years and remained elevated for a period of six years. Mortality for women aged 65–69 years was 27% higher in the first year, normalizing thereafter (Katsiferis et al, 2023, Denmark). Children bereaved of a parent during their childhood are at persistent risk of themselves dying early (Li et al, 2014; Smith et al, 2014). Parents whose baby or young child dies have a markedly increased risk of mortality up to 25 years after their child's death (Harper et al, 2011). Parents who have

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		experienced the death of a child have an increased risk of early mortality (Espinosa & Evans 2013, Song et al 2019)
E04	Under 75 mortality rate from cardiovascular diseases	Mothers and fathers bereaved of a child have an increased risk of death from heart disease and circulatory causes (Schorr et al 2016). Older people in the UK with pre-existing cardio-vascular disease show a reduction in uptake of all annual measures in the year prior to the death of a partner, and a reduction in medication coverage following their bereavement (Shah et al 2013).
E09	Premature mortality in adults with severe mental illness	While bereavement itself is not a mental illness, it does increase the risk of a range of mental health difficulties including complex grief reactions, depression, PTSD symptoms and anxiety, and also increases the risk of mortality (Stroebe et al, 2007).
E10	Suicide rate	Bereavement is associated with an increased risk of suicide in the bereaved person (Stroebe et al, 2007), including if the bereavement was itself through suicide (Wilcox et al, 2010; Pitman et al, 2016).
E11	Emergency readmissions within 30 days of discharge from hospital	Rates of early readmissions spike for both men and women around the time of spousal death. For women, these rates decline steadily and return to baseline three years after being widowed while for men, rates decline much more slowly and remain much higher than baseline three years on (Jin and Chrisatakis, 2009, USA).

Adult Social Care Outcomes Framework 2023/24

<https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-handbook-of-definitions/adult-social-care-outcomes-framework-2023-to-2024-draft-handbook-of-definitions>

The Adult Social Care Outcomes Framework is used both locally, regionally and nationally to measure local authority social care progress against key priorities and strengthen transparency and accountability. Importantly, it measures how well care and support services achieve the outcomes that matter most to people. The indicators for which bereavement is relevant are outlined below.

Objective 1: Quality of Life		
1A	Quality of life of people who use services (ASCS)	This measure is an average quality of life score based on responses to the Adult Social Care Survey. Relevant questions for bereaved people using social care services include those on social participation, occupation and dignity. See 4.13 and PHOF 1.18.
1C	Quality of life of carers (SACE)	<p>Among carers, those providing palliative or end of life care are most likely to report a negative impact of caring on their physical health (Carers UK 2018)</p> <p>Risk factors during caregiving that are associated with worse outcomes in bereavement include high levels of pre-death distress (eg depression and anxiety); high levels of burden, feeling exhausted and overloaded, lacking support; reporting more benefit from the experience of caring; not being prepared</p>

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		for the death (Schulz et al 2008a). People experiencing problematic grief including prolonged grief disorder, complicated grief and major bereavement-related depression have reduced quality of life (Zisook and Shear, 2009; Boelen and Prigerson 2007).
1D	Overall satisfaction of people who use services with their care and support (ASCS)	Widow(er)hood increases the odds of using domiciliary care services among respondents aged 70 and over, even when other factors including health status are taken into account (Glaser et al, 2006, UK).
1E	Overall satisfaction of carers with social services (for them and for the person they care for) (SACE)	Carers' perception of the support they and their cared-for person received at the end of life is related to their level of grief and mental health after the death (Grande and Ewing, 2009, UK). The annual VOICES survey collected bereaved people's views on care at the end of life for people over 18 until 2015. In 2015, 41.8% people reported this as outstanding or excellent, 48% as fair or good, and 10.2% as poor (rising to 13.3% of those whose relative died in hospital). 54.1% those who cared for the person at home reported not getting enough care and support for their caring role during the last three months (rising to 61.9% of those whose relative died in hospital) (Office of National Statistics, 2016).
Objective 3: Empowerment		
3B	The proportion of carers who report that they have been involved in discussions about the person they care for (SACE)	In 2015, around a quarter of people registering a death didn't get to discuss their worries/fears about the person's condition, treatment or tests with their GP as much as they would have liked in the 3 months prior to the person's death. 76% report being as involved as they wanted to be in decisions around the person's care and 23% wanted to be more involved (this figure was higher among those whose relative died in hospital) (Office of National Statistics, 2016)
3C	The proportion of people and carers who use services who have found it easy to find information about services and/or support (ASCS, SACE)	In 2015, less than half of those who wanted to talk about their feelings about their relative's illness or death with a health, social care or bereavement service got to do so (Office of National Statistics, 2016). One barrier may be knowledge of services: among respondents to the UK Commission on Bereavement who faced barriers in accessing bereavement support, 37% reported not knowing what support was available or how to access it (UKCB, 2022). Barriers among those bereaved during the pandemic included a lack of information about how to get support, feeling too uncomfortable or upset to seek formal support (Harrop et al 2021)
Objective 5: Social connections		
5A	The proportion of people who use services and carers, who reported that they had as much social contact as they would like (ASCS)	See Public Health Outcomes Framework outcomes B18 and B19

Conclusion

This guidance has set out how bereavement contributes to relevant health and care outcomes frameworks. For suggestions of what needs to be in place to mitigate these risks, and how to set out a vision for bereavement support in a local area, visit our wider resources at <https://nationalbereavementalliance.org.uk/ourpublications/commissioning/>

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The National Bereavement Alliance is hosted by the National Children's Bureau, registered charity no 258825.

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This work has been funded through the VCSE Health and Wellbeing Alliance, jointly managed and funded by Department of Health and Social Care, NHS England and UK Health Security Agency. For more information, please visit: <https://www.england.nhs.uk/hwalliance/>