Lived Experience of Suicide Service Guidelines: Aftercare

Aftercare Service Guidelines

GUIDANCE FROM PEOPLE WITH LIVED EXPERIENCE OF SUICIDE

These guidelines have been designed by 131 people, who have lived experience of a suicide attempt or of caring for a loved one who has made a suicide attempt, through 16 face-to-face and online sessions, and a further 61 participating through surveys.

- Consultations were also held with a range of community organisations and services that represent and work with priority groups for suicide prevention.

- All the content of the guidelines has been derived from participants in the co-design sessions or consultations with community organisations and services.

- The guidelines are intended to be used by services, communities and governments in the design, commissioning, and evaluation of aftercare services.

We are enormously grateful to all the people with lived experience of suicide throughout Australia who contributed to this project.

Support

SUPPORT SHOULD BE INDIVIDUALLY RESPONSIVE AND HOLISTIC

Aftercare services should provide individually responsive and holistic support. This means the support is decided with the person and is customised for their specific circumstances, taking account of the whole range of needs a person may have. Aftercare services should not leave critical needs a person may have – such as their personal safety (if they are experiencing domestic and family violence for example), housing or financial stability – without further support. This will help to ensure that the circumstances that have given rise to the person's suicidal crisis are effectively addressed, rather than merely their completion of an aftercare program, and will contribute to them being less likely to experience a resurgence of their distress. Aftercare services have an essential role in connecting people with longer term support where required, including any clinical care they need.

Aftercare services should be delivered with compassion and a focus on building human connection with the person being supported. It is important that service staff are able to provide a sense of sufficient time and space for the person being supported. People being supported should have the capacity to change their support worker without any issues or negative consequences.

REFERRAL PATHWAYS NEED TO BE BROADENED

Aftercare needs to be available more widely than for those who have made a suicide attempt warranting hospitalisation. Referrals into aftercare should be accepted from settings such as hospitals, general practice and mental health professionals. Self-referral should also be available, as the above referral points may not be aware of an aftercare service, know what aftercare is or realise the person has made a suicide attempt. Self-referral promotes individual agency and helps to enable people to articulate what they need from a service. It is important that aftercare be available to people who have experienced a suicidal crisis irrespective of whether an attempt has been made. Details of the relative severity of the suicidal crisis or whether self-harming behaviours have taken place should not determine whether the person is supported.

PEER WORKERS HAVE A PRIMARY ROLE

The person being supported should have their first contact with a peer worker who has lived experience of a suicide attempt or suicidal crisis. This is so the person's first interaction with the service is with a worker who relates to the person's feelings, such as hopelessness, isolation and shame, following a suicide attempt or suicidal crisis. Peer workers can provide empathy and a sense of hope for people in crisis. The peer worker should remain a key point of contact for that person. Aftercare services can also link people to other forms of peer support through groups, phone lines or other strategies as standard practice.

It is crucial for the sustainability and retention of peer workers that services value and understand their roles and that their managers, who may themselves have lived experience of suicide, undergo specific training to provide the most effective managerial support. Peer workers also require access to external lived experience supervision, professional development and networking opportunities with other peer workers.

AFTERCARE'S PURPOSE IS TO RESTORE A MEANINGFUL LIFE

The key purpose of aftercare is for the person to re-establish a meaningful life through redeveloping important relationships and purposeful connections they may have lost with their community. Rediscovering a sense of purpose, re-establishing interests and passions in life, and reducing feelings of being a burden are critical for aftercare's effectiveness.

FLEXIBLE ACCESS IS REQUIRED

Aftercare services should be easily accessible through a range of methods, including phone, text, video-call, email and in-person. People should be asked what form of contact with the service will work best for them and be able to switch from one form of contact to another based on their needs at the time. It is important the means of engagement does not affect the quality of support provided. Physical locations of aftercare services should be easy to access, be away from hospitals and provide a warm, homely environment that does not feel like a medical setting. Physical spaces should take account of sensory needs and ideally be co-designed by people with lived experience of suicide. Outreach to people's homes is essential to increase access to support and not require people to travel in order to be supported. Where outreach to the home occurs, this should be conducted discreetly without branded vehicles or uniforms worn by staff, to protect privacy and maintain confidentiality. Outreach may also occur in other locations near the person's home, such as a café or a park. It is important that aftercare services also have well developed pathways into emergency care should this be required.

DURATION OF SUPPORT IS TO BE AS-NEEDED

Aftercare services should be centred on the needs of the person and provide support as long as it is required, rather than only on the basis of a time-specific program. This is particularly important where there is no other appropriate local support services to which the person can connect. It is critical that the person agrees to aftercare support being ceased. Transition out of the service needs to be well-planned, gradual and consensual. Completion of aftercare support should be affirmed as an achievement and the person's transition supported with a personalised take home pack containing information on further services and resources relevant to them.

SUPPORT FOR FAMILY AND FRIENDS IS ESSENTIAL

Aftercare services are to provide support for the family and friends of the person in crisis, as determined by the consent of that person. Aftercare services should also be available to provide support and information to the families and friends of people who have not accessed the service themselves. This support can be crucial in helping people keep their loved ones alive and prevent suicide attempts or re-attempts. Family and friends should be defined broadly to include non-biological or chosen families, and other important personal relationships.

PROVISION FOR 24-HOUR SUPPORT IS REQUIRED

Suicidal thinking and suicidal crises can occur outside of business hours and can be at their most acute overnight. It is vital that aftercare services provide a form of support that can be available outside of hours and on weekends, even if this is limited to online chat or phone support, for example, until more comprehensive support can be provided. Support outside of hours may be provided by the same service providing support during business hours or by an appropriate partner service.

FOLLOW UP AND THE ABILITY TO STEP BACK IN IS VITAL

The person should be able to step back into aftercare support if their wellbeing deteriorates or they feel the need to access support again after they have transitioned from the service. Periodic follow up (for example after three, six and twelve months following their last contact with the service) is needed to remind the person that the service remains available for them should they need it. Follow up can be in the form of text messaging, e-postcards or other unobtrusive methods.

Oversight

COMMISSIONING NEEDS TO INVOLVE LIVED EXPERIENCE

Commissioning of aftercare services should have specific roles for people with lived experience of a suicide attempt or suicidal crisis. This includes a place on assessment panels or in assessment processes for aftercare service proposals. Appropriate preparation and pre-briefing provided to people with lived experience involved in commissioning activities will ensure they understand the process and are fully aware of what is required of them.

CONSORTIUM APPROACHES ARE STRONGLY ENCOURAGED

Local consortia, with a national organisation providing oversight for consistency and quality, are especially preferred as the service providers of aftercare. Consortia arrangements that require local service providers to collaborate and combine their expertise can reduce needless competition between organisations and fragmentation of services. Consortia should include organisations with demonstrated capability in delivering peer-based or lived experience-informed programs. The involvement of religious organisations, who do not have longstanding and deep connections to the LGBTIQA+ community, is not preferred as this can create concern about a lack of culturally appropriate service delivery. Many people from the LGBTIQA+ community will simply not access a service if it is delivered by a religious organisation.

LOCAL CO-DESIGN OF AFTERCARE IS ESSENTIAL

Aftercare services should undergo local co-design processes that include local people with lived experience of a suicide attempt or suicidal crisis. Co-design can ensure the local characteristics of the community and the needs of local people are properly taken into account in the delivery of the service. It is necessary for sufficient resources and time to be made available for co-design to be undertaken with authenticity and integrity. Meaningful and genuine co-design involves people with lived experience at the beginning of service design.

GOVERNANCE SHOULD INCLUDE LIVED EXPERIENCE OF SUICIDE

It is critical that aftercare services have people with lived experience of a suicide attempt or suicidal crisis integrated into local governance structures. There should be more than one person with lived experience included in governance structures (such as steering committees or advisory groups) to avoid isolation and provide collegial support. Due pre-briefing and transparency of governance processes will ensure people with lived experience can meaningfully participate in decision making. The boards of organisations that deliver aftercare services should include representative positions for people with lived experience of suicide.

People with lived experience of suicide can encounter power imbalances in governance structures. This can be remedied by proactively educating other participants in governance structures on the value that people with lived experience of suicide bring to governance, and the policy-based rationale for their participation.

There are innovative roles for people with lived experience in evaluation of aftercare services. These roles can include peer researchers and analysts and advisors considering data and formulating recommendations. Suicide prevention research is always strengthened by incorporating insights from lived experience. Evaluation of aftercare services should be transparent, and results made public and easily accessible.

Access

SERVICES ARE TO BE INCLUSIVE OF NEURODIVERGENCE

Aftercare services should anticipate that they will support people who are neurodivergent and have differing developmental histories and individual communication styles. In many cases, people may not yet have received a diagnosis of autism, ADHD or other neurodivergent conditions. Aftercare services should therefore not rely on disclosure of neurodivergence but instead approach all interactions with people being supported using a range of communication methods. These can include the use of diagrams, drawing, photos, miniature models, and other visual aids to better enable the person to represent their feelings and needs. Environments should be quiet with low level lighting to minimise sensory stimulation. Sensory tools, such as stress balls and fidget toys, can help a person to reduce tension and remain calm.

YOUNG PEOPLE REQUIRE A DEDICATED SERVICE

Dedicated aftercare services are needed that are specifically for young people, especially people aged under 18. These services should be youth-friendly and employ communication methods appropriate for young people (using messaging apps for example). They should take a broad family and community approach, be co-designed by young people, and employ youth peer workers to support young people. Support from youth aftercare services should never be abruptly ceased because the person being supported has turned 18. Additionally, all aftercare services should expect that, at times, very young people and their families may access support. Having an age-appropriate support strategy ready in these instances is critical so that young people are not turned away from support due to being too young.

SERVICE STAFF SHOULD REFLECT THE DIVERSITY OF LOCAL COMMUNITIES

The staff who work at aftercare services need to reflect the cultural and linguistic features of their local communities. This is necessary for services to be culturally safe, accessible, and relevant to the people who need them. Services with staff that are broadly representative of their local communities are more likely to be approached, and more likely to effectively connect people with other services they may require. This should be a key consideration in recruitment processes. A gender mix in staffing is also important.

There are a range of communities that services should anticipate they will support, and services need to be ready for these communities to safely and easily access the service. Staff should understand that family and support structures may be distinctive and more collectively based in particular communities, including Aboriginal and Torres Strait Islander communities, Culturally and Linguistically Diverse communities, and LGBTIQA+ communities.

Signals of safety, such as the Aboriginal and Torres Strait Islander flags or the pride flags for LGBTIQA+ communities, should be matched with staff training and a thorough understanding within the service of the suicide prevention needs of those communities. This is especially important for groups with very high suicide rates, such as trans and gender diverse people who require affirming service delivery and are easily excluded by the use of inappropriate language about sex and gender when collecting information or providing support.

Many people are more likely to access a service if they are aware it has been designed with people who have lived experience of suicide. Where this is the case, this should be a key point made in communications and promotion of the service.

VETERANS

Staff should be aware of entitlements for veterans and ensure the service is able to proactively identify veterans (through a routine question, for example) so these entitlements can be accessed. It is possible the veteran being supported may themselves be unaware of these entitlements. Veterans may, at times, feel undeserving of support and that they are taking the place of others in greater need, which can lead to withdrawing from support even when their need is very high. It should be recognised that some veterans do not trust services associated with government agencies due to previous traumatic experiences, and so may prefer to only access non-government services.

DEAF COMMUNITIES

Deaf communities have unique access considerations related to their specific culture and language but require aftercare services to focus on their suicide prevention needs and not only their deafness. Although this may be challenging for many services, it is the responsibility of services to provide support, not the deaf person's responsibility to educate the service in how to support them. Services should have readily applicable strategies to provide equitable access for deaf people. The preferred approach is for deaf people to engage directly with the service in Auslan. This means they can more clearly communicate with the provider, avoid supply issues and privacy concerns with interpreters, and means their culture is understood and shared with the provider.

PERINATAL PARENTS

Parents experiencing suicidal thoughts during the perinatal period can face severe stigma, judgement and a fear of disclosure. Anonymity is a key safety measure for services supporting perinatal parents, while care for their child without the fear of child removal as they receive support is essential. Workforce training and links with expert organisations for assistance when needed is vital.

GREATER PROMOTION OF SERVICES IS URGENTLY NEEDED

It is critical that people become aware of what aftercare is, that it is available and how it can be accessed, ideally before they or someone close to them enters a period of distress or crisis. Much wider advertising of aftercare services will educate communities about the meaning and benefits of aftercare and reduce the stigma of accessing suicide prevention services.

SERVICES REQUIRE A CONSIDERED APPROACH TO CULTURALLY AND LINGUISTICALLY DIVERSE COMMUNITIES

Aftercare services need to carefully consider how they will support people from Culturally and Linguistically Diverse communities in their area. Employing staff from the major local Culturally and Linguistically Diverse communities, while desirable, is not a comprehensive strategy. Developing connections with community leaders is essential, especially in areas where there are many different Culturally and Linguistically Diverse communities, and where there are emerging communities and refugee settlement.

Promotional material can identify a Culturally and Linguistically Diverse community contact for the service, whether or not this person is an employee of the service. Indicating that the person is trained and has an official affiliation to the service lends added credibility. Services should not assume that a person from a Culturally and Linguistically Diverse background will always want to be supported by a Culturally and Linguistically Diverse worker. It is best to ask the person what they prefer and offer them a choice. Some people may also prefer to be supported by a worker of the same gender as well as the same community.

In some Culturally and Linguistically Diverse communities, families will approach religious leaders for advice and support on mental health or suicide-related matters, making these leaders an important focus for outreach and education about what the service can provide. Religion can strongly influence how communities respond to a suicide attempt. As a result, it is necessary to not only understand the community culture, but also the community's religious value system and how it regards suicide. Services should develop their knowledge and sensitivity so these communities can be effectively and appropriately supported. People who have made a suicide attempt may be especially stigmatised in communities where religious perspectives regard suicide as a grave sin.

It is important not to make generalisations about the prominence of religion in all Culturally and Linguistically Diverse communities, however. Some Culturally and Linguistically Diverse communities may not be strongly faith-based but may nonetheless have cultural norms regarding fear of asking for, and offering, help that will have implications for how services best support these communities outside of religious faith.

People being supported may be concerned about the privacy of local interpreter services. Using an interstate interpreter can help to reduce these concerns.

Where aftercare is needed for school-aged young people, it is critical to work both within school communities and with the parents and families. This is because these young people are crossing between their family's culture and the school environment's culture, which may be very different.

RURAL AND REMOTE ACCESS REQUIRES A SPECIFIC APPROACH

People who live in rural and remote areas need to be considered specifically and services delivered to reach them. Although online and phone-based approaches are needed, limited or poor access in rural and remote areas makes outreach strategies necessary as well. Nonetheless, it is preferred that local people who live in rural and remote areas deliver aftercare services to their own communities. This requires innovation, appropriate resourcing and a decentralised but well supported workforce. Distinctive needs regarding privacy in small communities, isolation and transport challenges also have to be met to ensure that aftercare services are relevant and accessible for people in rural and remote areas.