

*“Suicide can’t always be prevented, but it can  
be postponed”*

Lived experiences of providing care and  
support to people who suicide attempt, and  
those who have gone on to die by suicide

**A report prepared for the National Suicide Prevention Advisor and  
National Suicide Prevention taskforce**

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# Executive Summary

## Background and purpose

There is currently very limited information about the impact of suicide attempts on the wellbeing of those close to the person before, during or after the attempt. This involves family members, friends, work colleagues, those studying or playing sport together and a range of other relationships. Some may be involved in formal caring roles, while others may be more peripherally involved. All included in this report have been affected by the suicidal thoughts, behaviours and/or death of another. Many have sought to assist the person in accessing the support and provided care for the person to try to prevent their suicide. Not all survived. The impact on those around them is described as profound, and many also have struggled with their own suicidal thinking and behaviours prior to, or following, the support they were providing to another. There are stark differences for these two groups in how they understand suicide and their navigation of the support systems. For the purposes of this report, unless otherwise specified, all are collectively referred to as ‘carers’ to acknowledge that all were in some way caregiving to their person. This term is wholly inadequate to encapsulate this experience, yet we do not have another word as yet to describe the breadth of these caregiving relationships. There is a wide continuum of caregiving roles, some are intimate kinship relationships, while others are informal caring roles without deep emotional connections. The quote provided by participants throughout this report are provided verbatim, and depict these differing roles, and the activities undertaking to try and support the suicidal person; given freely yet at considerable personal cost.

This report is drawn from the analysis of two datasets; 1) University of New England, Lived Experience of Suicide Study (2019-2020) and 2) a collaborative project between the University of New England and SANE Australia – the Better Support project (2017-2020). Each dataset is analysed through the lens of seeking to understand the carer experience, as well as the ways in which the perceived reasons for attempting, impact of provision of care and engagement with the system (defined differently within each data set).

## Key findings and recommendations

The analysis of the data highlights that carers do not often define themselves as ‘carers.’ The provision of support is characterised by emotional support, practical assistance, personal care and surveillance-like attention (i.e. ‘suicide watch’) in what is commonly an extension of a pre-existing relationship. Analysis revealed that conversations about the action of caring is often absent, meaning that boundaries as to what a person’s role is not always clear. This can have an impact on decisions made when engaging with the health system where formal roles are required for information sharing.

Carers, who do not disclose a history of their own suicidality, note that the vicarious trauma of witnessing, or being intimately involved with another’s suicide, is impactful and that placing emphasis on their capacity to keep a person safe can lead to high levels of anxiety and sometimes a sense of failure. When engaging with health and social care support systems, carers reflected that follow up after suicide decreases, leaving them vulnerable and uncertain about how to keep a person safe. The intersection of practical up-skilling in suicide first aid, coupled with emotional support away from the person they care for is desperately needed.

For those who did disclose their own history of suicidality, their own suicide experience and the provision of care was at times enmeshed with the person at risk of suicide – merging of personal experiences with those being experienced by the other person. This overlapping of personal experiences, while assisting others, can resurface levels of grief and sadness about past experiences, and can trigger suicidal thinking in the carer. Yet, a carer’s own lived experience of ‘the system’ and their own views about suicide, could be more conducive to the provision of care as they too had ‘been there.’

**Recommendation 1:** The experience of carers of those who suicide attempt are a distinct sub-group of the broader carer population and as such require dedicated recognition in suicide prevention.

**Recommendation 2:** Carers require psycho-education tools, in addition to therapeutic support, that allows them to understand the trajectory of suicide and to support their own wellbeing.

**Recommendation 3:** Training for health professionals, particularly in the lead up to hospitalisation, during inpatient treatment and in discharge planning that includes carers in discussions regarding risk, is required.

**Recommendation 4:** Suicide prevention strategies should view the needs of carers as an extension of the experience of the person who has attempted suicide.

## Background

Suicide, defined as an intentional and self-inflicted death, remains a global public health issue with around 800,000 deaths per year worldwide (World Health Organization, 2019). In 2019 suicide rates in most developed countries were typically between 10 and 20 per 100,000 persons (World Health Organization, 2019). In 2019, 3318 deaths in Australia were recorded as suicide (Australian Bureau of Statistics, 2020). Data recording the number of suicide attempts annually is inaccurate and thought to be an under-representation due to reliance on medical records as a way of recording attempts while many occur in the community and go unreported. However, the World Health Organisation (2014) estimates that suicide attempts are likely to be at least twenty times the number of suicide deaths recorded. Those who have made a prior suicide attempt are at greatest risk of dying by suicide (McKenna & Harrison, 2012). While medical and non-government support services may provide support following a suicide attempt, the bulk of all caring is done by family members and friends (Grant, Ballard, & Olson-Madden, 2015).

There is currently very limited information regarding the impact of suicide attempts on the wellbeing of those providing care before, during or after the attempt (hereafter referred to as ‘carers’). Previous studies have suggested that carers of persons who have attempted suicide experience increased levels of both objective and subjective burden (Castelli Dransart, 2017; McLaughlin, McGowan, Kernohan, & O’Neill, 2016; McLaughlin, McGowan, O’Neill, & Kernohan, 2014). The few studies available suggest that providing care has a profoundly negative impact on the carers own physical and psychological health and they may experience adverse health, financial and functional outcomes collectively described as ‘caregiver burden’ (Chessick et al., 2007; McLaughlin et al., 2016; McLaughlin et al., 2014). Yet this objective burden reflects primarily on observable impacts on the carer such as financial strain, household disruption, increased physical responsibilities, and impaired interpersonal relationships within the family and social network rather than understanding how better responding to the needs of people who provide care, could impact both the support person and the person needing care.

Subjective burden refers to emotional stress from the caregiving experience such as painful feelings of shame, stigma, grief, worry and resentment (Chessick et al., 2007; Hoenig &

Hamilton, 1967). There is little focus on the benefits and honour of providing support, and the way that care is often the extension of what may already be an established and respectful relationship.

Stigma is also a common theme across the studies, regardless of the country or culture in which the research is based (Buus, Caspersen, Hansen, Stenager, & Fleischer, 2014). In an Irish study of 18 families, McLaughlin et al (2014) found that all participants reported adverse effects on their physical and emotional health due to the increased stress and hyper-vigilance required to manage suicide risk within the family. Caregivers also reported heightened feelings of helplessness and guilt, believing that they were not doing enough as carers or had exacerbated their loved one's condition. Another strong determinant of caregiver burden relates to the competing pressures from other daily life issues that stifle their capacity to focus solely on the suicidal family member. These include work and social commitments as well as the health issues of significant others (Owens et al., 2011). Importantly those who have current concern about the safety of someone at risk of suicide are themselves at higher risk of suicide (Maple, Sanford, Pirkis, Reavley, & Nicholas, 2019).

Several factors moderate the effect of suicide attempts in the family on caregiver burden including the family member's relationship to the person they provide support to (Prabhu, Molinari, Bowers, & Lomax, 2010). Chessick et al. (2007) found that parents reported a greater level of role dysfunction burden than those who were caring for a spouse. However, this is in contrast to a Norwegian study that revealed no significant difference between spouses, parents and adult children in their level of concern that their loved one may attempt suicide (Buus et al., 2014). Though some carers are entrenched in social networks, many of their peers may lack the confidence to advise the carer about their concerns, particularly if they do not have sufficient knowledge or qualifications (Owens et al., 2011).

Several shortcomings of mental health services and staff in their attention to the needs of suicide-affected caregivers have also been reported. Common complaints include inadequate knowledge, education and communication with healthcare providers to prepare them for recognising signs of a suicidal crisis and properly care for a family member following a suicidal attempt (Cerel, Currier, & Conwell, 2006; Grant, Ballard, & Olson-Madden, 2015; Kjellin & Östman, 2005; McLaughlin et al., 2016). There are further reports that healthcare staff do not take the concerns of suicide-affected family members seriously with one study reporting almost a third of family members felt stigmatised by staff (Cerel et al., 2006).



Mental health nurses are perceived as frontline workers in suicide prevention since they are directly tasked with identifying warning signs of suicide and assessing the patient's suicide risk (Sun, Long, Boore, & Tsao, 2006). Although they are encouraged to develop a close relationship with the person they provide support to, it is also necessary for mental health nurses to build rapport with carers and family members to assist with the emotional burden of caregiving (Hagen, Hjelmeland, & Knizek, 2017).

Despite reports of caregiver burden, the evidence suggests that when family members are actively involved in the recovery of their loved one following a suicide attempt, they can be a protective factor in preventing repeated suicide attempts (Grant et al., 2015; Morgan et al., 2013). A current study exploring the experiences of care following suicidal crisis, with an emphasis on the time post-discharge, identifies the care interventions in this period have the potential to significantly decrease risk (Rosebrook and colleagues, 2020). It is therefore important to identify potential points of intervention, not only to benefit the health and wellbeing of caregivers, but also improve the experience of care provided.

For those exposed to suicide death, after providing care in the lead up to an attempt, or when suicide attempting is a repetitive risk for a person, the impact on the support person can be profound. Erlangson et al (2017) notes that partners of people who die by suicide have poorer physical and social health outcomes, as do parents (Bolton et al 2013). In addition to health outcomes there are also impacts associated with how the death is viewed, or acknowledged by the broader community, that have demonstrated how people exposed to suicide death can feel high levels of guilt, shame and trauma (Feigelman et al., 2009) and risk of suicide (Maple, Cerel, Sanford, Pearce, & Jordan, 2017; Pitman, Osborn, King, & Erlangsen, 2014). A recent study by Azorina and colleagues (2019) also noted that in comparison to bereavement support following sudden death, those bereaved by suicide may receive less support, and that decreased support can also raise concerns about suicide risk for those left behind. Less than five percent of all postvention research has focused on interventions specifically for those bereaved by suicide (Maple et al., 2018).

To better understand the experiences of those providing care to someone who has attempted suicide and for those who are bereaved by suicide, this report highlights the experiences of those family and friends who have provided or are providing care and those who are bereaved by the loss of someone to suicide. To do this, two existing datasets have been reanalysed with the following questions guiding analysis:

1. What do those affected by suicide understand to be the reasons for the person's distress and behaviours?
2. Do these reasons and situations align with findings directly from those who have been suicidal themselves? And,
3. How do those affected by suicide experience health and support systems they have interacted with in their role as carer?

The two data sets used to answer these questions are the 'Lived Experience of Suicide Study' (UNE, 2019-2020) and the Better Support project (2017-2020) which was undertaken collaboratively between SANE Australia and the University of New England.

# Report One: Lived Experiences of Suicide – The lens of carers and bereaved by suicide

## Background

In June 2020, Maple and colleagues provided a report ‘*They can only talk themselves out of it if they’re talking*’ to the National Suicide Prevention Advisor which detailed public, private and empowered voices of lived experience of suicide from the point of view of the person who had attempted suicide or thought about ending their life. The public voices component of this report utilised data drawn from an online survey (UNE HREC Approval HE19-242) which was open to Australian adults (18 years and over) from December 2019 until October 2020. This survey not only asked people about their own suicide attempt history, but also included experiences of carers and those bereaved by suicide (and commonly a mix of these experiences). In addition to exploring how participants defined lived experience of suicide, the survey further asked participants to consider why suicide happens from their perspective and the experiences they have had with health and support systems.

## Methods

For the purposes of the current report, all participants of the survey until the end of October 2020 were included. These the 1856 responses to the survey were filtered to include only those who reported exposure to another’s suicide attempt and/or were bereaved by suicide. This also includes those who have also made suicide attempts or thought about ending their lives who have had exposures to suicide of others. This resulted in a sample of 728. Data were extracted from Qualtrics into Excel. Two members of the research team independently coded the responses in relation to the research questions focussing on reasons for attempt, impact of provision of care and engagement with support services. The third question sought to understand what the experience was of connecting to individuals and organisations external to the person they were supporting. The data relating to each question were then thematically analysed. Verbatim quotes are used to illustrate the analysis. These have not been corrected for spelling errors or grammar, however any unsafe language or identifying

information has been redacted and is evident via square parentheses. Descriptive analysis of demographics and suicide experiences was conducted based on questionnaire responses, with the free text responses used to identify caring and suicide experiences, specifically, if a person had cared for a person who had made a suicide attempt or died by suicide, were bereaved by suicide or in another sort of caring role (e.g. workplace contact, support of friends or colleagues); and type of direct suicidality experience (thoughts of taking own life, suicide attempt).

## Results

### Participant Characteristics

A total of 728 participants identified as a carer or described caring for a person who had made a suicide attempt or who had died by suicide. The vast majority (99%) of these participants had been born in Australia and females comprised over four-fifths (87%) of respondents. Over half (58%) of the sample were 45-64 years of age. Most participants reported multiple exposures; over half of the sample (53%) were carers, nearly three-quarters (72%) of the sample reported bereavement by suicide; a minority (7%) described carer roles that were associated with workplace or community exposure. Own suicidal thinking was also common (54%), and 28% reported making a prior suicide attempt. Further demographic information is presented in Table 1.

	Carers (no suicidal thinking/behaviours) (n=299)	Carers with suicidal thinking/behaviour (n=433)	Total (n= 728)
<b>Country of birth</b>			
Australia	291 (99%)	426 (98%)	717 (99%)
Not Australia	4 (1%)	7 (2%)	11 (1%)
<b>Gender</b>			
Male	29 (10%)	54 (13%)	83 (11%)
Female	262 (89%)	370 (85%)	632 (87%)
Non-binary	2 (1%)	8 (2%)	10 (1%)
Not stated	2 (1%)	1 (0.2%)	2 (0.3%)
<b>Age group</b>			
18-24 years	8 (3%)	45 (10%)	53 (7%)
25-34 years	21 (7%)	33 (8%)	54 (7%)
35-44 years	51 (17%)	82 (19%)	133 (18%)
45-54 years	94 (31%)	142 (33%)	236 (32%)
55-64 years	89 (30%)	102 (24%)	191 (26%)
65-74 years	28 (9%)	26 (6%)	54 (7%)
75-84 years	3 (1%)	3 (1%)	6 (1%)
85+ years	1 (0.3%)	0 (0%)	1 (0.1%)
<b>Carer experiences</b>			
Have cared for someone who attempted suicide or who died by suicide	125 (42%)	264 (61%)	389 (53%)
Bereaved by suicide (family member, close friend)	216 (73%)	310 (72%)	526 (72%)
Other caring role (e.g. workplace, community, friend)	24 (8%)	23 (5%)	47 (7%)
<b>Direct experience of suicidal thoughts</b>			
<i>Have thought about taking my own life</i>	0 (0%)	430 (99%)	430 (60%)
<i>Have attempted suicide</i>	--	392 (91%)	392 (54%)
		203 (47%)	203 (28%)

Table 1: Demographics and suicide experiences and exposure

### Participants understanding of the reasons for suicide thoughts, attempts and deaths

To answer the first question, participants explanations as to the reasons why the person they knew had attempted to, or had, ended their life were analysed. Not surprisingly, many participants had multiple experiences that spanned the continuum of a one of suicide attempt through to knowing or caring for someone who has made multiple suicide attempts or lives with chronic suicidal ideation. While many were able to articulate reasons, some stated that they had no understanding of why a person had attempted suicide. Not being able to

determine a reason for the suicidal behaviour resulted in significant challenges for the participants, which has previously been reported as particularly challenging among a sample of parents (Maple et al., 2007) in relation to the importance of meaning making and the resultant unanswered questions and inability to accept the finality of that loss.

#### Reasons for suicide

Participants described complex lifelong health issues, as well as emergence of complex mental health conditions that they believed contributed to a person's attempting, or death by suicide;

*My father in law suffered with depression and anxiety for many years and spent some time in a clinic for help. He would mess around with medications and would experience all the side effects associated with said medications to the point where doctors had to keep changing them. He did not sleep very well. He would not socialise very often even with family and would miss many events due to his illness. (Female, aged 45-54)*

Some circumstances related to co-morbidities with addiction to medication and other drugs, often described as being a way to self-medicate to treat declining mental health;

*My middle son aged 18 at the time was under the Early Intervention Team for about a year, for depression, and had been taking medication. Prior to this he had been self-harming and self-medicating with street drugs which only became apparent to me when his school attendance and grades plummeted and I noticed he was self-harming (Female, aged 45-54)*

In addition to health issues, and co-morbidities eating disorders were also provided as a reason for suicidal behaviours;

*My sister suicides at the age of 36 after battling anorexia and Bulimia since the age of 15 (Female, aged 35-44)*

Other narratives spoke of an overwhelming list of conditions that exacerbated a person's capacity to live a meaningful life. Childhood trauma and intergenerational trauma were often described;

*Mental illness is the main reason I have known for the people I've known to end their lives. Some have struggled openly and reached out for help over a number of years but a few struggled silently. A couple had been abused as children and subsequently used drugs and alcohol. A few went completely off the rails and were delusional and a danger to others. Sadly I sometimes think there are just some people that aren't compatible with living a happy life (Female, aged 45-54)*

Other traumatic events and losses were described as contributing to suicide;

*A friend suicided 11m ago, 3 months after his wife died. He was receiving professional help and had many friends supporting him (Male, aged 55-64)*

Situational stressors were also viewed as contributing to the background to suicide. Such stressors arose from many and varied situations, including accident or illness, or sudden shifts in people's lifestyles, including job loss, that may have contributed to the suicide attempt or death by suicide;

*I was psychologically overwhelmed due to workplace bullying and systemic failure of my workplace to acknowledge my distress or act supportive in anyway (Female, aged 25-34)*

Participants provided intra- and inter-personal and situational reasons they believed contributed to the suicide ideation, attempt or death of the person known to them. These reasons do not differ from those given by participants in the study who had thought about or attempted suicide – the reasons are generally long and complex, or short and sharp. They are simultaneously everyday stressors and those which are overwhelming. Certainly, there is similar evidence of the cumulative inability to take on additional stressors that appears to shift an individual into thinking about ending their life.

The complexity of the life events leading to the suicide resulted in a multitude of reactions for participants given their close proximity to the suicidal person. The impact on the carers was markedly different depending on whether they themselves had also experienced suicide thoughts or behaviours or not. The following presents the findings related to impact of the suicide on the carer. Each section is divided into two groupings of data: i) experiences of suicide and ii) experiences of support systems. These are explored below using participants

verbatim quotes to illustrate firstly the experiences of those without their own suicide history, and second, those with a personal experience of suicide as well as being a supporter of someone else experiencing suicide distress.

Participants experiences of exposure to suicide – those who did not report own suicidality

### *Experiences of suicide*

Due to the nature of caring for someone whose link to life is becoming precarious, participants described trauma associated with engaging in a carer role. The nature of the care, involving fluctuating ‘life and death’ situations left indelible marks on the participants psyche. Their responsibilities typically included having to manage emergency situations where they were under immense pressure in trying to keep the person alive, as well as challenges in accessing care for the suicidal individual with mental health professionals. The changing nature of the relationship as one takes on the role of ‘life saver’ was highlighted as trauma-inducing;

*My younger sister has attempted suicide countless times, in one particular experience both of my parents were out and I was responsible for calling emergency services and performing first aid. I am severely traumatised by this (Female, aged 18-24)*

For some participants, the carer role became a lifestyle rather than just a part of each day;

*Waking up every day felt like hell. I just wanted to disappear. The responsibility of looking after everything and everyone was overwhelming when once it was a breeze (Female, aged 35-44)*

The nature of the trauma from exposure to the graphic nature of the suicide also tended to inflict lasting memories for some participants and induce PTSD-related symptoms. Some of the descriptions also raise questions about the expectations of carers or family members in the aftermath of a suicide;



*then girlfriend slit her wrists whilst in a small toilet cubicle. Long story short, it was an absolute blood bath and extremely traumatic. I still have flashbacks (Female, 45-54)*

Participants described continuing to be haunted by the scene of the suicide;

*a friend [died by] suicide [redacted]. She could have stopped [redacted]. That she didn't haunts me; how much pain she must have had in her determination to end it (Female, aged 55-64)*

In situations where the person had died, commonly the participant described being involved in the scene of the death and managing the situation;

*I had to deal with inappropriate family members, police and visit the garage where he hung himself to finish cleaning out his belongings (Male, aged 55-64)*

The support participants provided was oftentimes focused on physically preventing suicide attempts from occurring which in turn increased a sense of responsibility in protecting their loved one's life. The analysis revealed that this was more pronounced if the carers had additional vulnerabilities such as being children or young adults at the time of offering care;

*my mother has been suicidal all thru this time too and I remember holding her back at a train station ... 'cause she was ready to jump in front of the train. I would have been no older than 14 at the time (Female, aged 35-44)*

Other vulnerabilities, subsequent to being exposed to these suicidal ideations or attempts, were also shared by people in regional and remote communities;

*It takes an emotional toll supporting people with thoughts of suicide. In rural communities, people also have increased access to lethal means such as guns which increases the risk and the emotional toll of providing support. Following bereavements, my dad has described to me suicidal*

*ideation and detailed plans about how he would end his life [method]  
(Female, aged 25-34)*

Experiences of compassion fatigue, or burnout were expressed, particularly as taking on a carer role was often an isolating experience, with limited support or recognition;

*I have cared for two people who died by suicide. I felt some regret that I did not do more and some frustration /surprise at the behaviour of others before and after the death. The lack of discussion and care from colleagues and workplace was not helpful (Female, aged 35-44)*

The carer role was also compared to a managerial position where the person had to make decisions and ‘coordinate’ how they would provide care for their loved ones.

*My sibling was receiving psychiatric help as well as taking multiple medications. Taking care of them for so long without sufficient support led to my own burnout and subsequent depression (Female, aged 18-24)*

For those participants who reported carer roles for friends reflected on the different boundaries between friends, as opposed to family members, and that this boundary ambiguity could contribute to feelings of helplessness or guilt;

*A good friend was trying to get me to visit for a couple of weeks, but I was going through some stuff myself and couldn't make it when she wanted me  
(Female, aged 45-54)*

Some participants spoke of the regret they felt post-death of not doing more to prevent the suicide;

*A close friend chose to end his life. I was a very close friend at the time, had just been minding his house while he was away. Something happened once he returned and then abruptly he ended his life. I took it really really hard and blamed myself big time. I have still not recovered and fundamentally still blame myself nearly 20 years later (Male, aged 45-54)*

The experience of providing care appeared to be somewhat different for people who were trained mental health professionals. For instance, some participants noted that they were nurses trained in counselling and psychology and they have frequently engaged with people who experience suicidal ideation or attempts. Despite their training, not all suicides could be prevented in their personal lives, and similarly, training in mental health may not prepare you for the grief experience following suicide loss;

*As a mental health professional, I had a lot of knowledge and tools to help others. I think it helped me too up to a point. I had to allow myself to be a non-professional and go through the grief process (Male, aged 25-34)*

Given the experiences of suicide that participants reported, they also provided information on how these experiences led to changes to their understanding of suicide and how they perceived suicidal thoughts, behaviours and deaths following on from their caring experiences;

*I understand why a suicide in a family can cause a cascade of other suicides...the shock, guilt, self-recriminations, shame and destruction of identity (Female, aged 65-74)*

Some participants disclosed details about the grief experience they endured following a suicide death and its lasting impact;

*Living through that intense period of family grief, and seeing the long-lasting impact of that loss in my family is I believe why I'm still alive today (Female, aged 25-34)*

There were mixed responses but among the common themes was an increased compassion regarding why people live with suicidal ideation or alternatively, more opposition to it;

*For myself, I have contemplated suicide, however since my brother did it, I couldn't put my mother thru the pain, so I pushed thru on a very difficult path of isolation (Female, aged 35-44)*

Participants also reflected on the consequences of the suicide loss, particularly for family relationships;

*Our family lives with the impacts of my brother's suicide daily. His death damaged many relationships in our family and this continues 20 years hence (Female, aged 45-54)*

Shifts in worldview were also reported, often linked to how the participant approached future relationships;

*It is an guilt driven grief for the person who has committed suicide. It plays on your mind often. It changes how you view life, how you view relationships and loved ones. It cause you to question many things in life, about yourself (Female, aged 45-54)*

The impact of suicide exposure can also instil a sense of fear in the carer or person exposed that they may suffer a similar fate or that they are also vulnerable to suicidal ideations;

*once it becomes an answer in your head, a way out...others start thinking it might be an answer too (Female, aged 35-44)*

Such exposure to suicide did open up the possibility of suicide for some;

*One of my best friends killed herself about three and a half years ago. Ever since then, I've also considered suicide as a possibility whereas before, I did not (Female, aged 25-34)*

The ripple effect of suicide exposure is well-documented, although the mechanisms to understand for whom exposure to suicide may result in suicidal thinking and behaviours are unknown at this time;

*Her brother also died of a result of suicide...Now a new generation begins with my son recently diagnosed with extreme anxiety and depression. I live in fear of history repeating itself (Female, aged 45-54)*

This must be considered in support services for carers who are vulnerable to social learning;

*I struggled with mental illness for several years and had a friendship with someone who was also ill and experienced suicidal thoughts. Because I was not trained in mental health and was unable to safely distance myself, I began experiencing suicidal thoughts too (Female, aged 18-24)*

#### *ii) Experiences of support systems*

Participants in this survey were not specifically asked about how or when they may have sought formal support services for the suicidal person they identified they knew or cared for. Nevertheless, many described interactions with healthcare services, and/or how they tried to engage such services for their person;

*it felt like I had to prove to others that I had a connection to her that had taken a part of me when she died (Female, aged 35-44)*

As the relationship between the participant and the suicidal person may not have been a formal caring arrangement, participants spoke of the difficulties in trying to access help and support;

*So much heartbreak. So much we didn't know about, so much the people charged with assisting him in his mental illness didn't know. Felt like apathy. Felt like the system let us down - we were powerless to act, even with knowing his intents (Female, aged 35-44)*

The limited communication with mental healthcare staff was a recurring theme, as was the sense of apathy or disengagement from the system. Carers may feel that they are not a

priority or that the needs of the patient and health professionals take precedent over their own needs to understand what is happening for the person to know how best to support them;

*As a parent of an adult child in stress, you have to take 2nd place, or even 3rd as the privacy acts prohibits the carers, and trained professionals of giving you anything other than general information. This actually creates so much angst, and worry for the parent - I considered ending my own life in the midst of our crisis because I could get no answers on whether my child was going to survive or not, initially (Female, aged 65-74)*

The way in which privacy legislation is interpreted and implemented in situations where a person is actively suicidal can inhibit care and accurate knowledge of the dangers of the situation. This is evident in the following illustration where a participant raised a complex scenario where mental health professionals had permitted a suicidal individual to cease medications if they wanted to, without discussing this important information with the carer;

*The service refused to share this information with me despite my concerns the week. Prior to his suicide. He died, they used the excuse that he had a right to suicide if he wanted to! Of course he didn't really want to. He needed to be medicated to function properly! (Female, aged 55-64)*

This case raises questions about the autonomy of the patient but also the rights of carers in helping make decisions about the best care plan and how best to support their person through their suicide journey which subsequently added to their distress;

*I look back and think just how wrong his treatment was medicated, brain zapped, psychiatrists. It all just added to his distress and caused more problems. They did nothing to help us, his family, know how to support him (Female, aged 55-64)*

Participants commonly reported that the type of care provided by formal healthcare systems tended to be heavily focused on medication rather than longer term psychotherapeutic interventions that individuals at high risk of suicide may require;

*Access to care was inadequate, access to prescription medication was over adequate. Multiple doctors hand the suicidal person a loaded gun in the form of amitriptyline etc. We are left heartbroken at the lack of treatment even when sought by our girl (Female, aged 18-24)*

Such experiences were not reported as occurring in isolated instances, with participants reporting accessing many services they found to be inadequate or ineffectual;

*Before killing himself...he went to a total of 30 doctors, all of them prescribed sleeping pills and talk therapy, which was no help (Female, aged 45-54)*

Where positive experiences with the system were reported, participants disclosed times when they had close involvement with their loved one's formal care and were able to be physically present;

*The best detail I can provide is recent first-hand experience. When I had to take a friend and local men's shed member down to a counsellor after his brother had suicided the night before. I was asked to sit in on the appointment and fortunately for me the counsellor did excellent work in dealing with my friends' issues (Male, aged 65-74)*

Participants experiences of exposure to suicide – those with their own suicide history

Those who had been living with their own suicidal challenges reported markedly different responses to exposure to another's suicide behaviours or death than those without prior

personal suicide history. These participants prefaced their own needs, more so than the needs of the person who attempted or died. This group accounted for more than 60% of responses –

which is also likely due to the nature of recruitment for this survey. In presenting the analysis of these data, it is important not to confuse these overlapping experiences with a hierarchy of exposure to suicide, but rather view this as a continuation of awareness between their own history, and the ways in which care has been a feature of the role of suicide in their lives. The descriptive nature of the survey responses allowed for a unique analysis of experiences, revealing those that may not have been commonly shared openly. The complexity of living with your own suicidality alongside providing support and care for others is evident in the responses.

#### *i) Experiences of suicide*

For those who also disclosed their own history of suicidality along with caring responsibilities had similar and different experiences of suicide. These participants provided a unique perspective by explaining their experiences of both living with suicide in their own lives and simultaneously supporting others, and this was described as a ‘lonely hell,’ featuring distress and trauma with limited capacity to speak openly about what had been occurring behind closed doors;

*A world so weird like you have entered a twilight zone, without the person you need to help you through it (Female, aged 55-64)*

Others spoke of the silent nature of attempting, making people feel emotionally exhausted, and often traumatised by prior and intergenerational traumas which were compounded by suicide events;

*It is fully entrenched in your life story ... it informs who you were, what you have become ... and the personal journey of life and letting go of things you had no control over as a child. My father didn't do it to me, he just did it... but that has taken a few years to get to (Female, aged 55-64)*



Consistently, throughout these participants narratives was the finality of loss that occurs due to suicide death;

*Learning to cope with the outcome. The grief, what if, how could I of helped...Bringing up a son whose father has suicided (Female, aged 45-54)*

Participants reflected on the way in which the broader community responded to their own needs, as well as them sharing their caring journey;

*As a crushing pain in the chest that ebbs and flows like a wave. Smothering you then retreating to lurk in your memories and then returning time and time again. Lived experience of suicide is a life sentence of loss (Female, aged 55-64)*

Explaining the loneliness and difficulties this type of loss incurs;

*People cannot understand the complexities of losing someone to suicide. The devastation and complex nature of grief is different to any other. I don't tell people about her death as I don't want to explain how she died. [redacted]. I don't want people to ask me how she died so that is shut down. Emotions repressed. (these are) my thoughts. (Female, aged 45-54)*

This participant further described these experiences as being alienating;

*The felling of worthlessness, not fitting in society, past trauma that still has impact throughout one's life with no acknowledgement of the wrong that was done to you, so the words you were told over and over become more real and you embrace the reality that you don't deserve to live a normal healthy life...whatever that is (Female, aged 45-54)*

In this analysis the participants revealed the potential ways in which those who have their own suicide history may have changed or shifted their perceptions of suicide from experiences of others suicidality. For some the inclusion had been normalised over time;

*My cousin killed himself when I was a child and that has followed me all my life. For a very long time I struggled to understand why he would take his own life, but after my own subsequent suicide attempts, I can understand and empathise with the pain he must have been in. As a queer transgender man from a poor socioeconomic background, and an unhealthy relationship with both of my parents, my life has been less than pleasant and there have been many occasions where it has felt like the only choice I had was to end my life. Part of this is due to social stigma surrounding my identity, and part of it is due to the pattern of volatile relationships and fear of abandonment that has been prevalent throughout my life. (Female, aged 45-54)*

A similar response was shared by a male participant noting that within the LGBTQI+ community exposure to suicide was common;

*Unfortunately due to my identity, and my close association with other people in the greater queer community, suicide is a fact of life, and most people I know have either attempted it, or repeatedly thought about it. Sometimes they have [died] (Male, aged 18-24)*

For other participants, suicide was seen through a more pragmatic lens;

*At the end of the day it is a choice... stay or don't stay. (Female 45-54)*

With perhaps the most poignant response from the oldest respondent to the survey. This male participant identified he had professional experience of caring for people at risk of suicide, both his wife and son had died by suicide, and that whilst he was not currently suicidal, he intended on following his wife's path;

*My original religion-based belief that life is sacred and must be preserved at all costs, only to be taken away by an unknown force, often in terrible and distressing circumstances, now makes no sense to me. I now see suicide, and especially assisted suicide, as an acceptable sociological tool, provided it is used within proper guidelines. That is the sting in the tail (Male, aged 85 or older)*

## *ii) Experiences of support systems*

Participants who shared their experiences of health systems often viewed these through the lens of their own experiences of suicide when they were supporting others. Intimate awareness of the system, long histories, and in some instances, generations where seeking support for concerns about suicide was a feature of their family life. Analysis of how participants managed their interactions with support services revealed four inter-related themes; the work required in the lead up to an event, responsiveness of the system to carer needs, inclusion of self in the system and carer responsibility during periods of crisis and beyond. All themes speak to the multifactorial nature of suicide.

### *Participants experiences of exposure to suicide – those bereaved by suicide*

From the total amount of survey respondents, 100 people identified that their lived experience of suicide was a result of being bereaved by suicide.

Reasons for the suicide consisted of participants own meaning making and could be assisted by the finality of the death and the subsequent investigation from Police and Coroners Court. The participants noted less ambiguity in their descriptions of the death, than those in the broader survey. Primarily responses relating to complex mental health conditions, with childhood, or situational trauma, also being explored in the stories;

*My step brother [died by] suicide in 2019. He was 34 with a wife and young family. He had been diagnosed as bi-polar but we had no idea, only his wife did. He had a history of suicide in his family as his own father had [died by] suicide when he was a baby so he had never known him but had always been fascinated with the details of his own fathers death (Female, 35-44)*

The survey responses relating specifically to bereavement, were overrepresented by individuals identifying as female, with only 10 responses from individuals identifying as

male, and one as non-binary. What was also noted was the impact of caring on individuals who had died by suicide, and the silent or invisible impact of that caring relationship prior to the person's death;

*My partner and soul mate lost his life to suicide. I was a big part of his family for 15 plus years in roles such as helping his parents with their farm and their medical appointments etc. Father in law now with dementia and several falls needing hospitalization still allowed home. My partner had to work full time, care for father twice a day and deal with mother's refusal to believe professional help was available. Lots of details not mentioned here but this particular morning my partner and I shared kisses, cuddles and I love you. I was at the supermarket picking up stuff for tomorrow's lunches when his mother phoned me. He had hung himself. I don't think I will ever "get over it" (Female, aged 45-54)*

And;

*My close friend lived with a physical disability. Her mental health suffered but she found it hard to access funding and resources for stable care with her disability and her mental health problems that stemmed from that. She always had to fight for everything she could get from the NDIS and govt welfare. She had a few close calls but usually called one of us day or night in that case. She [died by] suicide late last year (2019) and she never told anyone she was on a downward spiral this one time. It was devastating. Throughout her last few years carers and the quality of care administered was insufficient. She struggled to look after her daughter who had both physical and intellectual disabilities too. It was a very hard life she had due to no fault of her own (Female, aged 35-44)*

The impact of the suicide death referred to individual, familial and societal ripple effects of deaths that occurred recently and over some time. There was a focus on the perceived catalyst of the events that led to the death and the regret experienced by either the family being unable to intervene to 'save' the person, or regret based on the ways in which the health system was able to assist;

*On the 21/01/18, my nephew, died by suicide. He was 20 years old. My sister, his mother had experienced a severe mental health episode following the end of her marriage to his father. She was hospitalised. She has been absent emotionally since that time. Still is. He was her oldest child. We...don't know exactly what went wrong. I accept that we never will. The November before his death, I spent time with him and his mum over coffee. He was not okay. He was speaking really fast and dominating the conversation, interrupting. It wasn't like him. I live in another state. I called my other sister. She spoke to his mum's psychiatrist. He asked if he was still working, socialising and attending uni....the answer was yes to all of those questions. The psychiatrist assured us that all was okay. But to keep an eye on him. I returned home to Queensland. Other than normal stuff, as normal as stuff is when you're scared for your mentally ill sister's children, the next call I had about him was to tell me he was dead (Female, aged 55-64)*

In relation to carers interactions with health systems prior to the death, participants spoke of multiple engagements of trying to obtain the help needed to help support the person, which on occasions was obtained, and others not;

*She first attempted suicide at 15 years and made at least 6 attempts before succeeding. She had 18 hospital admissions during these 9 years and 3 rehab admissions. Sadly she became heavily addicted to legal and illegal drugs. We spent a fortune trying to get help for her but found help sadly lacking and treatments usually useless. The superiority attitude of most of the so called psychiatric professionals was most unhelpful. After she passed away we discovered she had been sexually abused as a child (she had left behind a journal) but no one was ever able to address this (Female, aged 65-74)*

The impacts of the bereavement also shaped the subsequent or cumulative losses experienced by people, that the death by suicide became part of the trauma history within families;

*Life is all about how you handle the bad stuff. Living though the suicide of a parent and the consequences of losing your home (due to the death of the primary earner in the home) was pretty tough. We were initially quite poor and had to live very differently to how we had lived before my father died.*

*But, if you have strong positive role model you can make it through  
(Female 55-64)*

Lead up work required by carers

Due to their own intimate knowledge of support services and systems from their own experiences, participants provided insight into how carers could develop their own expertise in developing ways to seek out support when a situation was becoming riskier;

*Perhaps emotional support. Practical information. Stories of other people's coping mechanisms. Identifying suicidal ideation and how to give "first aid" (Female, aged 65-74)*

Suggestions for improvements were also made. For example, the focus on inclusion of the peer workforce being akin to a 'living library' of expertise in speaking through the ways that risk can be managed so that the person at risk, and the carer are traumatised less. Others spoke of the need to focus on more than developing awareness of 'warning signs' but to attach strategies that allowed for responsivity to those warning signs – such as lists of ways to intervene safely, identifying that suicide was an imminent risk, and teaching people about the difference between thoughts of suicide and plans for suicide.

*I now know the warning signs regarding my own thinking which leads to suicidal thoughts...all of these things are in my view about my lived experience (Female, aged 55-64)*

The need to examine a person's whole being, rather than viewing them only as a person in suicidal crisis, was suggested as a way to better understand the person in their context beyond the current risk focused attention. This was promoted as a way to allow carers, and in turn the

health system, and first responders to consider what has occurred in a person's life rather than an emphasis on the level of risk of harm of death by suicide;

*Not sure you can prevent suicide, without preventing trauma (Female, aged 35-44)*

### Responsivity of the system to people's needs

One of the challenges highlighted by participants was the current focus on being asked to 'just talk' when reaching out for support. Such an approach requires an ability to adequately identify when difficulties are emerging – and yet this was seen as a significant difficulty as the situation was deteriorating. This is further compounded when also providing care with carers needing to find both the capacity to state they are not coping, as well as practically finding the time to reach out for support; making the intricacies of help-seeking even harder – particularly when not clear on what support was even needed;

*Perhaps emotional support. Practical information. Stories of other people's coping mechanisms. Identifying suicidal ideation and how to give "first aid". Spiritual counselling and self-help groups in the aftermath. (Female, aged 65-74 years)*

Carers also reported empathy for the challenges that being faced with suicide has on first responders;

*Please thank our police and paramedics for seeing this all too often (Female, aged 45-54 years)*

Participants reported that whilst allied health staff had some capacity to respond meaningfully to their needs, the impact of services and institutions like Police and Coroners Court had a very 'black and white' approach, that sought responses to questions, rather than questions about the impact of the attempt or the death;

*I found the police, Coroner's did little or no investigations they got dates I asked questions and their reply was it won't change anything or you don't know he may have cried wolf a number of times. The coroner's report was like they were just ticking boxes as if my son didn't matter (Female, aged 55-64 years)*

As noted throughout this report, there was also identification by carers that responsibility to provision of care, was often hampered by not knowing ‘*what happens next*’, carers with lived experience of suicidality noted that carer resources needed to expertly blend the practical pursuit of information and referral combined with emotional support.

#### Ensuring inclusion in the system

Many advocated for further inclusion of those with lived and living experiences of suicide, that is, contributions from those who are experts through experience. This should routinely be included in the development and assessment of care and support services. They spoke of the ways in which carers need to be invited to be part of policy and practice developments to inform future practice given their observations of how they see care delivered, and how they have been provided with care themselves;

*I think the role of consumers and carers with lived experience of suicide is a historically overlooked and under recognised essential component for effective suicide prevention. Lived experience of suicide can be greatly enhanced by listening to the voice, needs, and experiences of those with firsthand experience. I believe without this inclusion, understanding and suicide prevention is starkly incomplete. (Female, aged 35-44 years)*

There was a focus on the need for shared experiences to be encouraged as these provide the catalyst for help for people, who see how help can transform the lives of others;



*I believe that often when we can connect with someone who truly understands through shared experiences that can be a catalyst for helping.*

*It can be as simple as listening and understanding a person who is struggling and they could very well feel more heard from someone who has been there before (Female, aged 35-44 years)*

#### Carer responsibility during periods of crisis and beyond

While support systems were reported as places that should be providing care, for those who had their own experiences of suicide, it was their experiences that informed their sense of responsibility during and beyond periods of crisis. Participants noted the need to acknowledge early on that they cannot control the person at risk of suicide as a way of creating their own self-care practices;

*Lived experience is not just those who attempt suicide, it is those who are affected by it, the constant surveillance, the anger, the mistrust, the disappointment, the guilt, and the grief even when those who try, live (Female, aged 45-54 years)*

The impact of hypervigilance was commonly reported as being a key driver of fatigue, with a resignation that this was required;

*It is relaxing into a normal pattern that can be upended, by unexpected normal emotions of that attempted, taken by a carer to be more than it often is, to increase surveillance - nearly a suppression of a type of PTSD reawakened (Female, aged 45-54 years)*

The constant nature of the potentially changing nature of suicide risk clearly left a toll on carers. While they may appear to support services as though they are in control of the situation, this cannot be assumed;

*For me the one that attempted appears to be free of the burdens that once haunted him, replaced by the haunting of those who must remain ever*

*vigilant, the duck that seems tranquil on the surface of the water, whilst paddling furiously only when the tides turn (Female, aged 45-54)*

Several ways in which support could be better provided were suggested, primarily focussing on mental health literacy. This was both from the point of view of the community better understanding the suicide experience, but also how best to support the person while also considering suicide prevention more broadly;

*There is almost no information, written in plain English, to help people understand the signs, triggers, and the practical things they can do to help someone. The mental health organisations focus too much on literature reviews and reports rather than harnessing people in the community - parents especially - to help them reduce suicide in our community.  
(Female, aged 45-54 years)*

## Summary

### Carers who did not disclose own suicide behaviours

#### *Experiences of suicide*

- Carers identified boundary ambiguity in the care relationship. This is exacerbated by vicarious trauma of witnessing or hearing about an attempt, uncertainty with relationships and how these impact caring (such as friends who are commonly viewed as ‘less-close’ relationships) as well as the impact of geographical isolation for regional and remote communities.
- Caring can be experienced viscerally – concern of ‘what if this happens to me’ when witnessing living with attempting, obligation leading to a sense of failure if attempting continues and shifting notions about how a carer views suicide (taboo versus acceptance)

#### *Experiences of support systems*

- Limited follow up after the suicide risk decreases.
- Offers of care and support, for the carer, are inconsistent.
- The way in which the person at risk is treated, can expose the carer to secondary trauma in witnessing that treatment.
- Best practice, as perceived by the respondents, would be to connect practical and emotional support provision targeting only carers.
- Health professionals who go one to care for a loved one may not offer a dress rehearsal for better coping, but may enhance understanding of the system.

### Carers with own suicidality

#### *Experiences of suicide*

- When a person provides care, as well as having a history or living with their own suicidality, experiences can become blended. There may be limited delineation between the lived experience and the care experience.
- The needs of the person are symbiotic with the perceived needs of the person requiring or asking for care.

- Observing a person's suicide crisis, can be a reminder of the persons own history of suicidality which may feel like a 'living loss' – a sense of witnessing what has been lost and letting go of the life they perceived for themselves.
- Caring can exacerbate feelings of loneliness and social isolation.
- There can be the development of a trauma identity where the persons lived experience and their care experience can be the primary focus of their life.

*Experiences of support systems*

- As with the first analysis of care needs, there are limited spaces where the needs of carers are prioritised.
- Those who have their own history of suicidality may be more accepting of the inclusion of attempting in a person's life.

## Report two: Better Support – understanding the carer experience over time

### Background

The Better Support Research Project was conducted from 2017-2020 as a partnership between SANE Australia and the University of New England, with funding from Grenet Merin and Ian Potter Foundation. The focus of the project was to create an evidence base for the development of carer resources to support carers of someone who had attempted suicide. This was a three-phase project (Ethics approval number HE17-210) with individuals who self-identified as providing care for someone who had previously attempted suicide, but were not themselves currently at risk of suicide. Phase One (August 2017- December 2018) was an online survey of Australian carers of people who had attempted suicide (n=758). Phase Two (April – August 2018) was 32 semi-structured interviews with carers from Phase One to explore more deeply their caring roles, the impact of caring on their own mental health, how they interacted with others, and what additional supports may be required. Phase Three, was a follow up survey of Phase One participants who had provided their contact details which was completed in June 2020 (n=112). This information, along with input from carers involved in two Think Tanks was used by SANE Australia to develop the ‘You are not alone’ web resource exploring the pathway of practical and emotional support for carers of people who suicide attempt.

### Methods

Phase One and Phase Three quantitative data were analysed using SPSS to determine the experiences of carers over time (MM and NB). Phase Two qualitative data was analysed to mine the data to understand how carers understand suicide and their experiences of support systems. This was analysed by two authors (SW and AM). Discussions to reach consensus were undertaken facilitated by Miro, an online collaboration tool. The results were then grouped and written up to represent the lived experience of carer.

## Results

The results from the quantitative analysis are presented first, followed by the qualitative findings.

### Quantitative Findings – Phases One and Three

During Phase One, participants were asked to report the types of supports they accessed to assist them in providing care for a person who had attempted suicide. The most common (multiple responses permitted) support sought was emotional support (69%), assistance with accessing services (51%) and practical support (45%). In accessing these supports, participants were provided with a range of resources (multiple responses permitted), including: verbal information and advice (19%), referrals to other services (6.5%), brochures (5.5%) and online resources (3%). However, 49% of participants reported not being provided with resources when seeking assistance and support. Support services were accessed; however, the most common support was reported as being family/friends (29%), then health care workers primarily psychologist/counsellor (24%), general practitioner (12.7%), psychiatrist (6%) and social workers (3.8%). Helplines (6%) and online chatrooms (3%) were also used. Over one-quarter did not seek formal supports (29%).

The Phase Three survey also asked participants the time period between the suicide attempt and when they sought external support. Table 1 shows the time between the attempt and when carers commenced looking for help, and the types of support accessed at different timepoints.

		<b>How long after person made suicide attempt did you start looking for help?</b>			
		Immediately	Within 1 month	Within 6 months	More than 6 months after
Where/how did you find it?	Online	11 (23.4%)	8 (40%)	4 (25%)	3 (60%)
	Family member/friend	7 (14.9%)	6 (30%)	4 (25%)	0
	GP	11 (23.4%)	4 (20%)	6 (37.5%)	2 (40%)
	Organisation I knew of	16 (34%)	8 (40%)	4 (25%)	0
	Professional	18 (38.3%)	7 (35%)	5 (31.3%)	2 (40%)
	Other	5 (10.6%)	0	5 (31.3%)	0

Table 1: Time since attempt and type of support sought

The results from this table provide some useful insights into the ways in which need and source of information change over time. In the immediate aftermath of the suicide attempt, participants reported finding professional information from medical practitioners, organisations (they were already aware of) and professionals as being most important to them. However, over time this shifted to being predominantly online after six months (where 60% reported this was the source of their information).

Of those who received support, carers generally rated the support on the poor to mediocre end of the scale. Concerningly, just under 10% rating their care as excellent, as shown in Figure 1.

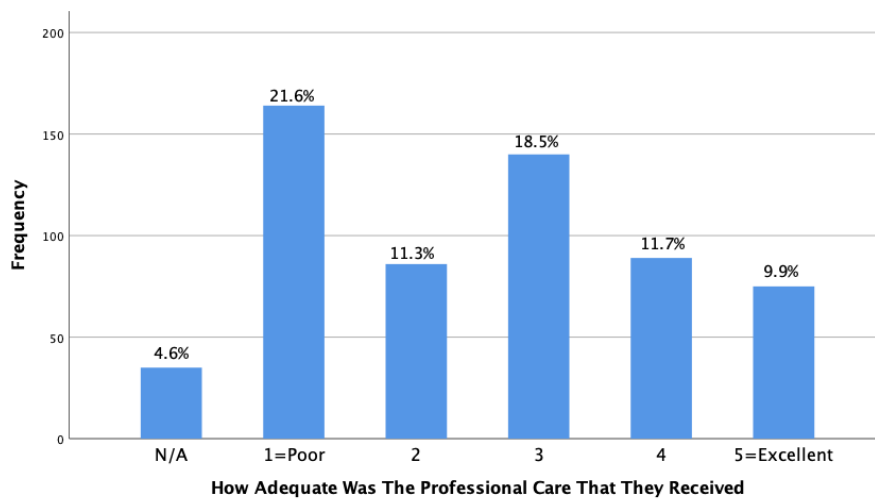


Figure 1: Adequacy of professional care

Carers who participated in this research predominately felt unsupported in their caregiving role as shown in Figure 2.

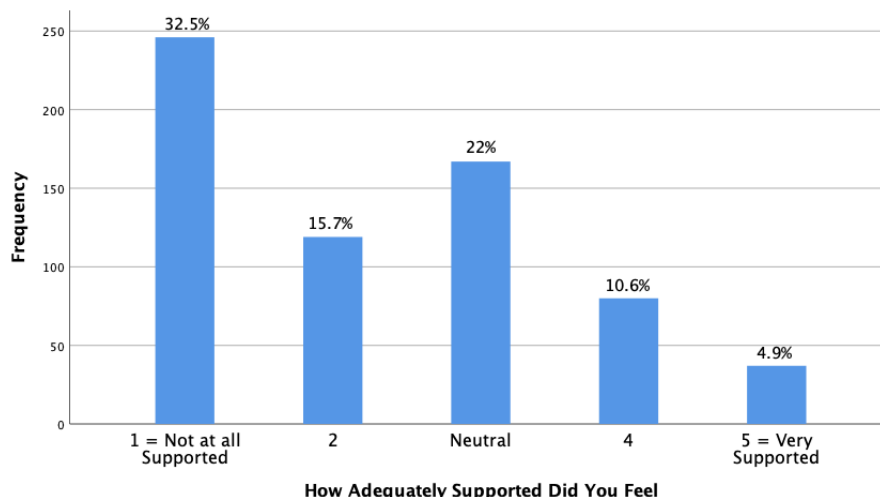


Figure 2: Adequacy of support

Next, we examined caring roles of participants at Phase Three (2 years after Phase One data collection). Table 2 shows the roles carers were providing during Phase Three including caring for the same person they had been caring for at Phase One (42.9%), no longer providing care as the person no longer needed their assistance (28.6%), for 13 carers the person had since died (11.6%) and two carers had taken on new caring roles. The ‘other’ group included responses such as the person died by suicide, providing lesser care for the person, the person is now independent, have lost contact with the person and no explanation.

Table 2 also shows the summary data of Phase One (T1) and Phase Three (T2) data on caregiver burden, psychological distress and suicidal ideation.

Phase Three: Caring Roles		Caregiver burden		Psychological distress		Suicidal ideation	
Are you:	n	T1 M (SD) n=43	T2 M (SD) n=46	T1 M (SD) n=44	T2 M (SD) n=46	T1 M (SD) n=44	T2 M (SD) n=46
Still providing care for the same person who had attempted suicide that you were providing care for in 2017	48 (42.9%)	50.14 (17.02) n=43	43.22 (16.52) n=46	23.77 (9.70) n=44	20.48 (7.25) n=46	5.55 (11.08) n=44	3.07 (6.89) n=46
No longer providing care as the person no longer needs assistance or the situation has changed	32 (28.6%)	43.46 (17.54) n=29	-	20.74 (9.45) n=31	18.81 (6.71) n=31	6.19 (8.84) n=31	4.29 (8.06) n=31



No longer providing care as the person died	13 (11.6%)	48.50 (18.36) n=4	-	21.25 (13.79) n=4	22.25 (9.97) n=12	10.75 (19.55) n=4	6.08 (8.95) n=12
Providing care to another person who has attempted suicide	2 (1.8%)	70.00 (-) n=1	39.00 (16.97) n=2	36.00 (-) n=1	26.50 (9.19) n=2	5.00 (-) n=1	0.00 (0.00) n=2
Other	14 (12.5%)	47.38 (18.17) n=8	-	20.63 (8.80) n=8	23.43 (10.57) n=14	8.63 (13.62) n=8	11.21 (9.61) n=14

Table 2: Carer roles and impact – Phase One to Phase Three

Results indicate that overall carer concerns do decrease over time in relation to caregiver burden, psychological distress and suicidal ideation. However, for those where the person they had cared for had died, psychological distress increased between Phase One and Phase Three. Overall, participants in this study are a moderately to highly distressed group. K10 results show less than one third reporting low psychological distress, illustrated in Figure 3 below. This is in contrast to the general Australia population, with ABS population level data (2015) indicating that in 2014-15, 11.7% Australians adults experienced high (8%) or very high levels (3.7%) of psychological distress; whereas 68% of adults experienced a low level of psychological distress.

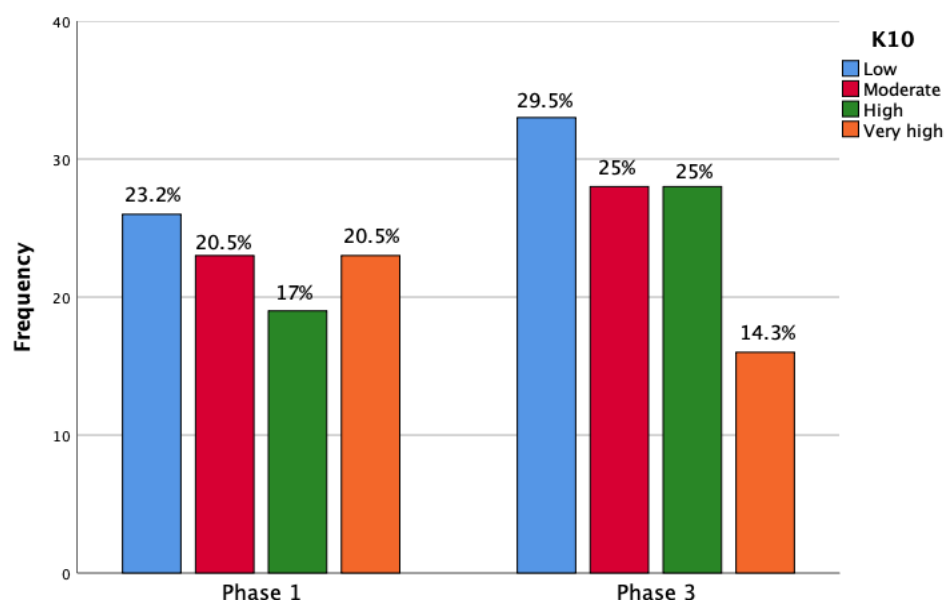


Figure 3: K10 results at Phase One and Phase Three

Given recent reports that those currently concerned about another person being at risk of suicide (Maple et al., 2019) also being more likely to be thinking about suicide themselves,

we performed a bivariate correlation between psychological distress, suicidal ideation and caregiver burden scores from Phase Three shown in Table 3 below.

Variables	1. Psych distress	2. Suicidal ideation	3. Caregiver burden
1. Psychological distress	-	<b>.63<sup>***</sup></b>	<b>.49<sup>***</sup></b>
2. Suicidal ideation		-	.27 <sup>ns</sup>
3. Caregiver burden			-

<sup>\*\*\*</sup> $p < .001$ ; <sup>ns</sup>not significant,  $n=48$

Table 3: Bivariate correlations between psychological distress, suicidal ideation and caregiver burden

These results suggested that psychological distress was significantly associated with high suicidal ideation and caregiver burden. However, there was no significant relationship between suicidal ideation and caregiver burden. Thus, carers are an important group to provide focused suicide prevention strategies and general support to help with decreasing their psychological distress.

#### Qualitative Findings (Phase Two)

The findings from the interviews with 32 participants are presented below through i) their perceptions of reasons for suicide attempt, ii) the impact of suicide attempts and deaths on carers and iii) the ways in which they experienced engagement with the system. The narratives revealed this was more than the health system, but the ways in which the community responded to people and welcomed or denied them the chance to seek support. Participant demographics are presented in Table 4 – with participant quotes corresponding to their interview number, to assist with identifying the type of care relationship.

Code	Male/Female/Non-binary	Rural/Regional/Metro	Relationship of person being supported	Deceased
15	Female	Regional	Kin - Husband	No
67	Female	Metro	Kin - Partner	Yes
70	Female	Regional	Kin - Child	Yes
92	Female	Regional	Kin - Husband	No
204	Female	Metro	Non-Kin	No
62	Female	Metro	Kin - Husband	No
2	Male	Regional	Non-Kin - Friend	No
89	Male	Rural	Non-Kin - Friend	Yes
107	Female	Regional	Kin - Parent	No
118	Female	Regional	Kin - Family	No

Code	Male/Female/ Non-binary	Rural/Regional/Metro	Relationship of person being supported	Deceased
128	Female	Regional	Kin - Partner	No
131	Female	Metro	Kin - Child	No
167	Male	Metro	Non-Kin - Friend	No
175	Male	Metro	Kin - Child	No
197	Male	Metro	Kin - Child	No
205	Female	Regional	Kin - Child	No
215	Male	Regional	Kin - Wife	No
236	Male	Regional	Kin - Family	Yes
240	Female	Regional	Kin - Child	No
10	Female	Metro	Kin - Child	Yes
29	Female	Metro	Kin - Other	No
78	Female	Metro	Kin - Child	No
96	Female	Regional	Kin - Child	Yes
100	Male	Metro	Kin - Child	No
125	Female	Rural	Non-Kin - Client	No
135	Female	Metro	Kin - Parent	No
150	Female	Metro	Kin - Child	No
154	Female	Regional	Kin - Sibling	Yes
201	Female	Metro	Kin - Parent	No
210	Male	Metro	Kin - Child	No
224	Female	Metro	Kin - Child	No
230	Female	Rural	Kin - Child	No

Table 4: Phase 2 participant demographics

*i) Understandings of reasons for attempt*

Given the purpose of Phase Two of the Better Support project differed from the purpose of this report, it is important to note that specific questions relating to why a person may have attempted were not explicitly asked. However, due to the narrative format of the interviews, the participants generally provided an overview of their relationship with the person they provide/d care for, what the suicide journey was, and what their understanding for the suicide was. A line by line analysis of the transcripts was undertaken identifying a number of perceived reasons as to why a person may have attempted.

Carers disclosed some of these reasons themselves, when describing the introduction to caring, or the impacts post attempt, whereas others were informed by the person specifically

or from a care team (either in hospital or from a community provider). The responses revealed a continuum of attempting with a central focus on a description of mental ill-health, despite international literature suggesting that mental illness is not always co-related to attempting. The reasons carers discussed as being related to suicide are presented in Figure 4 below.

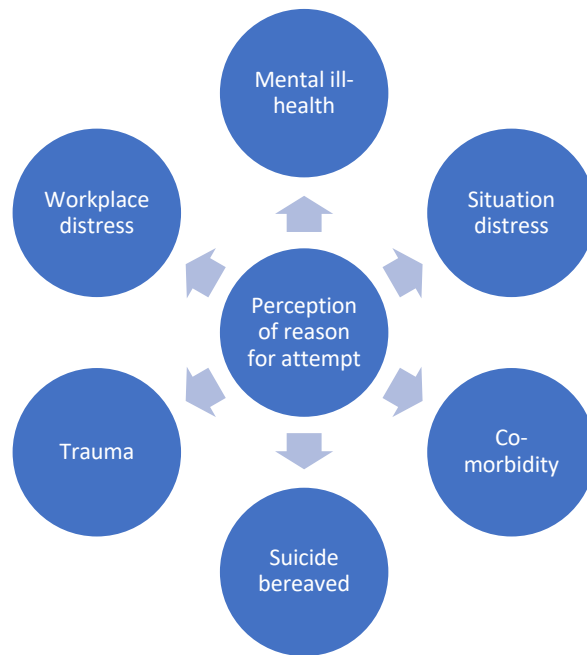


Figure 4: Carers perceived reasons for suicide

These reasons are explored below with quotes from participants used to illustrate their experiences.

The participant narratives spoke about mental ill-health or diagnosed mental illness being a central factor in the perceived reasons for the suicide attempt (or multiple attempts);

*His depression, fatigue and numerous physical and emotional side effects from medication were horrible and severely debilitating (62)*

Some narratives spoke of a significant lead up period prior to the attempt;

*Because he's had anxiety and mental health issues, I can track back quite a long way (100)*

For some carers, focusing on the diagnosis was seen as an overt explanation of why the attempt occurred;

*Look she's had three, four. She's had schizophrenic, schizoaffective disorder, bipolar and psychotic... you know treatment (197)*

Whereas other participants focused less on the label of mental illness and more on the external factors like medication, used to treat a diagnosis but also perceived as a contributing factor to the lead up to the attempt;

*his medication became ineffective and then he was put on a medication which was absolutely dreadful for him and it took a long time to convince the psychiatrist that it really wasn't a suitable medication for him ... I mean he suffered severe, severe depression and really unpleasant side effects and horrible dips over the last year (62)*

Prior traumas were also presented as a key reason as to why the suicide behaviours commenced, including child abuse, sexual abuse, witnessing a traumatic death, or knowing someone who had died by suicide for example;

*he was actually on the phone to my daughter and [killed] himself. (78)*

In addition to these descriptions of trauma, carers also noted disenfranchised examples of trauma – where there is minimal community understanding of the impacts. These referred to, for example, serving time in the defence force as well as workplace bullying and relationship breakdown;

*I got also involved in mediating between her and her ex-partner which was also the reason...part of the reason why she made the attempt because her relationship fell apart (204)*

Within these high-level descriptors participant narratives focussed on identifying how trauma shaped the person's capacity to stay safe and the role of living with long term trauma, and how it was related to suicide attempting;

*I knew he was pulling away but I didn't realise how serious it was. I knew he was struggling with something but I didn't know what and then I started to realise it could've been the PTSD and when he wouldn't answer, I would*

*send him a text message with an App for PTSD, trying to get him to work on something because he had told me he was struggling before he went to the WA. So and then he was like pulling away, like I couldn't contact him and he'd give me excuses and I'd try and say, 'Hey look you've got to ring me. I'm worried. Or I'm coming over to find you' or things like (70)*

Addictions were commonly mentioned in carers understanding of suicide. These were viewed (especially in combination with poor mental health) as exacerbating people's levels of distress, leading to an attempt. As with reflections on mental health impacts over time, some of the narratives noted longer lead times, or longer-term engagement with the mental health system;

*he wasn't able to maintain work and he wasn't able to maintain friendships. He couldn't cope with financial matters and would use cannabis and alcohol to self-medicate for what he said was anxiety and depression. He had also been through...well we'd both been through some grief with deaths in the family and the fact that I'd left him at the age of 19 to support other family members and he felt quite abandoned. He then had the grief of losing his mother (100)*

Specific workplaces were noted by participants that were seen as contributing to the suicide attempt, including first responders and Australian Defence force;

*He was experiencing some pretty awful things himself as a police officer and he was only young himself (78)*

Additional reflections about workplace focussed more on relationships with others, and the impact of poorly managed workplace bullying;

*Well it actually happened in his workplace. And it was through a lot of problems with staff under him and not getting the supports through management. (107)*

Seven of the 32 participants reflected both on their experience of caring for someone who had attempted suicide, and then the experience of being bereaved by suicide. Some of the additional aspects, that could be attributed to a stronger sense of certainty in relation to the

reasons for the attempt, may have been enhanced by Court systems, Coronial System inclusion, police investigations or written evidence relating to the death;

*Yeah because there was also then the breakdown of her marriage, grieving that she wasn't be able to see her son because of what she would've done to her son. She...you know in her eyes she wasn't [dying by] suicide; she wasn't trying to take her son away but she was wanting to be able to sleep for a long time. So yeah just her wording was like...yeah and believing that because her family...some of her family disowned her, so grieving for their love. Grieving...you know help me support her at the court case or anything like that yeah. (118)*

*ii) The impact of suicide on the carer*

What was evident from the participant narratives was the significant impact that the suicide behaviours had on the caregiver. This was apparent through intra- and inter-personal experienced. In this context, the definitions of both relate to a) intrapersonal taking place or existing in the mind, and b) interpersonal relating to relationships or communicating with people and the environment around them, an overview of which is presented in Table 5 and described below.

Primary Theme	Examples
Theme 1: Intrapersonal Impacts	
Mental health Impacts	Anxiety, Depression, Stress, PTSD, Trauma, Hypervigilant
Physical health impacts	Sleep, Pain, Physical Fitness
Emotional impacts	Despair, Loss, Failure, Anger, Shock, Fragility, Guarded, Toll, Distress
Theme 2: Interpersonal Impacts	
Financial Impacts	Loss of job/income, impacted lifestyle, relocation, changed dynamics
Relationship Impacts	Breakdown of normal structures, loss of friendships, altered relationship, social isolation

Table 5: Impact of suicide on carers

**Intrapersonal**

Participants discussed the ways in which the action of caring prompted internal reactions that were both transient and long lasting. What was interesting to note was the ways in which caring manifested itself in the wellbeing of the individual, not just as a fleeting experience,

but a reaction that had scope to shape the identity of the individual and how they coped long term. One of the greatest impacts for carers was on their own mental health, where participants noted feelings or diagnosable conditions;

*I don't know. What you'd have to say? I mean I've slowly gone mad you know, and depressed pretty much. You know I've slowly gone mad and depressed and all I do now is to sit on the internet and growl at mental health because you know...I've got to stop what they're doing you know, somehow. (197)*

For some participants the impacts felt like a trauma to themselves with some reactions akin to post traumatic stress disorder. These were noted in the narratives of people witnessing an attempted suicide or reflecting on the gravity of the situation;

*I think so and then...well, when [hurt himself, I was down in the bedroom and he came down and he came down to the hallway and he had [injuries]. So, I mean I spent six years on dialysis and I'm pretty much immune to blood but after seeing that, I can't stand like the colour red now... And then I'll go to make my grandson a bubble bath and then this red coloured bubble bath...I just freeze. I just...anything like that, because it just reminds me of blood and that...I mean one day I sneezed and I got a bloody nose when I was in the toilet and just the sight of the blood in toilet it brought it all back to me and... (150)*

As a result of exposure to suicide and caring for someone who had attempted suicide, some participants found they were then considering suicide as an option for themselves;

*I know one of the aftermaths of her...you know, thinking she would die because she was at grave risk of liver failure, was I just found myself in a very dark place and I found myself thinking, if she was going to die, I would have to too and I found that appalling because I had two other children you know. That I could actually contemplate that that's what I would do if she didn't live. (135)*

Repetitive stress was consistent throughout almost all of the interviews, and the short- and long-term impact of stress had ramifications for carers in their day-to-day lives as they cared



for their loved ones, with many finding it difficult to locate the energy to keep moving forward;

*Very, very stressful for everybody. His family at that time blamed me. It was my fault. (67)*

A prominent feature of all the interviews was the necessity to become hypervigilant, and all-encompassing need to never leaving the person they cared for a second;

*for me immediately after the event, it is sort of...I feel like...what am I? I feel like I'm on duty. You know I'm hypervigilant (2)*

For many this has lasted years, having a significant impact on their lives;

*Yes. I think...you know just go into hyper... I'm an early childhood teacher by profession...so, I think what I would do for a group of young...very young children, you know in a situation where there was a crisis of some description, where you go into righty-oh, got everything under control. You know, you've got to do this. We're going here...reassurance, calm, you know that's like...so, I sort of go into hypervigilant/teacher mode and try to be as much in control as I can be (29)*

Participants also spoke of the impact that the caring role had on their physical health, including sleep patterns, headaches, pain and an overall reduction in physical fitness. As a result of the role of caring, participants spoke of prioritising the needs of the person they were caring for over their own needs;

*Cause it seemed like a whole...it just seemed like the whole time I was more worried about how everybody else was coping and feeling and sort of like, and sort of put myself on the back burner (150)*

This could result in declining physical health, or putting off care they themselves needed;

*Well I'm supposed to have surgery...hysterectomy a couple of years ago and I've had to literally put it off because I can't get the time to go to hospital and the six-week recovery time will be impossible. So I live with constant pain and discomfort. There's nothing that I can do about that apart from the Panadol and physio etc. So that's really frustrating cause*

*it's holding me back of being the fittest and the happiest that I can be. It affects my sleep. Definitely I wake up several times at night cause of the discomfort etc. Yeah lots of headaches which I think is to do with stress*  
(205)

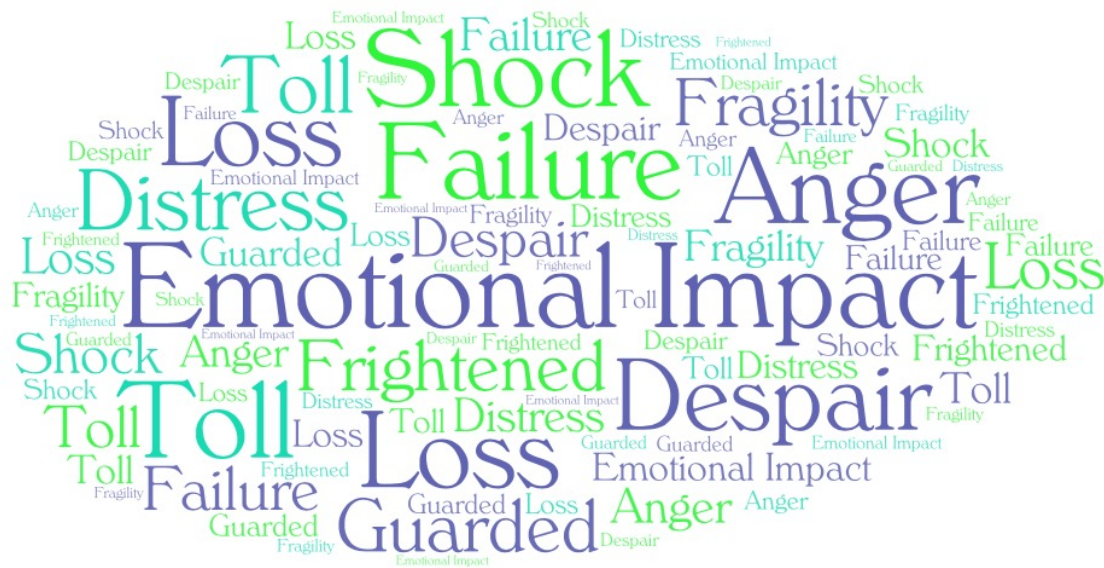
While this example is of delayed surgery, there were also examples of putting of everyday health maintenance activities to ensure the caring role was the primary concern;

*Look probably the biggest thing is I really had to...in way neglect my own, you know going out to exercise groups and that sort of thing because I feel that when I've been at work all day, I need to get home to him. ... And relieve, you know relieve my...mainly my son who's there most of the time. That I just sort of feel I have...I've had to give up a lot of things. ... In that private...you know like private stuff, to go to exercise class, to...I mean I don't...you know I go to appointments if I need to but I certainly think twice before I go and do things for me personally (15)*

Throughout the interviews, the ability to have high quality rest, with regular sleep patterns was clearly absent. The need for good sleep hygiene was understood by carers as being important for their own wellbeing, but the caring role took precedence and so sleep was clearly affected;

*I wouldn't get to sleep much cause he'd say, you know I won't be here when you wake up in the morning, you know what I mean? I was like, I'll sleep with one eye open (128)*

While the prior impacts have focused on the physical nature of the toll of the caring role, there were clearly significant emotional burden carried by these carers. This can be seen in the Phase One and Three survey data, as well as in the Phase Two qualitative data. The feelings were broad ranging and often shared with tears and strong emotion when describing their experiences to the research team. Common expressions are highlighted in the word cloud below.



For some carers they experienced feelings of loss and failure in maintaining safety for the person they cared about, as well as recognising that no matter what they did, they couldn't always prevent what might happen in the future;

*you know that was kind of compounded my guilt I suppose, you know how can I counsel anyone...I can't maybe help my own son (96)*

For many participants there was an emotional rollercoaster that was triggered by the caring role and trying to obtain the care needed;

*This is also my anger with the way that it was...the way the health service actually even responded and treated and it was just unbelievable cause I feel like I did the whole thing on my own. (92)*

This was often expressed as anger, which lay on extreme frustrations;

*And I was really angry with the system for letting him come home so soon and I was a bit horrified actually and I think because we were still in shock and tired and like you know, let's get out of here and come home. And then of course that's when reality hit, sort of like shit he should've...why didn't they keep you in hospital? Like that's ridiculous, you know why didn't someone do a psychological evaluation? (92)*

Further adding complexity to the emotional response was a profound hopelessness and despair and fear for the future – both for the carer themselves, as well as for the person they cared for;

*I feel a certain sense of hopelessness. I do what I can but I can't make her better. I'm in equal parts you know, frightened of her dying and frightened of my dying and leaving her without the support because she's highly dependent on me, you know emotionally (135)*

Such an emotional toll was exhausting for participants;

*I'm a bit exhausted now and since she is...you know, that sense of hopelessness has grown since she relapsed and has become worse than she was. You know because she's bulimic now as well as anorexic and...and I can't...I feel like there's not a lot I can do apart from you know...be there (135)*

There was also a sense of fragility given the significance of the caring role;

*we were all really, really shaken up by stage. I think...I sort of managed when it happened but when he came home that's when I realised like, how much it had affected me and I was very fragile and so was my son and of course you know, you go through all those things ...by that stage I was crumbling. (92)*

Rarely this fragility was recognised and respite arranged;

*I was really emotional and I just...even the mental health nurse came to the house on the Wednesday, she just took one look at me and actually said 'Tim, I'd like to offer you some respite in hospital' and when I spoke to her after, she said it was more for your benefit because yeah we were pretty. We were really fragile (92)*

As a result of the magnitude of the caring role, participants spoke of creating an emotional boundary or wall to protect themselves from the emotional impact of caring;

*I think one of the things I note about myself in terms of impact is I have...I did...I'm a bit guarded about my emotions, you know particularly*

*more...more difficult emotions. So, sadness or anger you know that I experience .... I think at times there are...for a carer who's in a situation where emotional wellbeing is part of the mix, then I can see myself checking my emotions (29)*

There was an awareness of how guarding one's emotions took from their broader life and ability to be emotionally responsive in other situations;

*I suppose my main concern is you know I do feel that I'm losing some humanity that I would've 20 years ago accused others of. And it's just sad that it...you know I still can compassion but I'm not as emotionally empathic as I once was. Yeah. (89)*

## Interpersonal

Beyond the internal impact of the role of caring, participants also talked about the interpersonal impacts on them. The word cloud below provides an overview of the interpersonal components of the participant interviews. These are discussed below.



The participants of the study spoke of the significant financial burden in providing care. Participants shared stories of the need to give up work or reduce their hours to manage the caring;

*I've gone from 110,000 a year in the public service cause I was year one level and now I'm on a carer's pension.... And we have the same mortgage. There's pros and cons to it, the pro... the cons are you know, I lost a good*

*income because I had to give up work. I just couldn't keep working, it was impossible. (128)*

Meanwhile as income was decreased due to caring, everyday expenses continued;

*So I've reduced my work to 0.7 (FTE) so that I can maintain work with the fibromyalgia but the psychologists fees are too expensive. I can't fit it into the budget (10)*

The responsibility for financial decisions often fell on the carer, adding additional burden they may not have previously felt;

*I have had to make all decisions for the household, for example you know financial decisions cause he's still not working. And he is still not really in the right frame of mind to make any decisions. He can't drive so I've had to basically become the main person of the household. (15)*

This change in relational dynamic also had a substantial and long-lasting impact on relationships and life plans;

*probably just the whole episode has...has totally changed basically our lives, you know in that you can't plan a holiday. You know you don't know what your future's going to be and I think that's probably the sad part in how our lives have changed so much because we are...we have grown up children. We should be at the stage, we go okay let's take off a week here or there or stuff like that and let's go to a show or...and that's just all basically gone and that's the impact that it's had on me you know and him (15)*

As a result of this financial impact, and the responsibility that comes with being a carer, there was also an impact on how people choose to use their spare time;

*You know so it's...you can imagine, it's a pretty different lifestyle for me, like our lifestyle was totally different from having a good wage to you know (128)*

To achieve the care required many participants had geographically relocated, especially those in rural areas of Australia, to ensure appropriate access to services;



*but that's why we've ended up moving and buying a place closer to the city where she can live and access her doctors and counsellors and psychiatrists and get help (240)*

As noted in the quantitative survey data from Phase One and Three, these carers are psychologically distressed. Given the situations in which they find themselves, it is not surprising that many also spoke of relationship breakdowns. This included relationship and family breakdown, loss of friends and other extended relationships and changes to interactions with social connections;

*My boys were all broken. We weren't even communicating properly. We couldn't help each other. You know we weren't functioning. (70)*

For some carers, this change in dynamics, was a reflection on how little control they had about the ways in which they navigated shifts in relationships with others;

*I hate dealing with the medical profession basically and you know, it's not like I want to go along to all my husband's appointments and have to be looking after him and stopping him from harming himself you know. It's not the role I signed up for. (125)*

For other carers, their relationship with the carer seemed to be forever altered;

*(My daughter) still struggles to understand how she can return to the role of "daughter" after so much has changed in the mother-daughter relationship. (201)*

For other carers, the impact seemed far greater;

*Everything changes. From how you perceive the world, the value of life, and not to mention the positive/negative impact on the relationship between survivor/carers. (201)*

Another common impact that emerged from the participants narrative was the feeling of social isolation as a result of caring. This emerged from having to maintain the rigour of hypervigilance, to also learning to live with a greatly reduced financial support network. For some this process was gradual, yet for others it was immediate and long lasting;

*after that second suicide attempt, I really became something of a hermit. And I still sort of feel a bit like that. If I'm...you know, I don't want to go out all that much or you know...I mean back when...you know before that suicide attempt of my daughter, I was quite active in you know, my parish and my...the high school that my sons were at and I was you know, co-chair of the high school board. I was teaching scripture. I was coordinating a sacramental program and I...you know, I gradually had to give all that up and she got sicker and then...and I didn't have the emotional energy and then you look back and think. I can't imagine doing that anymore. I can't even imagine wanting to do that let alone being able to. (135)*

The impact of the intra- and inter-personal events on the carer led to other negative events occurring that would leave them further isolated. Many impacts had a cascading effect. The loss of employment, led to loss of financial stability, which in turn led to a sense of isolation and in some cases ill health;

*Yeah it sounds like you really were doing this on your own. You didn't really have a lot of support. Most definitely (70)*

#### Experiences of support systems

Participants talked about their interactions with support systems along an integrated continuum including interactions specifically with the health systems, through community supports and across the way in which society structures and views these supports, as presented in Figure 5 below.



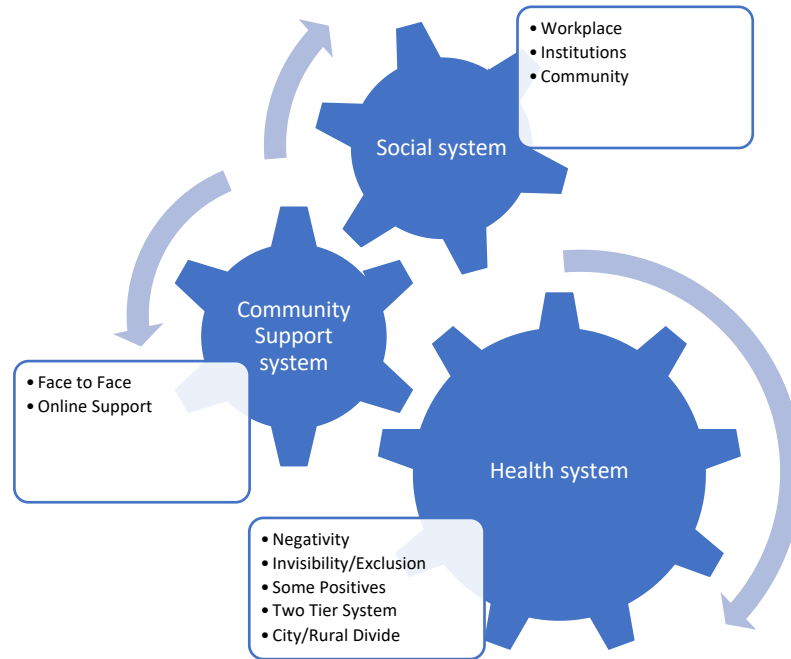


Figure 5: Different explorations of the systems carers engaged with.

### *Health System*

By far the largest number of experiences participants shared involved their engagement with the health system. This is defined as emergency department, hospital response, first responder response, and community mental health response. Many of these experiences were negative. However, it must be remembered, that these carers and their stories are recollected from a very distressing moment in their lives, and focussing on the positive experiences was not always possible. The sampling method for this project – being those who responded to advertising to participate in an online survey (Phase One) may also include more of those who were motivated to participate to share experiences of the health system. However, on analysis of these motivations, they were primarily altruistic in nature (Maple, Wayland, Spillane, Coker, 2020). Some of these experiences were recent, however some were also considerably in the past, spanning over more than 15 years. It is possible that some experiences may not occur in the present day, while others continue to occur. Nevertheless, the impact on participants of these experience prevail. For some participants, even many years later, a sense of negativity (even anger, hatred and disgust) is reported. Often this stemmed from a sense of exclusion or a prevailing view that the carer was invisible;

*I was absolutely horrified actually by the attitude of the so-called clinical services. The attitude of, well if somebody wants to take their own life,*

*they've got every right to do that and I'm thinking, no. You don't understand. They don't actually really want to do it. (10)*

Stories of self-described atrocious or horrifying attitudes within the health system were shared, severely undermining the confidence of carers that their loved one was being treated compassionately in their time of distress;

*One nurse actually sewed up her arm, outside the toilet door, lying on the floor and said to her and her partner, 'look we've got people here who want to be alive, that we're trying to tend.' And because that she felt even more guilty and tried to take her life two weeks later (78)*

For some participants they experienced trauma as a result of experiencing the mental health system alongside the person they were caring for;

*Going to the ED and having to wait 5 to 8 hours through the night before he gets to see a mental health professional is not an acceptable level of crisis support. I've never experienced greater difficulty, and these events were harmful and traumatizing (for me). (62)*

Participant stories highlighted experiences of promised follow-up, simply not materialising;

*After the incident last year the team...that emergency team, they said that they would pass my name on to a person in the team who'd get in contact with me which never occurred which is fascinating. (29)*

For a large number of carers, their overwhelming experience with the health system was one of invisibility. To many carers, they did not exist in the eyes of the medical teams – that is until they are needed when their loved one is sent home;

*I guess you don't feel like you're a person in that. I think you feel like you're a...a transport officer type of thing, not a person who feels informed and things like that. So, I guess I felt...I think to be less invisible would be good. I think probably we are quite invisible generally, yeah carer's are quite invisible cause you know how much...I'd hate to think how much we contribute to the wellbeing of the whole nation, but...and perhaps someone*

*who was a bit more tuned. I realise it's difficult in an acute situation when there are people involved and you know. (29)*

This was felt particularly keenly among parents of adult children who no longer had access to their child's medical records even though they were providing care;

*I think when she turned 18, like they said she's an adult now, we don't have to talk to you and they wouldn't talk to us because she didn't want us to talk to them. And I said to them, well hang on a sec. You know, we're the ones that's taking her home from...you know, once this is all over, like we're going to be looking after her. What do you mean we're...you can't even talk to us? And they said, well you might be part of the problem. (78)*

This led to further interventions which further alienated the carer;

*No one would talk to me about it and eventually I had to...you know, I broke down cried and yelled and they said to me...have we got to go and get security and carry you away and I said, I just want someone to tell me what's going on (78)*

Whilst being excluded from information related to care, carers also reported feeling being scrutinised for their caring efforts. This resulted in feelings of being judged and misread, with their intentions constantly questioned. This had the effect of undermining their confidence to be an effective carer going forward;

*Over ten years I have been absolutely scrutinised, so you do feel like you're being judged and you're not good enough and you don't know if you're being judged as a mother or a carer or both. It's very confusing (205)*

This participant continued, expressing how she felt her ability to be a professional, a mother and a carer were questioned;

*You know there's also the perception that if you work in the health profession that you're caring yet some of the...some of the thoughts that have been shared with you have been to leave your health professionalism at the door and be the mom. You can't win. I've been sort of...I was a martyr as well because I was caring too much, so you cannot win. A*

*mother/carer, you're always going to be judged and too much of or too little of... (205)*

Such scrutiny further isolated carers from potential support systems;

*that was the day it really hit me badly and I was a bit of a mess and I would have to say, I've never felt so alone because not one person came near me (78)*

A lack of information shared further compounded feelings of isolation in which participants found themselves trying to provide care and advocate for their person;

*They got a junior registrar to call me back and her instruction was to tell me nothing, so she told me nothing....it was almost out of spite that she told me that he'd been taken off the CTO. And I'm...well, when did somebody ask for my opinion? Well, it's none of your business. He's over 25 and don't need to discuss anything with you (10)*

Yet the moment their loved one was to be discharged; it was expected the carer now knew everything they needed;

*I felt really out of the loop. That no...as a carer I should've been involved in his discharge and that you know...he's got a mental illness, it's not just up to him to be discharged. It's up to everybody else, who he's going to come home...who's going to have to look after him (67)*

Participants most often felt excluded from conversations and care options;

*Yeah. When you enter into the system as a parent of an adult child that attempted suicide...because the privacy and confidentiality issue, many of the professional are either not able or choose not to be able to share information or try and gain information. So, they actually stop asking the questions and then won't share any information about potential support or treatment options. (100)*

For many carers, there was a lack of recognition by the health system of the stress, trauma and other mental health impacts on the carer themselves;

*I think the impact of chronic stress and chronic trauma and hyper vigilance that's required for me as a carer is really not recognised, acknowledged or supported on a community level or by a health professional (205)*

While many of the experiences carers had with health systems were negative in nature, there was also descriptions of positive events of inclusion;

*You know the staff were...the staff at the local hospital were good. They were empathetic. They were you know...I didn't feel completely left out (135)*

And empowering experiences characterised by small moments of connection and humanism;

*Yeah well look the...the psychiatrist and the psychologist that treated my daughter for that...I suppose it was almost a three year period. .... they were fantastic. So I couldn't have asked for better...we couldn't have asked for better support than what they gave not only her but us. They were conscious of how it was impacting on us and we'd have meetings down there with...they'd bring their team together and we'd discuss what...they always...we were always included in anything even though she was an adult. We were always included in everything that needed to be done. Like when she had the ECT treatment and when she went into the psychiatric unit they would always talk that through with us first... ...you know in terms of what we received I couldn't...I couldn't fault what they did. They were great (175)*

Where participants were able to identify positive experiences, it was often in relation to a specific person going above and beyond the expected role;

*it was a nurse manager in that area who offered me some support and listened to my concerns and gave me some advice and those sorts of things. I think that's...that was really powerful for me at that time. Because it was such a scary time and so I think that in that situation if you can get some face to face support for families, that's really helpful (107)*

Underlying these interactions with the people within the health system, carers had to work out – unravel – how the health system works and the changes constantly occurring to be able to navigate it to obtain the care needed;

*Yeah. I think it's changed generally in the last...I keep saying five years but that just seems to be where mental health has stepped up the game a bit and then when she first started. So yeah I think it has been a little bit more...before when she first started down this road I was only spoken to because she was under 18 and still passed as a child. Once she turned 18, that was it, nobody talked to me. You know because it's a private thing between the doctor and the adult and I felt that I was shut out because you know, it's their business and now yours and you know they weren't that forthcoming. But now the doctor's seem to try and get the families involved and you know the care person, whoever that might be (240)*

Far too often, participants from rural and remote areas shared stories of limited resources and inaccessible services. For some this meant relocating to access services, for others it meant tapping into resilience and finding a way to cope;

*we've had to learn to deal with this because we can't rely on community services in town (128)*

Many participants noted the challenges for those reliant on public mental health systems in comparison to those for whom private care is accessible;

*Once we sold the car, we started buying mental health...sorry, we started buying health insurance because it really is a two tier system when it comes to mental health in Australia (128)*

### *Community Support System*

The stories shared by carers revealed a mixed experience with engaging with community support system. This system includes the face to face support in the community (including psychology, aftercare, postvention, pastoral) as well as online support or reference material (online and hard copy).

## Face to Face

The experiences of working with face to face community support systems was varied. While some participants reported finding some services useful, others did not;

*I didn't feel like I sort of connected that well with but also because she was focusing on mom and how mom was and...I actually went to a psychologist just for me and how I was. So I didn't end up seeing her again but I found another psychologist on recommendation from a friend and she was brilliant and I guess what...and I still see her now (100)*

Where services were free and easily accessible, they were generally positively experienced;

*We both had...my partner and I both had counselling a couple of times but I am actually still seeing a counsellor there. There's no charge to see them. And you can go for as long as it's necessary and for me it's still necessary so I see my counsellor there fortnightly these days and I make a donation to them in my son's memory (10)*

Unfortunately for many participants, the costs of seeking additional or fee-for-service support was beyond their means;

*I am not financially able to get assistance through a private psychologist now however, because with the other help issues my medical costs are reasonably high and I'm trying to maintain work (100)*

In addition, carers often found services inaccessible and inflexible, especially around timing and availability;

*they couldn't see me outside work hours. They didn't have any evening slots so I told them to go jump...Well I didn't say it like that but you know (70)*

When participants reported positive experiences with face to face support services, it was generally due to service provider seemingly going out of their way, being more. These 'small touches' or 'going the extra mile' demonstrated an opportunity for connection and for people to demonstrate that they cared;

*they got my lawn's mowed right and I got home and I sat in the car in the drive way and I cried tears of joy because that was the first bit of help I'd actually gotten through the whole thing. I know. I know, mow someone's lawn, like who would've thought? You know like...but that's because...it was because that was a message of hey, someone cares and someone knows we're doing it tough and this is all we can do but we're doing all we can do for you. You know and that's what mattered...that's what mattered (128)*

Many reported these kinds of activities occurring through religious based community services, where people were focused on pastoral care of those in need;

*through Uniting Care that we got gardening support and cleaning support and some things like that (62)*

When carers were able to come together and meet with others who had similar experiences, this peer connection and mutually understanding was always reported positively;

*meeting with other families who had similar experiences and the training program itself was quite...I learnt more from that program than 13 years of education learning and development programs. So the way that was presented and the model of that being presented as a skill development and family support and individual support was huge. ... So, that connection has then led to some positive friendships where you were able to talk to other families about what it's like to have a child attempt suicide (100)*

## Online Support

Online support was reported by participants as being available when they need them, a limitation of traditional face to face community supports. Social media has become a significant source of support for many carers, with a wide range of experiences. For some carers it was useful, especially as point of contact, no matter what time of the day or night they needed it;

*So I got a lot of support off Facebook chat groups. Yeah, yeah like there's one in there and like I admin one of them now and ... cause that's 24/7 cause it's people all over the world you know and there was always someone you could just reach out to and go... So that was good and then*



*just a few key people but not many but you don't want to overload them  
either (128)*

While online information provided quick and easy access to information, the downside of this was the sheer bulk of information and trying to ascertain what information was credible, and determine how to best spent time online to shift through all the pages;

*I found that trying to find something useful was difficult in the way  
of...there's so many different sites out there and then you'd have to go  
through pages and pages and then find the relevant information for you  
(70)*

The ability to normalise their experiences by hearing about others experiences was also particularly useful;

*I do find reading other people's experiences of this helpful because I think  
oh my god, this just happened to me you know. So, distressing because I  
know exactly what they're going through but...connecting at the same time  
(29)*

However, not all experiences were positive, with many expressing a degree of cautiousness, particularly when dealing with online unmoderated groups;

*There are a lot of support systems like informal support groups that have  
now come out through social media and I find some of them absolutely  
amazingly supportive and positive and great. There are also some really  
horrendous ones where I see people feeding off the toxicity of each other  
(100)*

This ability to harness others negativity, or to push a particular issue, could be dangerous for others during periods of vulnerability;

*And I think you know support groups are wonderful. They can be wonderful  
but they can also be slightly dangerous. If someone's on a soap box and  
you know, sometimes it can be not so helpful. So I think that's why I didn't  
really go down the whole support group thing with mental health. I was*

*just cautious that I didn't want to get bad advice and I didn't want to make comments or receive comments that might not be helpful (131)*

### *Social system*

When exploring the participants narratives around their experiences with society as a system more broadly, the role of carer was viewed as to have changed their interactions with others socially – often this was due to the reduction in employment or job loss, geographic relocation, as well as the time spent caring and attending to medical needs. For some, workplaces had been flexible and allowed the participant the additional time they required to undertake the caring role;

*Well they haven't been supportive to us really at all. They...at the same time it was recognised as workers compensation so that's one good thing out of it (15)*

For others, the workplace seemed to quickly forget what the carer has been through;

*I suppose...probably the hardest thing is being in the work place because the incident happened at my work place as well, like we both work there and that was...that was very difficult for me to walk back in there you know within a week of it all happening. I...you know and I really didn't get...other than them saying, are you okay? Which you know was sweet...when they don't realise how...how hard it is and what's going on at home and that was like the day I went back and since then, I've had absolutely no one other than a couple of people really say, how are you doing? (15)*

Some carers were nervous returning to their workplace after a period of absence due to caring responsibilities or the loss of their loved one to suicide, feeling a sense of shame about what had happened and being judged;

*When I came back to work I was really nervous because I knew that everyone at my workplace knew what had happened. ... And it took, yeah a couple of weeks probably to feel good about going back to work (107)*

Maintaining a sense of competence was also difficult to balance for some carers. When was it ok to be open and when did they need to be cautious;

*You know, I've had situations where I have been fairly open about the mental health...you know, myself as a carer and people will come up to me when I'm doing my work, you know and I feel like I have to be a bit more guarded there because I'm on show a bit...the professional person so I do have to feel I'm a bit more guarded there. I think in other situations, I do...I'm conscious of not just...not despairing too much. You know, I don't want to...cause I am this...cause I do have optimism in my veins which is...thank goodness...I feel like, I don't want to give...I don't want to give it too much energy (29)*

Many carers experience in the workplace centred around the difficulty in having conversations with work colleagues – conversations about what had happened, what they had experienced, or even “normal & everyday” conversations;

*Amongst work friends, I didn't know how much to talk about because you know, it was pretty bad but amongst my fiancé who also was with me when we discovered [name] and the little child...we could talk about it amongst ourselves and then mutual friends (118)*

Interactions with other, non-health-oriented services were presented as difficult, including for example, interactions with banks, schools, government agencies etc. For many, trying to navigate and get support was a difficult experience on top of the emotional toll of dealing with the suicide attempt and/or death;

*deal with the bank, with the mortgage and that was a nightmare (175)*

For others, the lack of acknowledgment as a carer was exasperating.

*one of my frustrations with this is that Centre Link refuses to recognise that I'm a carer (62)*

However, not all experiences were negative. For many, there were reassuring events, and these made all the difference;

*I would have to say that that school is amazing and very supportive. They just said, whatever we can do to help you get through we will do (131)*

Like the workplace, many carers found the experience of reengaging with friends and family a challenging experience. Having difficult conversations were often avoided, and the shame and stigma of mental illness and suicide, made having normal relationships again, a difficult prospect;

*I think for other friends... I felt that they were really terrified and didn't really know how to cope. Some of the people, with this suicidal attempt and I think it's to do with the stigmatisation and pathologisation of those experiences, yeah so, I think what the big grade in general would be if the attitudes were different in general yeah (204)*

As a result, many carers expressed a reservation or cautious approach to be able to openly communicate;

*I guess in the situations where I find myself having those conversations, it's...it's you know...I feel a bit...I do feel a bit guarded about that. You know, I...you know feel like if I...I don't tell everybody everything but I do...yes, I do have conversations with other people, not formerly but informally (29)*

This could leave the carer socially isolated, or looking for other avenues in which to socialise, or finding friends who were able to manage their own emotions and support the carer;

*People walk across the street rather than talk to me, cause they didn't know what to say and that was really, really hard. But then I found who my real friends were and ...you know I can count on one hand that have been my lifelines for the last four years and still are (96)*

Many found friendships dwindling and after many initial enquiries, those offers of support evaporated;

*there's been no sort of follow up...apart from one or two people that asked after him, that they haven't really sort of like...it hasn't changed (215)*

However, on the positive side, some carers found new friendships and opportunities to communicate as a result of their experiences;

*So a few people actually came and talked to me about their own issues in their family or for themselves, were very supportive because they kind of got it. And so sometimes I would find myself talking to someone who I didn't expect to be talking to but who really was very understanding so that was helpful (131)*

In summary the systems depicted by the participants noted that each system had a focus on who their 'customer' was – in this case the person who had attempted suicide – and that this created a sense of there being two sides to each story, which in itself impacted the way that people sought help. There was little to no service offered to carers and yet they were expected to provide care. For some engagement was a neutral experience, it was transactional, however those circumstances where a small 'touch' led to a feeling of being seen, could be enriching for a person at risk of burnt out. Likewise where a small remark, or unhelpful tone by a service provider or health professional could shape a carers experience, or exacerbate ill-health. Many experiences shared were historical, however despite the system being responsive and changing over time, negative experiences, even many years ago, continued to shape a person's sense of community and a sense of being supported.

## Summary

The SANE Better Support project (2017-2020) provided carers across Australia to explore their lived experience of providing support, as well as those who had provided with care prior to experiencing a death by suicide.

### *Reasons for suicide:*

- Carers reported a wide variety of reasons they believe contributed to the suicide attempt and/or death. These reflect the common reasons for suicide, including challenging life transitions, trauma, and losses, and are not dissimilar to the reasons individuals who attempt suicide state as their reasons for doing so.

### *Impact of suicide:*

- There are significant intrapersonal and interpersonal impacts of providing care and support.
- The intrapersonal relate to the emotional health needs of carers, the physical health implications of providing ongoing and at times traumatic levels of care and the impact of relationships needing to shift to a 'new normal' following a suicide attempt or death.
- The interpersonal factors relate primarily to financial strain, housing challenges, rural/metropolitan divides and the inclusion of new routines of care, that must be balanced with the persons intrapersonal needs.

### *Engagement with systems:*

- Engagement with health systems were often poorly experienced. Carers reported barriers to engaging with the health system focusing on common experiences of negativity when spoken to, or a sense of invisibility when care decisions are made. Enabling factors refer to carers locating their own resilient strategies, and that this is reliant on increasing their own knowledge base as to how the system 'works'.
- Engagement with community support, including community services, workplaces online supports, were experienced as both positive and negative. This was often to do with workplaces being flexible/inflexible, and information being relevant or not knowing how to sift through information to find relevance. Much of this is located by the carer and reliant on self-referral, rather than proactive referral. It is sourced in the carers own time, and sometimes at their own expense.

- Social system engagements were similarly experienced as both positive and negative. Negative experiences often related to others inability to know how to manage the carer and their experiences with suicide indicating stigma is still prevalent. Positive experiences were generally when others recognised and responded to the carers needs.

## Key findings

Those who provide care to another who has thought about or attempted suicide, or died by suicide are the central focus of this report. Using two existing data sources – an online survey of those with lived and living experiences of suicide and from a collaborative project with SANE Australia, data were reanalysed to understand three topics:

1. How carers (family, friends and others) understand the reasons for suicide,
2. What the impact of suicide has been on them, and
3. What their experiences of health and support services has been.

*The main finding is that carers are often viewed as an extension of the suicidal person, rather than as individuals needing their own support while supporting another with compassion, dedication, energy and, at times, with great personal sacrifice.*

### How carers understand reasons for suicide

In asking people about the reasons why individuals may be at risk of suicide, we acknowledge that the ‘true’ story of that intentional or unintentional decision of another, can only ever be a second-hand understanding. The perception, by those who provide support, will be shaped by the sharing of the story from the person seeking support, from services who may wish to include carers or drip-feeding of information to gatekeep the experience away from carers. This action, as demonstrated by the analysis of the research, can exacerbate loneliness and confusion for those who step in to support. The reasons given for suicide aligned clearly with those well publicized as being suicide risk factors. This is promising, as it reflects a fairly well-developed understanding of the challenges that some people face that result in suicide thinking, behaviours and death. Yet the demographic of carers is less understood. However, the emerging literature on impact of suicide exposure, which aligns with the experiences reported in both data sets, demonstrates carers as an important risk group for suicide. They are often in touch with health systems in their role as carer, and thus are easily accessible as a population needy of support to reduce suicide among carers.



## Impact of suicide on the carer

Caring is a female dominated industry, and is more likely to be delivered by partners, parents or children. The role of caring following a suicide attempt or death is life-changing, and how this is experienced is dependent on where people live, their experience of access to services, and their own personal resources. The ways in which carers seek help themselves is not immediately clear to carers, as evidenced by this report. Carers may never have envisaged that care would be part of their relationship. Nevertheless, this analysis highlights physical health risks and financial implications of deciding to offer care, as well as changing relationships with friends, impacts on capacity to work, and a pervading sense of isolation and invisibility as a common experience.

Not all care relationships are negotiated in deliberate ways. Most of those in these data sources were involved in informal care, where there was an assumed agreement that they would provide care. Rarely were there formal care arrangements. Most commonly, caring was often an extension of a familial, intimate or friendship-based relationship. There is negotiation at different intervals depending on what the person wants in terms of care, how often they are invited to provide care and how well (or unwell) a person remains over time. This was particularly challenging where the carer was a parent of an adult child. This lack of certainty, and the ambiguous boundaries that exist in care relationships, can create uncertainty as to how the caring unfolds, and how people access information that assist them with caring. Carers understand that privacy laws and decisions regarding medical confidentiality are required in order to ensure a person retains their sense of agency, yet the lack of clarity regarding who is 'in' and who is 'out' of the decision-making process can further exacerbate the sense of trauma people may experience in those key times such as during an attempt, discharge home from hospital and when concerns about a future attempt begin to worry those who are seeking to support a person.

## Experiences of health and support systems

The health system relies heavily on the provision of care provided by informal carers, and yet this is not always acknowledged in policy, practice or engagement. Carers sit next to people at appointments, they provide transport to and from sessions, they call 000 when risk has escalated, and they offer a listening ear when situations are dire. It is not surprising that carers are impacted subjectively and objectively in this multi-faceted delivery of caring

services that do not have a job description, are often not remunerated and have no end point. The deliberate decision not to use the word *burden*, which has been previously used in the literature, in this report is echoed by the participant narratives. Irrespective of the impact of caring, a deficit approach to understanding the carer lived experience does little to create hope and compassion in the minds of people who suicide attempt. We must challenge the language of caring to being more than a deficit, and more than an incidental activity. Carer is an innately hopeful activity, and is both sustained and deliberate.

The touchpoints for carers, or people who provide support, just as noted in the Maple et al June 2020 report exists in places of accessibility and inclusion. Seeking opportunities to engage carers, whilst the person they care for, accesses a GP, a psychologist, a community mental health centre, may ease the juggle of finding time where a carer can just focus on themselves. Awareness in workplaces about the silence of caring and locating strategies to allow people to share, confidentially about how they provide informal care, and the way this impacts how much they work or how flexible their position may be, is required.

Understanding that care is an extension of a relationship, and is not always a deliberate choice, means that there is no before and after, it is just a blur of provision of support meaning that preparation for caring cannot be planned for. Seeing carers as having their own unique mental health, trauma and practical support needs rather than an extension of the person seeking mental health support for their suicide attempting may allow for people to speak up in a way that does not confirm the perceived burden or caring but views the way caring has shaped the identity of the person, is paramount.

Broader scope for carer support agencies to understand how suicide, as well as long periods of caring (particularly those followed by death by suicide), are not just focussed on the action of caring but the exposure to the trauma or attempting and the ongoing hypervigilance required in order to keep someone safe needs to be addressed.

If the goal is a national reduction in deaths by suicide, then the work provided, often at no-cost by carers, needs to be acknowledged, supported and celebrated, in a way that ensures easy access to services, easy access to speaking about the realities of care and not reducing the relationship to the transaction of caring, but responding to, and understanding that, repetitive crisis situations can and will have an impact on those who surround the person they are trying to keep safe.

## Recommendations

### Recommendation 1: Carers are a distinct group in suicide prevention.

Acknowledgement of the needs of carers is a priority. Carers require supports that are dedicated to their needs. These should be both offered through professional services, as well as through peer networks of carers. Those who have had this experience – peers – just like in other areas of suicide prevention and mental health more broadly, are an appropriate informal workforce who can assist in determining the needs of those who are providing support. Broad statements about the ways in which carers should seek out, or reflect on their own needs, requires space, trauma-informed care and capacity to engage safely with others. Placing the onus on the carer to seek out ways to care for themselves, can increase the burden. Thus, proactive offerings of support to these individuals – who are often in contact with support services in their caring role – is essential.

### Recommendation 2: Resources for carers

Carers require psycho-education tools, in addition to therapeutic interventions, that allow them to understand the trajectory of suicide attempts and support them on their caring journey. For those early in their caring journey to understand more about suicide, that for some suicide is a chronic companion and for others a one off or sporadic event/s, can assist carers better prepare for the future. Understanding the nature of suicidality, the ways in which safeguarding measures both practically (such as in the home safeguarding and accessing emergency care) as well as psychological first aid strategies regarding the traumatic exposure of suicide attempting, may be an effective prevention strategy for keeping carers well enough to provide the care they wish to offer.

### Recommendation 3: Training for health professionals

Health care professionals are often in contact with carers and can assist in providing relevant and timely information to assist them in their caring role. This should not be an afterthought to professional support services, but rather be provided as a situation is emerging, during a suicidal crisis and discharge planning and in the period after – for whatever length of time it is required. Specifically, identifying discharge strategies that include carers/support people in discussions regarding risk, is urgently required. Across the two datasets the identification of response to concerns for the safety and wellbeing of an individual, focus on the distinction

between perception that risk has been reduced, from the lens of the health professional, and the psychological safety of sending that person home with a carer to keep a ‘watch’ or close contact with the person can feel unsafe. Identification of new pathways to lessen potential trauma in the time between just after an attempt, and recovery from the attempt, that provides carers with an outlet to raise concerns, as well as acknowledges the responsibility placed on the person to ‘keep watch’.

#### Recommendation 4: Recognising the differing timelines for carers

Suicide prevention strategies should view the needs of carers as an extension of the experience of the person who has attempted. Carers do not see their experiences as an addendum. They perform vital roles in preventing suicide. Carers’ timelines of requiring support may be different than the person they are supporting. Carers reported that the initial stages after an attempt are focussed on practical aspects – securing appointments, notifying health professionals, negotiating physical health needs associated with injuries and ensuring the home environment is safe. The ‘fallout’ or impact of the attempt may come much later, once care pathways have been decided, or once the persons level of risk has been reduced. Asking as to the wellbeing of a carer in the immediate aftermath, or even in front of the person who has attempted, limits the opportunity for authentic engagement. Offering opt-out referral strategies, that reach out to carers and provide support may be able to engage people in conversations that might not currently be being heard.

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