

THE KASHIA FAUMUI FOUNDATION

Honour. Heal. Grow.

Lived Experience Engagement Policy

Engaging people with lived experience of mental health difficulties and suicide

Policy owner	Kashia Faumui Foundation Board of Directors
Approved by	Board of Directors
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Contents

- 1. About This Policy**
2. Our Commitment
3. Key Principles
4. What We Mean by 'Lived Experience'
5. How People Can Be Involved
6. Your Rights When You Participate
7. Our Responsibilities to You
8. How We Prepare and Support You
9. Looking After Your Wellbeing
10. Privacy and Confidentiality
11. Payments and Recognition
12. Feedback and Complaints
13. Definitions
14. Policy Review

1. About This Policy

The Kashia Faumui Foundation (KFF) was established in memory of Kashia Faumui musician, artist, and daughter whose life was shaped by Schizoaffective Disorder and whose passing in 2026 exposed critical failures in Australia's mental health system.

From the very beginning, the Foundation has been committed to a simple principle: the people who have lived through these experiences must be at the centre of the work. Not as case studies. Not as statistics. As partners, advisors, contributors, and leaders.

This policy explains how the Foundation engages people with lived experience of mental health difficulties or suicide, and what you can expect if you choose to be involved.

This policy is written in plain language so that everyone including people considering getting involved can easily understand it.

If you would like this policy in a different format, larger print, audio, or another language please contact us.

2. Our Commitment

"The Kashia Faumui Foundation recognises the significance and value of ensuring its work is informed by the specialised and experience-based knowledge of people who have lived experience of mental health difficulties or suicide."

Involving people with lived experience helps the KFF to build understanding, reduce stigma and discrimination, and improve the quality, relevance and knowledge translation of our research. It also gives individuals the opportunity to contribute to the community in a meaningful way."

We make the following commitments to every person who engages with the Foundation through their lived experience:

- ✓ **We will listen.**
Your experience and perspective will be genuinely heard and will shape our work.
- ✓ **We will be honest.**
We will tell you clearly what we are asking of you, why, and how your contribution will be used.
- ✓ **We will be flexible.**
We understand that mental health is not always predictable. We will work with you, not against you.
- ✓ **We will protect you.**
We will take your safety, privacy, and wellbeing seriously at every stage.
- ✓ **We will value your contribution.**
Your involvement is a gift. We will acknowledge it properly and fairly.
- ✓ **We will keep improving.**
We will ask for feedback and use it to make our engagement better over time.

3. Key Principles

Everything the Foundation does in this space is guided by seven principles. These principles are not just words; they shape how we design engagement activities, how we treat people, and how we measure whether we are doing this well.

1**Respect**

Every person's experience is unique and valuable. We treat all contributors with dignity, and we never ask anyone to justify or prove their experience.

2**Authenticity**

We engage people with lived experience because we genuinely want their input to shape our work — not to tick a box or meet a reporting requirement.

3**Voluntary Participation**

Involvement is always a choice. There is no pressure to participate, no pressure to share more than you want to, and no negative consequence for stepping back at any time.

4**Equity and Inclusion**

We actively work to ensure that the full diversity of lived experience is reflected in our work — including people from culturally and linguistically diverse backgrounds, First Nations people, Pacific and Pasifika communities, young people, older people, and those who have had multiple contacts with the mental health system.

5**Transparency**

We will always be clear about what we are asking, why we are asking it, how the contribution will be used, and who will see it.

6**Wellbeing First**

Sharing lived experience can be emotionally demanding. The Foundation prioritises the wellbeing of contributors throughout the engagement process — before, during, and after.

7**Meaningful Impact**

We will always tell you how your contribution has been used and what difference it has made. Lived experience engagement should never disappear into a process without result.

4. What We Mean by 'Lived Experience'

'Lived experience' means personal, first-hand experience of mental health difficulties, mental illness, or suicide either your own, or as a family member, carer, or supporter of someone who has experienced these things.

You have lived experience if you have...	You may also have lived experience if you...
• Experienced a mental health condition yourself • Sought support from the mental health system • Experienced a mental health crisis or suicidal thoughts • Lived with the impact of a family member's mental illness • Supported someone through a mental health episode • Lost someone to suicide	• Are a carer for someone with a mental illness • Have navigated the system on someone else's behalf • Have experience with the intersection of mental health and cultural, spiritual, or community identity • Work or volunteer in peer support roles and draw on your own experience

You do not need a formal diagnosis to have lived experience. You do not need to have been hospitalized. You do not need to be 'recovered' or 'well' to contribute. All experiences are valid.

5. How People Can Be Involved

There are many ways to contribute to the Foundation's work. The level of involvement is entirely up to you and it can change over time.

Sharing Your Story

You may be invited to share your personal experience through:

- A written or recorded story for the Foundation's website or publications
- A media interview or public statement
- A contribution to a research publication or report
- A speaking opportunity at the Annual Symposium, a community event, or a fundraiser
- A contribution to the Foundation's children's book series or creative programs

Advising and Reviewing

You may be asked to provide input into the Foundation's work by:

- Reviewing research proposals, reports, or publications before they are finalised
- Providing feedback on Foundation resources, programs, or communications
- Advising on whether a project or initiative is relevant and appropriate
- Participating in a focus group or consultation session

Governance and Leadership

The Foundation's governance structures include dedicated roles for people with lived experience:

- Membership of the Lived Experience Advisory Group an advisory body that guides the Foundation's work across all pillars
- Community Director on the Board of Directors a governance role specifically designated for a person with lived mental health experience or a family carer
- Representation on the Clinical Advisory Panel where appropriate

Program Delivery

People with lived experience may be involved in delivering Foundation programs, including:

- The Mana Collective as peer facilitators, mentors, or co-facilitators in the music education program
- Concert tour and visual arts exhibitions as performers, exhibiting artists, or storytellers
- Public education and awareness campaigns

Not sure where to start? That is completely fine.

Contact us and tell us a little about yourself and what interests you. We will suggest options that suit your availability, your experience, and your comfort level and there is absolutely no obligation.

6. Your Rights When You Participate

When you engage with the Kashia Faumui Foundation through your lived experience, you have the following rights no matter what type of involvement you have chosen.

Your Right	What This Means in Practice
The right to say no	You can decline any invitation to participate. You can decline to answer specific questions. You can end an activity at any time. You will never be pressured to continue.
The right to set limits	You decide what you share, how much you share, and how it is used. If you want parts of your story kept private or off the record, we will honour that.
The right to be informed	Before any activity, we will tell you clearly: the purpose, who will see the output, how it will be used, and what happens to your information.
The right to review	Where practicable, you will have the opportunity to review and correct any quotes, statements, or accounts attributed to you before publication.
The right to remain anonymous	You may choose to share your experience without using your real name or identifiable details. We will work with you on how to protect your identity.
The right to withdraw	You can withdraw your consent for your contribution to be used at any time before publication or distribution. Once material is published, we may not be able to remove it we will always tell you this upfront.
The right to support	We will provide access to wellbeing support before, during, and after engagement activities. You are never expected to manage difficult feelings alone.
The right to be valued	Your contribution will be acknowledged and, where appropriate, fairly compensated. You will always be told how your input made a difference.

7. Our Responsibilities to You

When you share your lived experience with the Foundation, we take on clear responsibilities. These are not optional; they apply to every Foundation staff member, board director, advisor, and volunteer involved in the engagement activity.

Before the Engagement

- We will explain clearly what we are asking for and why.
- We will provide sufficient information and enough time for you to make an informed decision about whether to participate.
- We will ask for your written or verbal consent before proceeding.
- We will check whether you need any adjustments or accommodations to participate comfortably.
- We will identify a named Foundation contact person who will be your point of contact throughout.

During the Engagement

- We will follow the agreed parameters we will not ask you to go beyond what you have agreed to share.
- We will monitor your wellbeing throughout and be prepared to pause or stop if needed.
- We will ensure that any facilitating staff or volunteers have appropriate training in trauma-informed practice.
- We will not use loaded, stigmatising, or clinical language unless you choose to use it yourself.

After the Engagement

- We will check in on your wellbeing after the activity, particularly if it involves sharing difficult material.
- We will provide a summary of how your contribution has been used or will be used.
- We will honour any requests for anonymity, review, or withdrawal.
- We will acknowledge your contribution appropriately.

8. How We Prepare and Support You

We understand that sharing personal experience particularly around mental health and suicide can be emotionally demanding, even for people who are experienced advocates. Preparation makes a real difference.

Before You Engage

Depending on the type of engagement, we will offer:

- A pre-engagement conversation is a relaxed, informal chat with a Foundation contact person to discuss what will be involved and answer any questions.
- A written brief, clear, plain-language information about the purpose, format, audience, and use of the activity.
- An opportunity to review questions or topics in advance particularly for interviews, focus groups, or speaking engagements.
- Connection with a peer support person or support worker if you would like one present.

During the Activity

- A named support contact will be available at all times.
- You will be reminded of your right to stop, pause, or skip any topic at any point.
- Activities will be structured with appropriate pacing, including breaks.
- For in-person activities, a private space will be available if you need a moment.

After the Activity

- A follow-up check-in within 48 hours of any in-depth engagement activity (interview, speaking appearance, workshop).
- A list of mental health support services provided in writing after every engagement.
- Ongoing contact from your Foundation point person for as long as you need it.

If at any point before, during, or after you feel distressed or unsafe, please reach out:

Lifeline: 13 11 14 (24 hours, 7 days)

Beyond Blue: 1300 22 4636

SANE Australia: 1800 187 263

In an emergency, call 000.

9. Looking After Your Wellbeing

The Foundation takes a trauma-informed approach to all lived experience engagement. This means we understand that sharing personal experiences of mental health and suicide can bring up difficult feelings including for people who feel very confident sharing their story.

What Trauma-Informed Means to Us

- We recognise that trauma is common and can have lasting effects.
- We design activities to minimise the risk of re-traumatisation.
- We understand that triggers can be unpredictable; we do not judge anyone for needing to stop.
- We create environments where safety and trust come first.
- We do not require people to share more than they choose to.

Safe Messaging Guidelines

When lived experience is shared publicly in media, on the Foundation's website, at events, or in publications the Foundation follows the Suicide Prevention Australia Safe Messaging Guidelines and Mindframe guidelines for communicating about mental illness.

These guidelines exist to protect both the person sharing and the people who will receive the message. Before any public-facing activity involving sensitive material, we will discuss these guidelines with you in plain language so you understand how they apply.

Signs That We Will Watch For

Foundation staff and facilitators are trained to watch for signs that a contributor may be finding the engagement difficult, including:

- Visible distress or emotional change
- Requests to stop or pause
- Disclosure of current crisis or safety concerns

If we notice any of these signs, we will pause the activity, check in with you, and offer appropriate support. Your wellbeing always takes priority over completing the activity.

10. Privacy and Confidentiality

The Foundation takes the privacy of all contributors seriously and complies with the Privacy Act 1988 (Cth) and the Australian Privacy Principles.

What Information We Collect

We may collect your name, contact details, and the content of your contribution (story, feedback, advice, or participation record). We only collect information that is necessary for the engagement purpose.

How We Use Your Information

- To carry out the engagement activity you have agreed to participate in.
- To acknowledge your contribution (with your consent).
- To report on the Foundation's lived experience program (in aggregated, de-identified form unless you have given consent to be identified).
- To contact you about future engagement opportunities, if you have asked us to.

Who Sees Your Information

- Foundation staff and board members who are directly involved in the activity.
- Third-party publishers, media organisations, or partner bodies only with your explicit consent.
- We will never sell or share your information for commercial purposes.

Anonymity and Pseudonyms

You may choose to participate anonymously or using a pseudonym at any time. We will agree with you in writing how your identity will be protected before any material is published or shared.

Storage and Security

Personal information is stored securely. Records are retained only as long as necessary and are disposed of appropriately.

Your Right to Access Your Information

You have the right to access the personal information we hold about you and to request corrections. Contact us using the details in Section 12.

11. Payments and Recognition

The Foundation recognises that lived experience is a form of expertise and expertise deserves acknowledgement.

Type of Involvement	Acknowledgement
Informal consultation or brief feedback	Personal acknowledgement; inclusion in relevant publication acknowledgements.
Focus group, interview, or consultation session	Gift voucher or equivalent honorarium to recognise your time. Out-of-pocket expenses reimbursed.
Public speaking, media appearance, or event contribution	Paid fee or honorarium agreed in advance. Travel, accommodation, and other expenses covered.
Lived Experience Advisory Group membership	Sitting fee for each meeting attended. Annual acknowledgement in Foundation Impact Report.
Board (Community Director)	Director's fee as agreed by the Board. Standard director induction and ongoing support.
Program delivery (The Mana Collective peer facilitator)	Paid facilitation rate per session. Full program induction and ongoing support.

We will always discuss payment arrangements with you before you commit to an activity. No one should be out of pocket for contributing to the Foundation's work.

If you receive government income support payments, payment from the Foundation may affect your entitlements. We encourage you to check with Services Australia before accepting payment. We can provide documentation to support this if needed.

12. Feedback and Complaints

We want to know how we are doing. Feedback including criticism helps us improve our lived experience engagement practice.

Providing Feedback

After every engagement activity, we will invite you to provide feedback through a short, optional survey or conversation. You can also provide feedback at any time by contacting:

Founding Chair	Garry Salale Faumui
Email	garry.faumui@booyahgroup.com
Phone	0403 310 757
Website	www.kashiafaumuifoundation.org

Making a Complaint

If you believe you have been treated poorly, that your rights have not been respected, or that this policy has not been followed, you have the right to make a formal complaint.

- Contact the Founding Chair directly (details above).
- Your complaint will be acknowledged within five business days.
- We will investigate and respond within 20 business days.
- If you are not satisfied with the response, you may refer your complaint to the Australian Charities and Not-for-profits Commission (ACNC) at acnc.gov.au or call 13 22 62.

No one will face any negative consequence for making a complaint in good faith.

13. Definitions

Term	Meaning
Lived experience	Personal, first-hand experience of mental health difficulties, mental illness, or suicide either your own, or as a family member, carer, or close supporter.
Engagement activity	Any activity where the Foundation invites a person to share or apply their lived experience including interviews, focus groups, advisory roles, speaking engagements, program delivery, or governance roles.
Trauma-informed practice	An approach that recognises the widespread impact of trauma, integrates knowledge about trauma into policies and practices, and actively seeks to avoid re-traumatisation.
Safe messaging	Guidelines for communicating about mental illness and suicide that are designed to inform and support rather than cause harm. The Foundation follows Suicide Prevention Australia and Mindframe guidelines.
Honorarium	A payment made to recognise a person's time, expertise and contribution where a formal fee-for-service arrangement does not apply.
Foundation	The Kashia Faumui Foundation registered as an Australian charity.

14. Policy Review

Review frequency	Annually, or sooner if significant issues arise
Next review due	April 2027
Review process	The Lived Experience Advisory Group will be consulted as part of every review
Approved by	Board of Directors
Version history	Version 1.0 — August 2026 (first issue)

When this policy is updated, we will notify people who are currently engaged with the Foundation through their lived experience. The current version will always be available on the Foundation's website.

"Kashia was open about her diagnosis and carried herself with honesty and dignity. She is the reason this work exists and the reason it must be done properly."

Garry Salale Faumui, Founding Chair

The Kashia Faumui Foundation

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In memory of Kashia Faumui — Musician · Artist · Advocate