

What should good bereavement service support look like? Findings from pre-pandemic workshop discussions interpreted in the context of the Covid-19 pandemic

Hannah Scott, Stephanie Sivell, Mirella Longo, Kathy Seddon, Jim Fitzgibbon, Annmarie Nelson, Anthony Byrne, Emily Harrop

Lists of bereavement service impacts and features captured on flipcharts from workshop group discussions

1 Desired impacts of bereavement service support for services users: Living and coping with grief

Group One – Bereaved group	Group Two – Professional group	Group Three – Professional group
<p>Dealing with grief</p> <ul style="list-style-type: none"> • Minimise negative consequences of grief • Information and understanding of bereavement and coping process (that experiences are normal, will have good days and bad days) • Having time to think about the person and enjoy memories • Channelling/being able to deal with anger (that comes from negative care experiences, etc) <p>Coping</p> <ul style="list-style-type: none"> • Recognising that coping is multidimensional (not just supported by counselling, eg accessing social support) • Being able to face the future • Meditation – helps to give distance (this should be more widely offered) • Being able to ‘enjoy’ sorrow (guilt-free, pure grief) 	<p>Resilience and coping</p> <ul style="list-style-type: none"> • Impact on personal coping/living with the grief • Visits to GP/primary care related to bereavement (physical/emotional wellbeing) • Ability to address finances • Ability to remember/talk about deceased person without being overwhelmed • Emotional and self-resilience and ability to function • Incremental moves from hopelessness to optimism • Ability to return to work • Being bereaved with additional caring responsibilities <p>Identity/sense of self</p> <ul style="list-style-type: none"> • Impact on/re-emergence of sense of self-identity (short and longer term) • Self-directed recognition of wanting to end sessions (not pathologising/medicalising grief) • Identifying and validating the positive consequences of loss 	<p>Psychological – understanding normality of grieving process</p> <ul style="list-style-type: none"> • Help with psychological wellbeing and capacity to bear • Coping with feelings of loss and grief • Discovering and strengthening resilience • Ability to self-manage and rely less on health services <p>Psychological – processing feelings</p> <ul style="list-style-type: none"> • Reduce anxiety • Reduce panic • Improve sleep quality • Understanding difference between depression and grief <p>Cognitive</p> <ul style="list-style-type: none"> • Making sense of experience • Understanding normality of grief and the consequences for others • Understanding others’ behaviours and actions • Identifying maladaptive thoughts and behaviours <p>Spiritual and belief systems</p> <ul style="list-style-type: none"> • Making sense of loss • Impact on personal identity (cultural and religious)

2 Desired impacts of bereavement service support for services users: Social support, interaction and adjustment

Group One	Group Two	Group Three
<p>Peer support</p> <ul style="list-style-type: none"> • Being listened to about all the little things (experiencing warmth, empathy, understanding) • Value of online, round-the-clock support (people to listen and talk to) • Need support of those with shared experiences and understanding (expectations of friends and family can be difficult to manage – just 'getting over it' is not always that simple) 	<p>Interactions</p> <ul style="list-style-type: none"> • Impact on social isolation (how it is managed) • Return to normal functioning in the external world for the bereaved person • Relationships with others and with their community • Did it help? Continuum of useful to useless • Managing how others treat them • Improved wellbeing (however or whatever that may be) 	<p>Social – individual</p> <ul style="list-style-type: none"> • Adapting to change, eg 'post carer' role • Normality (expected, common) • Healthy coping and lifestyle strategies <p>Social – family/wider society</p> <ul style="list-style-type: none"> • Help with connectedness and feeling less isolated • Ability to function in life roles and responsibilities • Relationships and communication • Managing conflict and misunderstanding (of different ways of dealing with grief) • Ability to deal with social and financial insecurities and circumstantial factors

Features of service quality and effective delivery

Group One	Group Two	Group Three
<p><i>Service level approaches to offering and giving help</i></p> <ul style="list-style-type: none"> • Allocated support for carer as well as patient (during end of life period) • Having formal offers of support at later stages (eg 6 months down the line – but not a case of a fixed time, need for the option of access at different times) • Recognising both emotional and practical difficulties/need for help • Publicity of services to raise awareness of what help is available • Provide insight/support for other family members so that they better understand what the bereaved person is going through. • Help with practicalities such as how to manage their possessions 	<p><i>Service provision</i></p> <ul style="list-style-type: none"> • Equity of service provision across all groups • Response to individual differences • What do participants want to get out of a BSS? 	<p><i>Organisational culture</i></p> <ul style="list-style-type: none"> • Transport links/accessibility • Information, signposting, navigation to/about service • Range of support with integration (with 'self' or 'others') – accessible when needed and in accessible formats • Staff, development, training and support • Recognition of and sensitivity to difference • Culture of integrity (including evidence-based knowledge) and commitment to Bereavement Care (BC) Standards • Clarity of scope <p><i>Accessibility</i></p> <ul style="list-style-type: none"> • Location • Timing • Formats (information – about service, about grief, about other services) <p><i>Integration</i></p> <ul style="list-style-type: none"> • Signposting • Collaboration and partnership