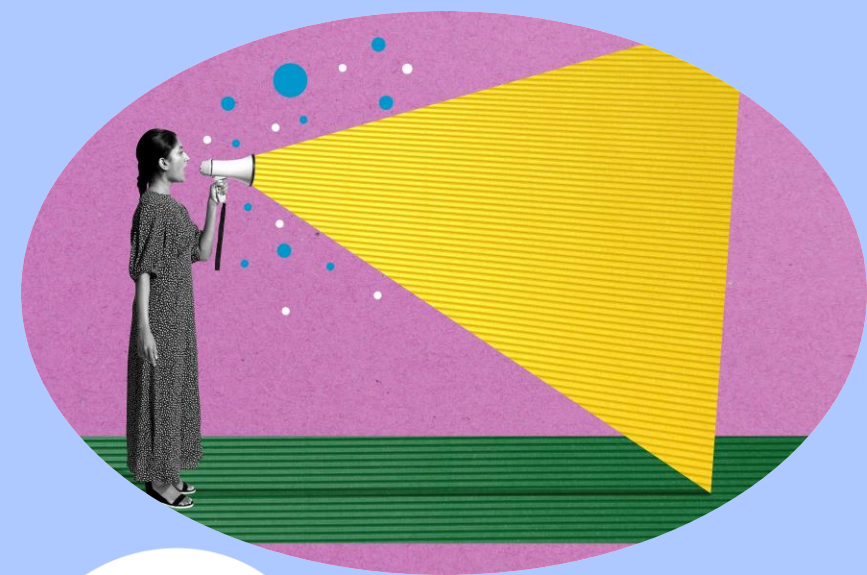


Communicating Lived Experience Effectively

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Why Communication Matters

- Builds trust and credibility
- Ensures your message is heard and understood
- Helps create impact and change
- Opens opportunities for influence



Key Communication Principles

- Authenticity: Speak from your real lived experience
- Clarity: Avoid jargon, use accessible language
- Relevance: Tailor your content, tone & examples to who you're speaking with
- Boundaries: Only share what you feel safe sharing



Audience Matters

- Different audiences require different:
 - Language & Tone
 - Level of Detail
 - Use of Personal Story
 - Purpose & Desired Outcome



Speaking with a Research Team

- Goal: Inform study design, ensure relevance, improve outcomes
- Tone: Professional, evidence-informed, collaborative
- Techniques:
 - Use precise examples linked to data/outcomes
 - Ask clarifying & probing questions
 - Show how lived experience connects to research implications



Speaking with Media Outlets

- Goal: Raise awareness, humanise the issue, reach wide audience
- Tone: Relatable, engaging, memorable
- Techniques:
 - Develop short, strong soundbites
 - Use plain language, avoid technical terms
 - Share a compelling personal story or insight
- Avoid: Overly technical detail, complexity, going off message



Speaking at Awareness or Fundraising Events

- Goal: Generate empathy, motivate action or giving, build support
- Tone: Emotional but balanced; inspiring; hopeful
- Techniques:
 - Begin with story / journey that connects emotionally
 - Highlight impact and possibility, not just suffering



Speaking at Awareness or Fundraising Events-Cnt'd

- End with clear call to action (donate / volunteer / share)
- Avoid: Overwhelming negativity; leaving audience without something they can do



Speaking at a Conference

- Goal: Influence policy, share lived experience perspective with experts
- Tone: Structured, informed, credible
- Techniques:
 - Use storytelling with clear structure (challenge → impact → insight → recommendation)



Speaking at a Conference- Cnt'd

- Ground personal experience within broader data/policy context
- Refer to wider consumer community perspectives where possible
- Avoid: Being too informal or anecdotal without broader context



Comparative Snapshot

Audience	Goal	Tone/Style	Techniques	Example rewriting of the baseline anecdote
Research Team	<ul style="list-style-type: none"> Inform study design Ensure relevance Improve outcomes 	<ul style="list-style-type: none"> Professional Evidence-informed Collaborative 	<ul style="list-style-type: none"> Use precise examples linked to data/outcomes Ask clarifying & probing questions Show how lived experience connects to research implications 	In my own treatment, fatigue was my biggest barrier. It wasn't just being tired, it changed everything about my ability to work, parent, and live normally. But I noticed my medical team often measured progress only through blood counts. If research could include outcomes that reflect daily functioning and wellbeing, it would give a much fuller picture of what matters to people like me."
Media	<ul style="list-style-type: none"> Raise awareness, Humanise the issue, Reach wide audience 	<ul style="list-style-type: none"> Relatable Engaging Memorable 	<ul style="list-style-type: none"> Develop short, strong soundbites Use plain language, avoid technical terms Share a compelling personal story or insight Avoid: overly technical detail, complexity, going off message 	When I was 32, with two small kids, leukaemia stopped my life overnight. Some days, just walking to the letterbox felt impossible. Fatigue was like carrying a backpack full of bricks. But what really made a difference was when a nurse simply asked me, 'What matters most to you right now?' — that moment reminded me I was more than my illness.
Awareness or Fundraising Events	<ul style="list-style-type: none"> Generate empathy Motivate action or giving Build support 	<ul style="list-style-type: none"> Emotional but balanced Inspiring Hopeful 	<ul style="list-style-type: none"> Begin with story / journey that connects emotionally Highlight impact and possibility, not just suffering End with clear call to action (donate / volunteer / share) Avoid: overwhelming negativity; leaving audience without something they can do 	Imagine being 32 years old, wanting to chase your children around the park, but not having the energy to even leave the couch. That was my reality with leukaemia. Thanks to programs supported by fundraising like tonight, I found support groups that helped me cope with fatigue and connect with others. Your generosity helps create those lifelines for people like me — and for thousands of families facing this right now.
Conference	<ul style="list-style-type: none"> Influence policy Share lived experience perspective with experts 	<ul style="list-style-type: none"> Structured Informed Credible 	<ul style="list-style-type: none"> Use storytelling with clear structure (challenge → impact → insight → recommendation) Ground personal experience within broader data/policy context Refer to wider consumer community perspectives where possible Avoid: being too informal or anecdotal without broader context 	From my perspective as a patient, clinical measures like blood counts didn't capture the full story. Severe fatigue limited my ability to work, to care for my children, and to engage socially. Yet it wasn't systematically tracked. My recommendation: integrate patient-reported outcomes, like fatigue and daily function, into both research and routine care — because these determine real-world quality of life just as much as treatment response.



Tips for All Settings

- Prepare 2-3 key messages beforehand
- Know what your audience cares about
- Practice timing (short vs long)
- Use language and visuals appropriate to setting
- Check your own emotional wellbeing
- End with hope, possibility, or action



Now It's Your Turn!

- Take some time and reflect on your story/ lived experience narrative
- First brainstorm & sketch
- Draft a 'baseline' narrative'
- Then with different audience lens try modifying your story for each audience
- Practice reading it aloud
- Make necessary revisions
- Consider sketching a 'short' and a 'long' version
- You are now ready for your next engagement
- Don't forget, rehearse, rehearse, rehearse!



Questions, comments?