

All At Sea: Experiencing Ambiguous Loss

Mini-Report with Key Findings

Ambiguous Loss UK

Foreword

Ambiguous loss is a type of living loss that most people will experience during their lifetime, however very little is understood about the effects of the grief endured. This includes emotional, physical and behavioural responses and other impacts on the ability to live well despite the loss.

There is a substantial gap in comprehending the scale of non-death losses and a lack of acknowledgement of the effect on individuals in our wider society. Our mini-report with key findings, "All At Sea: Experiencing Ambiguous Loss", aims to highlight these issues and develop a further understanding.

Many thanks to all the participants who so kindly completed the survey and shared their personal experiences of ambiguous loss.

The full report from the comprehensive survey is being compiled after further analysis. Contact www.ambiguousloss.uk for more details.

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"It's like navigating through fog without a clear path. There are feelings of hope and then grief and anxiety all while trying to cope with the unknown. It's turned my world upside down."

Background

The Ambiguous Loss Survey conducted by Ambiguous Loss UK, was launched on 2nd December 2023, during National Grief Awareness Week in the UK. During the six months it was collecting anonymous data, 183 individuals who were experiencing or had experienced ambiguous loss within the last three years completed the online form which closed at the end of June 2024.

The survey consisted of 10 questions, with nine of them compulsory - the last question on further comments was optional. The ambiguous losses could relate to a personal loss (eg. of their own health) or the loss of someone/something else (eg. family member with dementia). Participants were supplied with the following ambiguous loss definition by Darcy L. Harris -

“A loss that can be defined as an experience where there is a change in circumstances, perception, or experience where it would be impossible to return to the way things were before.”

The findings will not necessarily be representative of all ambiguous loss experiences, as the survey was self-selecting and only available online. This means that we cannot assume that the results will be generalisable to everyone with an ambiguous loss. However, the scale of participants brings confidence that the key findings are relevant across a varied population of people experiencing ambiguous loss worldwide.

Aims

Identifying experiences of ambiguous loss will help inform support services worldwide, with an aim to improve wellbeing and bring awareness to this type of non-finite living loss. The findings also hope to bring validation from the combined experiences, to people with an ambiguous loss.

1. Identify the broad range of ambiguous losses experienced
2. Understand the emotional, physical and behavioural responses from grief associated with ambiguous loss
3. Define the types of grief experienced by ambiguous loss
4. Understand secondary losses as a result of ambiguous loss
5. Identify broader impacts of ambiguous loss on the ability to cope well.

Key findings

- **1/3** identified estrangement as their most significant and impactful ambiguous loss
- **Over half** described their grief as ‘traumatic distress’
- **43%** feel suicidal
- **3/4** experience sadness
- **83%** have fatigue
- **70%** socially withdraw
- **Half** feel they have lost their identity as a secondary loss
- **1/3** have little or no hope for the future
- **5%** felt acceptance of their situation
- **93%** appeared to have found discovering the term ‘ambiguous loss’ beneficial.



“It shattered my heart into millions of pieces that I am still trying to find.”

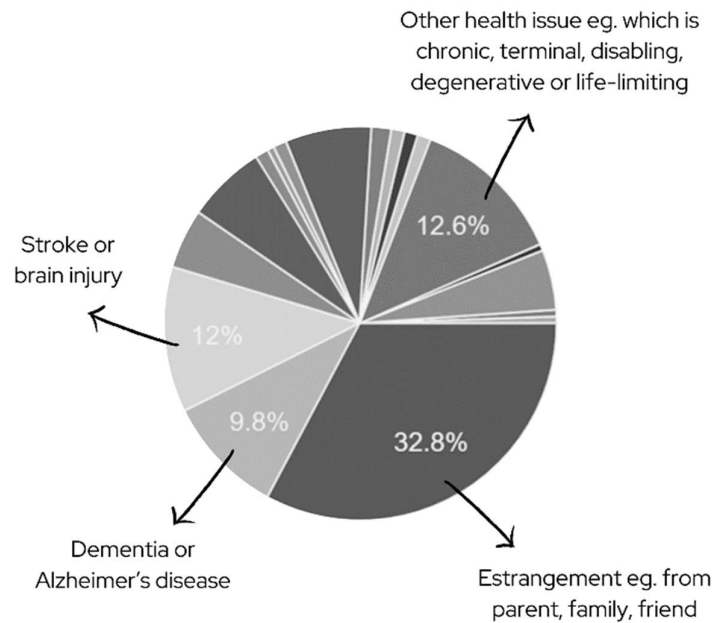
Types of ambiguous loss

The types of ambiguous losses are broad and complex. Ambiguous loss occurs when someone or something is physically absent but psychologically present; such as, with estrangement, adoption, missing people/pet, divorce or the climate crisis.

Or psychologically absent but physically present; for example, with dementia, brain injury, addiction or chronic illness.

Participants were asked to highlight their most significant and impactful ambiguous loss which had happened or been happening within the last three years.

The most chosen ambiguous losses in the survey are illustrated in the diagram, with estrangement being selected by 1/3 of participants (32.8%/60).



Describing ambiguous loss

We wanted to hear in participants own words, how they describe their most significant experience of ambiguous loss. The responses showed a variety of circumstances. Such as:

- *"My long-term partner developing chronic pain and health condition."*
- *"Due to my mother's addiction, I have no contact with any member of her side of my family. I haven't spoken to my mom in over 7 years, my brother in at least 6, and any other family member for at least that long. My children no longer have a grandmother. It breaks my heart."*
- *"The constant haunting of what is happening. I ache and miss my runaway missing transgender son and worry about his wellbeing, his comfort, whose loving him etc. He left at 16.... He'd be 21 now."*
- *"After my mom tried to kill herself after getting laid off and unable to gain further employment, she failed and became a ghost. Once so full of life and my best friend, I financially support someone who won't even talk to me."*
- *"My father was lost at sea in 1988, when I was 14. He was never found."*
- *"I feel like I'm going through a death although the person is alive, I fear he could take his own life and I dread that when I wake up in the morning, I will get the dreaded phone call that he's done it. My brother as attempted suicide 4 times and the last time he had to be revived."*
- *"The loss of my baby didn't matter to anyone. She wasn't old enough to count as a human, yet she had a heartbeat and I held her in my hands. Stillborn but still born."*
- *"Child with a stroke. Multifaceted emotions. Struggle constantly between happiness and sadness, hard to find contentment."*
- *"Loss of my adult son due to mental illness. I feel that the sweet child I once knew disappeared and there is a strange man I don't know in his place."*

Some participants mentioned fear of the future and possible further impact due to ambiguous loss:

- *"Uncertainty for the future and the heavy burden of becoming a single parent."*
- *"Painful, horrific and out of my depth, yet death is part of life's circle. Expecting the death each day is like living on a knives edge."*
- *"Overwhelming. I'm an only child and feel like I will not be able to survive when they have gone. It feels out of control watching them fade."*
- *"Sad for my dad's state of mind and panic about how it will affect him and others in the future."*
- *"It's a fear of them dying and how I will manage when they do. It's a deep sadness then so angry, it's by far the worst feeling."*
- *"It's in the fear of what could still be lost. What it means for my children and my children's children, all the generations to come."*

Loneliness and isolation were highlighted by participants:

- *"Isolating - people don't understand so you feel stuck with it on your own"*
- *"The loneliness and feelings of helplessness"*
- *"Lonely, acutely stressful, just so sad"*
- *"Others' disbelief, isolation, even in a crowd, loss of Me!"*
- *"The feeling of being abandoned, not accepted and all alone in the world"*
- *"Lonely and sad. Unable to see an end to the situation"*
- *"Continued sense of devastation, isolation and broken heart"*

Some participants mentioned the level of the sadness they feel:

- *"Sadness so overwhelming I feel like I cannot breathe and I don't want to live in this pain"*
- *"I am so sad most of the time"*
- *"Deep grief and sadness"*

Frozen, stuck and lost were often words used:

- *"Frozen in time and inability to carry on"*
- *"There is no return, no way out"*
- *"Cycling of Grief trying to accept the situation may never change, without being too hopeful that it could in the future."*
- *"Devastating, out of nowhere, who am I now and how do I move forward? Cheesy - but true"*
- *"I am lost now. I don't know what to do"*
- *"On a hamster wheel which is turning and turning and no way off"*
- *"Just feel lost empty heartbroken"*

It's clear to see from the responses the extent of the impact of ambiguous loss. The themes are very apparent, and consistent with a loss mixed with ambiguity and uncertainty.

"Overwhelming background sadness that takes away from my ability to live my life and thrive."

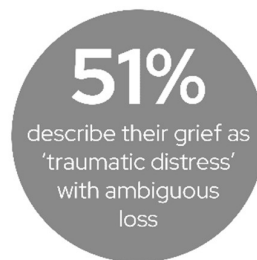


Experiences of grief

We were interested in how participants described their grief associated with ambiguous loss, so we offered some options and asked them to select all that they identified with. The results showed the highest number of participants (58%) described their grief as 'prolonged'. Over half of participants (51%) described their grief as 'traumatic distress' and 44% as 'ambiguous'.

The meanings of these words were left open to interpretation and we were keen not to pathologize grief which is a natural human reaction to a loss.

Prolonged	58%
Traumatic distress	51%
Stuck or frozen	50%
Ambiguous	44%
In limbo	43%
Minimalised or invalidated	38%
Debilitating	36%
In anticipation	22%
Repressed	18%
None of these	2%



"It is lonely, and frustrating, as I try to scream out to the world around me that this is an extended, anguishing grief."

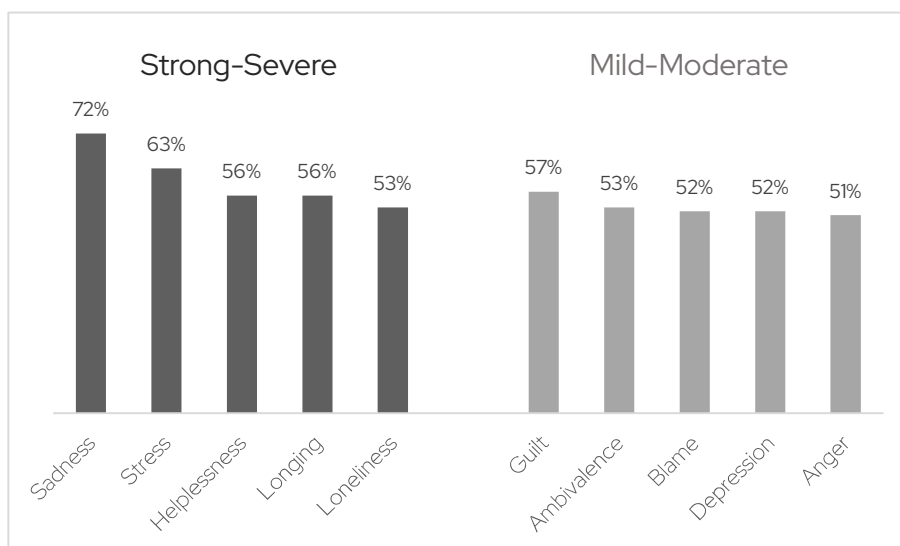
"Waves of overwhelming grief."

"I am still grateful to have found this term and its meaning. It helped me understand that I was actually grieving, and that I needed too. And so I could."

Emotional responses to ambiguous loss

"It is disorienting with a broad range of emotions - anger, resentment, deep deep sadness. I feel frozen and stuck in this liminal space. I try to find moments of joy and being present - and sometimes I am successful. But I am often overcome by intense sadness."

Emotional responses can vary depending on the type of ambiguous loss, so in asking the question we were aware we would get a wide range of experiences. We asked participants to rate their emotions in terms of intensity, with 'none' also as an option. 43% (79) of respondents said they felt suicidal (mild-severe) as a result of their ambiguous loss.



We discovered overall that the highest ranking emotional experiences felt (strong-severe) were sadness (72%), stress (63%), helplessness (56%), longing (56%) and loneliness (53%). 34% rated 'severe' for longing.

Whereas the lowest ranking emotional experiences (mild-moderate) were guilt (57%), ambivalence (53%), blame (52%), depression (52%) and anger (51%).

"Deep sadness, longing, daily hope of change and then despair. Rage. Angry with the world. Feeling ashamed of my feelings. No one understanding how I feel. Feeling very alone."

"Intense emotional pain and anxiety/dread. Not wanting to live but not wanting to die either. I don't want to live this way."

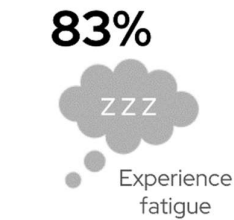
"Like having my safe space removed and all the oxygen in the universe suddenly appearing to never completely fill my mouth and lungs and the only thing I want to do is burrow down into the middle of the Earth and curl up in the dark silence so no-one will ever find me again."

43%

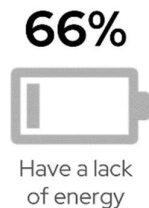
of people with an ambiguous loss feel suicidal

Physical responses to ambiguous loss

We asked participants to identify the physical symptoms of their ambiguous loss. 1,209 answers were recorded by 183 people. The most common were:



- 83% experience fatigue
- 72% are tearful and cry
- 66% have a lack of energy
- 64% experience insomnia
- 57% have muscle tension



"Difficulties in motivating myself to do things. Inertia in all aspects of my life due to a feeling of overwhelm caused by the pain of the experience. I find it hard to maintain contact with my friends who I don't see face to face because I don't have the energy or desire to write emails or have phone calls."

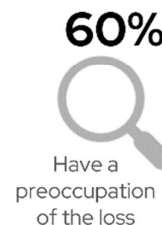
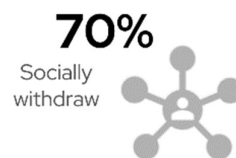
"Like my heart ripped out of my chest."

Behavioural responses to ambiguous loss

Participants were asked what their behavioural responses are or were to their ambiguous loss. 903 behavioural responses were recorded.

The most common were:

- 70% socially withdraw
- 64% experience changes to sleep
- 60% have a preoccupation of the loss
- 60% isolate themselves
- 50% avoid places or reminders of the loss



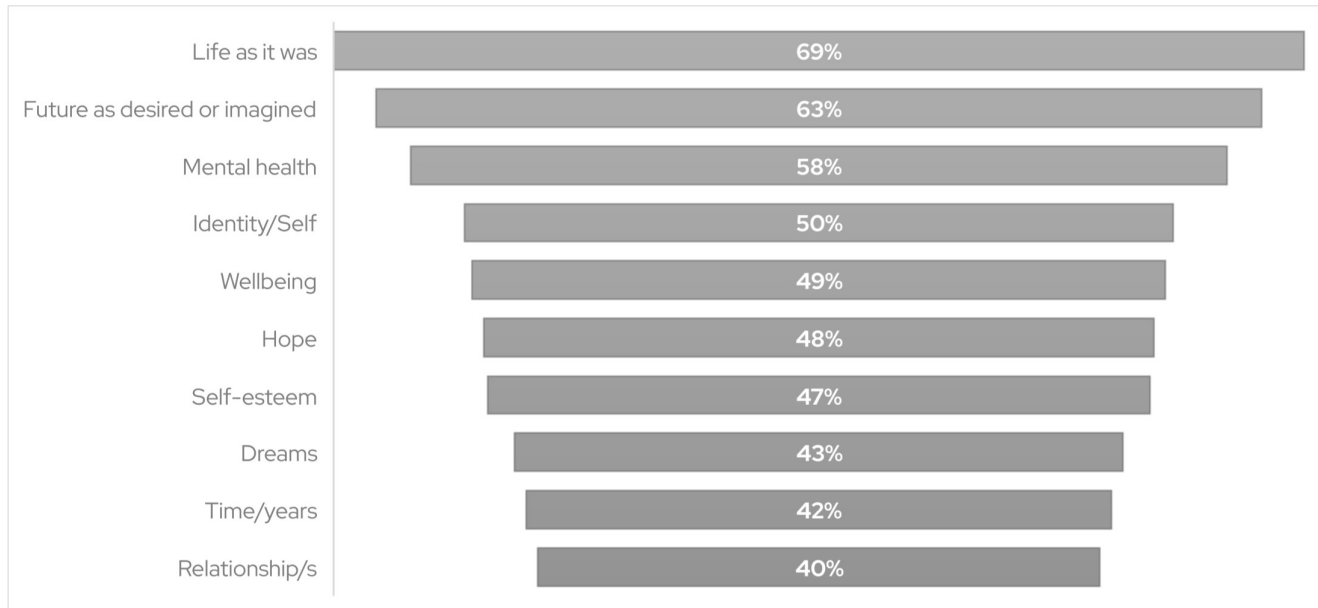
"Isolating. Feeling like the world continues around your grief but can't see it and therefore doesn't want to hear about it. Feels like there's a countdown on the compassion from others that runs out very quickly and once that's past, it's no longer OK to talk about the suffering and hurt without being considered an energy vampire, leaving one with no option but to keep it all in and paint on mask every day."

Secondary losses



Secondary losses are usual as a result of ambiguous loss, and we were keen to understand the effect they had on people's lives beyond their significant ambiguous loss.

Participants were asked to select types of loss that applied. The 183 participants made a total of 1,849 entries. The most common secondary losses were:



"Like being turned upside down and having to accept that this now is your normal."

Other impacts on life

Participants were asked 'How much of the following do you generally feel you have in your life?'. The highest scores were:

Resilience	A lot = 43%
Connection to others	Some = 47%
Control over your life	Some = 42%
Acceptance of your situation	Some = 42%
Hope for the future	Some = 49%

"Feeling like there's no point to anything - loss of meaning and control."

"Realizing that I had to accept, and grieve, the loss of a life I would never have."



Additionally:

- **Just over 1/4** (28%) said they had 'a lot-very much' connection with others
- **5%** felt they had 'very much' acceptance of their situation
- **Only 4%** said they had 'very much' hope for the future
- **15%** felt they had 'none-not much' resilience
- **1/3** (32%) felt they had control over their life ('a lot-very much')

"It feels like I've had to choose this (estrangement) - within my control - but ultimately the factors leading to it have been outside of my control."

Discovering the term 'ambiguous loss'

Participants were asked what their reaction was when they first heard the term 'ambiguous loss'.

- **39** participants used the word 'relief'
- **17** mentioned feeling understood or having a better understanding of their experience
- **6** people mentioned it gave them 'hope'
- **95** felt it made sense of their experience or they felt validation
- **11** said they were shocked or surprised
- **14** said they felt less alone.

Some of the responses were:

- *"It gave me a language to hang my confused feelings on."*
- *"It sums up the felt-state of limbo that was hard to put into words."*
- *"I felt like I had been thrown a lifeline. I finally felt like it could be possible to heal and not have to live in constant emotional pain. It gave me hope."*
- *"It feels good to be able to put a name to what I was feeling. It legitimized my feelings."*
- *"A light went on mentally. I was not going crazy after all!"*
- *"Relief. It was incredibly healing and validating to know that there was a name for how I was feeling. It helped me to understand that it was understandable that I felt the way I did. It was truly a turning point for me. I was able to drop the shame I felt and allowed me to express my deep sadness."*
- *"It describes everything I was feeling but couldn't express."*

Overall, finding the term appeared to bring benefit for **93%** of participants. For a small majority, it magnified their experience of ambiguous loss or didn't have much meaning. Comments included: *"Grief. Disbelief. Sadness. Emptiness. Sense of loss"*, *"Just another label - doesn't change anything."*

Some participants described how having the term resonated with their experience: *"That hits the nail on the head"*, *"It was like the last piece of the jigsaw!"*, *"Relief. A map of terrain which I could work out where I fitted into"*, *"It was like a lightbulb went on, I finally had a name for my experience. It was fairly empowering."*



Additional ambiguous losses

We were interested in understanding how extensive ambiguous loss was in people's lives so we asked participants to select any additional ambiguous losses they had experienced in the last three years (aside from their most significant one they highlighted for question one). There were 459 entries recorded by the 183 participants.

Of the top five most impactful ambiguous losses and additional ambiguous losses, estrangement still featured at the top. The table illustrates the difference and percentages:

MOST IMPACTFUL ambiguous loss	Percentage
1. Estrangement*	32.8%
2. Other health issue**	12.6%
3. Stroke or brain injury	12%
4. Dementia or Alzheimer's disease	9.8%
5. Baby or child loss***	7.1%

ADDITIONAL ambiguous losses	Percentage
1. Estrangement*	35.5%
2. Aging parents	31.1%
3. Menopause	28.4%
4. COVID-19 pandemic	26.2%
5. Other health issue**	20.2%

* Eg. from parent, family, friend

** Eg. which is chronic, terminal, disabling, degenerative or life-limiting

*** Eg. miscarriage, infertility, foster care/adoption, children leaving home

"Having to cope with menopause during this time made things ten times worse."

Further comments

There were many comments made in this optional question, including those supportive of the survey and acknowledging more needs to be done to raise awareness and ability to access support. Some included:

- *"There definitely needs to be more awareness around this. I have watched people sadly go through terrible tragedies in losing someone to death and somehow they seem to come out much better than I have. I don't minimise what they go through, but the outpouring of love, the gathering of people around to support, telling stories of their loved ones, the rituals and ceremonies etc are powerful in the healing process. I did not have any of this. In fact mostly it went completely unnoticed. Very sad. Thank you. I hope you can make a difference!!"*
- *"Grief support for those of us who are estranged from living people is much needed. Also discussion as to how this differs from 'standard' bereavement & how to cope with this loss."*
- *"Knowing the term Ambiguous Loss has given me some direction, I was I feel initially in 'Limbo'. Luckily I found the term fairly early on in my journey. I have shared it many times and seen the light bulb moment for others."*
- *"This was even beneficial to read for me!" [completing the survey]*

Conclusion

This mini-report highlights the need for further research around the topics of living and ambiguous loss. It's clear the extent the grief impacts people's lives and even in the completing of the survey, it was a helpful exercise for some people in feeling validated in their experience and a place to express how they feel.

Adding 'ambiguity' to loss creates a complex picture, observed in the results of the Ambiguous Loss Survey, and requires more investigation. Described by one participant: *"Compound complex stress and completely unsupported disenfranchised loss."*

A full report of 'All At Sea: Ambiguous Loss Experiences' will be available soon on www.ambiguousloss.uk

"Thank you for carrying out this survey. The worst thing about ambiguous loss is the silence around it. Having to grieve with no recognition or acknowledgment from friends/social circle/even relatives."