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Speaking Our Minds:

A guide to how we use our stories

Hey! It's my
story...





Speaking Our Minds

A guide to how we use our stories

Speaking Our Minds: A guide to how we use our stories

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Our Consumer Place

PO Box 354

North Melbourne VIC 3051

Email: service@ourconsumerplace.com.au

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Speaking Our Minds: A guide to how we use our stories

(Our Consumer Place Resource Centre Booklet Two)

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Cartoons by Merinda Epstein (www.takver.com/epstein/)

Foreword

This booklet provides an overview of storytelling from the perspective of people who have been diagnosed with 'mental illness' (in this booklet, we call ourselves 'consumers').

It is part of a series of consumer-developed booklets produced by Our Consumer Place (www.ourconsumerplace.com.au), a groundbreaking mental health resource centre run by consumers. Funded by the Department of Health (Government of Victoria) and auspiced by Our Community, we offer information and advice for individual consumers, groups of consumers and anyone else who supports consumer leadership.

Most of the available information on mental health has been written by other sorts of 'experts' – mental health professionals, mental health charities, or researchers who are not consumers. This booklet is different – it is written by people who have been labeled with 'mental illness,' based on *our* knowledge, drawn from our lived experiences.

The people who have contributed to this booklet have years of experience sharing their stories in various contexts – with friends / workmates, teaching mental health professionals from a consumer perspective, speaking to the media or speaking at public forums. This booklet is designed to support consumers getting the most out of these opportunities, without too great a cost to yourself.

Of course, people with a diagnosis of 'mental illness' do not all have the same views; we disagree with each other on many points. How you tell your story (and, indeed, whether and to whom and in what contexts you choose to tell your story) is entirely up to you. ***It is your story.*** In fact, as we explore in this booklet, you may have many stories, depending on the context, what message you want to convey or how you are feeling.

We know that you will find your own path – we offer this booklet in a spirit of "take what you like and leave the rest".

A note on language

Throughout this booklet, we use the word *consumer* to refer to people with a lived experience of 'mental illness.' This word is not perfect – it can be a bit confusing, not all of us identify with it, and lots of us dislike it! There are more thoughts about this issue on our website (www.ourconsumerplace.com.au). It's never going to be possible to find a word that we all identify with, but we use *consumer* because



it's the best word we have at the moment!

In this booklet we put many words into inverted commas (like 'mental illness' and 'carer'). We use these words because they are commonly understood in the mental health field, but by putting them in inverted commas we are acknowledging that not everyone agrees with their use – these terms are contested.

For example, the idea of 'mental illness' is not something that all consumers identify with – some will express sophisticated intellectual, political or spiritual critiques of this concept. Others find it profoundly useful. The term 'carer' is also a term that for some consumers misrepresents the role of support people in their lives.

By putting these terms in inverted commas, we are acknowledging and respecting the diversity of understandings amongst consumers without suggesting there is a "right way" to think about these issues. Again, there is more discussion on our website.

Dedication & Acknowledgements

This series of booklets is dedicated to all people whose lives have been cut short by 'mental illness', and/or their experience of community prejudice and trauma.

Booklet #2, *Speaking Our Mind*, is dedicated to two visionary international consumer leaders, Shery Mead and Chris Hansen, who have enriched our understanding of what stories are and how we can change our relationship to our own stories.

We also owe a debt of gratitude to the New Zealand *Like Minds Like Mine* campaign, as well as Ann Tullgren, the NSW Consumer Advisory Group, Bill Moon, Michael Lockwood, and all those who contributed information and inspiration for this booklet. It has been a truly collaborative process. We thank all of you for your wisdom and insights.

Thanks also to the Department of Health (Government of Victoria) and Our Community for providing the funding and the support that allows Our Consumer Place to exist.

Merinda Epstein & Flick Grey
Our Consumer Place
www.ourconsumerplace.com.au



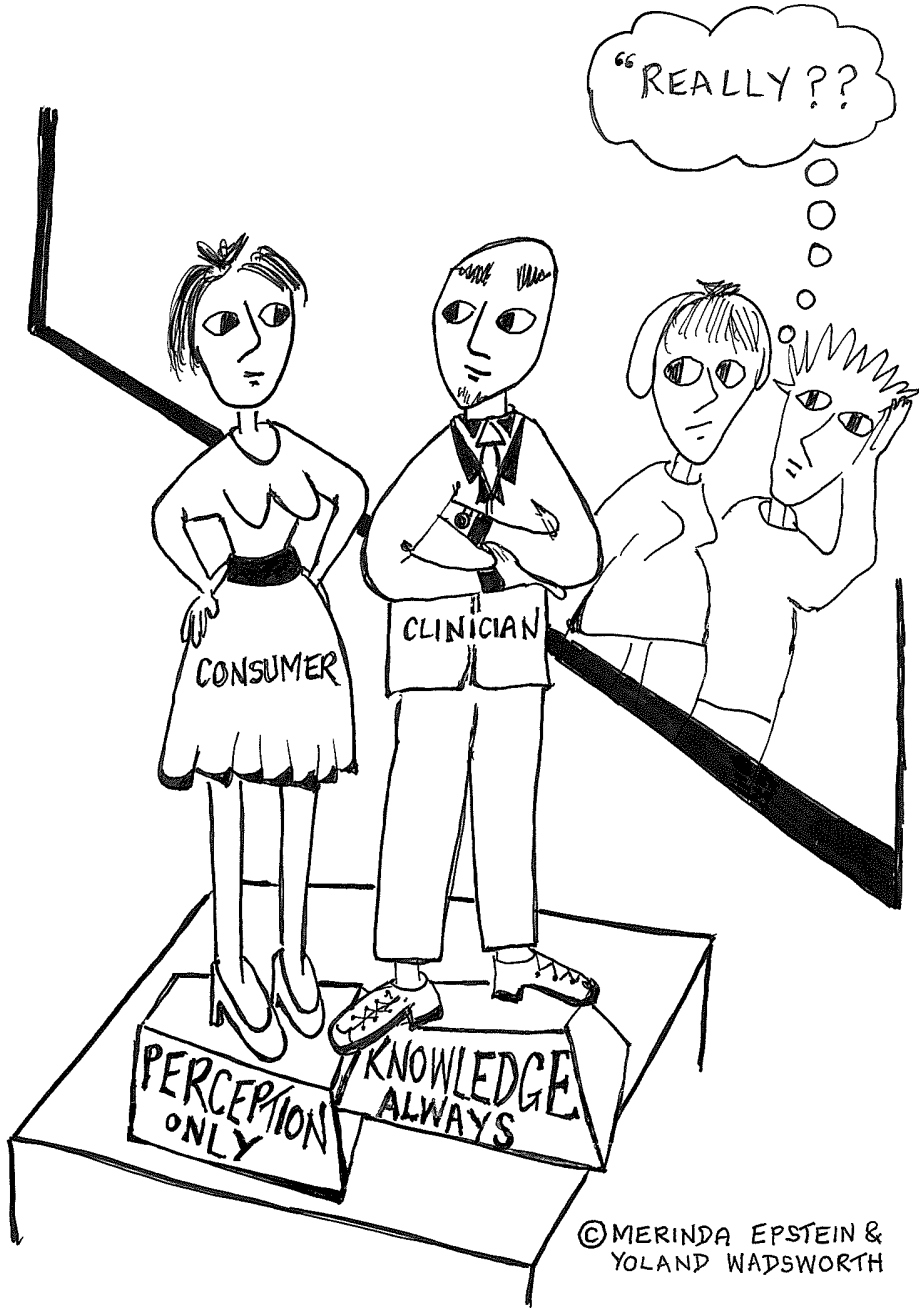
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Introduction



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The idea and act of sharing stories may seem fairly straightforward. But many consumers who have experience sharing their stories have found that there are many things to think about. Taking the time to do this thinking will make the experience more rewarding both for you and for your audience.

Storytelling can be a really powerful way to get a point across. There are skills and strategies that need to be developed in order to tell your story effectively, even for natural storytellers.

Many of us have told our story to various mental health professionals, sometimes different ones over many years and in very different circumstances.

Some of us have shared our story with friends, families or workmates – this can be a sort of “coming out.”

Others have shared our stories in public, in a range of settings from community events to conferences and classrooms.

And all of us have – in some sense – told our story to *ourselves*, making sense and meaning of our experiences.

There are also many different purposes for telling our stories: telling our story to a therapist during a consultation because we want them to help us involves a very different type of storytelling to sharing our story at a public rally to raise awareness of mental health issues, or disclosing our story to a colleague we intimately trust. We intuitively alter our stories depending on context and purpose.

‘Just’ telling stories?

An issue we tackle head on in this booklet is the idea that consumer stories lack legitimacy or authority. There are often negative connotations associated with the word ‘story’. Too often (our) stories are described as a ‘perception’ whilst (other people’s) ‘scientific knowledge’ is seen as the ‘truth’. This can influence the way clinicians and the general community perceive the value of our stories: pitting *truth/facts* on one side against *stories/perceptions* on the other. In such contexts, our stories may not be taken as valid knowledge the way professional knowledge is.

In many cultures, storytelling is a legitimate and indeed dominant method of conveying information – it is central to the very existence of the community and every child learns the skills of storytelling (including dance and music-making) from when they are very young.

While some recent migrant communities and Indigenous Australians have



these traditions to draw on, many of us don't have this background of a deep respect for stories. This is a terrible shame.

Our stories are a valuable resource for making meaning out of 'madness,' for changing perceptions and for educating the community and mental health professionals. There are many different contexts and purposes, ways to make your story particularly effective, and things to think about to keep yourself safe. This is what we explore in this booklet.

Using storytelling and story-making as techniques for communication

Storytelling is not just about telling our own personal stories. There are consumers all around the world who use the techniques of storytelling and story-making, particularly in their roles as educators. Here we have much in common with other oppressed groups including Aboriginal groups. These stories, as they are told, might have only minimal links to 'our own story'. For example, snippets from personal experience can be woven together to compare situations in an acute psychiatric unit that were experienced as life affirming, to others that were experienced as life negating.

The story is the tool that brings the learning clinicians' attention to the experiential parts of the way they interact with consumers. Sometimes story is used that comes from totally outside psychiatry. Every day when we walk down the street stories are played out and often these can be used effectively. Anything from the behaviour of a stray dog in the street to something that brings back memories of the actions of a school teacher who destroyed our love of learning can make a useful base for important story utilisation. Often in educational settings stories that come from places outside the immediacy of mental health services can sidestep the defensiveness or fear that shuts listeners down and means they do not make the connections we want them to make.

Another technique is to put yourself into a totally different part of your life where you had the power (rather than the 'consumer you,' who lives in a position of socially structured powerlessness). Most of us have wielded power over others (even if unintentionally) at some point in our lives. If we can convey to an audience that we now recognise we have, regrettably, also disempowered others, even if it was in a situation that had nothing to do with mental health, we gain an opportunity to dispel the defensiveness that can arise when people feel attacked. We focus

on the idea of power rather than the action of 'wrong doing' by others. By not giving the impression that we are 'all good' and another group is 'all bad' we open up important dialogue rather than close it down.

The idea of collaborative story-making is important as well. There are many contexts for this, ranging from peer groups writing and telling their collective



story of the group's evolution, challenges and triumphs through to a technique consumers use in running workshops with other consumers where we collectively construct a universal story of transformation or a 'better practice' story. There are many examples.

Finally, we can manipulate learning environments so active participation means that for a short while people experience psychiatric services through the persona of 'The Patient'. Two of the tools used by Our Consumer Place to affect this response are the Board Game, 'Lemon Looing' (Victorian Mental Illness Awareness Council 1993) and The Treatment Hunt (Epstein 2010). (Find out more about these on the Our Consumer Place website.) There is also a 'Hearing Voices' technique, which involves participants performing tasks wearing earphones that send them constant interruptions of auditory hallucinations.

Through these tools we can recreate situations of powerlessness, frustration, boredom, 'stuckness' and 'black humour' that are all-too-familiar parts of our story. Often the participants blame the tools for their frustration, becoming intimidated, bored and irritated (and sometimes only recognising that they've been pulled into our story when their experience is reflected upon at the end of the session).

'Narratives'

Sometimes the word 'narrative' is used in the mental health sector instead of 'story', partly because it doesn't have the same devaluing connotations, and partly because there are well-respected approaches that have been developed specifically using this term 'narrative'.

For example, the Dulwich Centre in Adelaide (www.dulwichcentre.com.au) uses a type of therapy called *Narrative Therapy*, which draws on the power of telling our stories for therapeutic purposes.

Another example is *Narrative Research*, which is a research method that explores narratives not for their therapeutic value but for their capacity to express social meaning. Narrative researchers are interested in the stories that people and communities tell to make meaning (e.g. see www.narrativenetworkaustralia.org.au).

Everyone's story counts

It's important to note that storytelling is not just 'for beginners'. People do not graduate from storytelling to something 'more learned' or 'more scientific'. Rather, experienced storytellers become more skilled at using their story to suit different purposes and different audiences. Some of us



are storytellers, some are not. Some of us choose to tell our own stories and some of us don't (and some people use stories, but not the 'story of their own life'). We resist any attempt to impose hierarchies on these differences amongst us.

It's equally important to realise that no one's story is more important, or more 'real' than anyone else's. We all have a story to tell if we want to. We also have the right *not* to tell our stories if that's what we choose: there are people who like to tell stories and people who don't. Neither is right or wrong. Storytelling is useful in so many contexts but it's not the *only* way of getting things done.

In Australia, much of the high-profile storytelling about 'mental illness' is left in the hands of a few celebrities, including high-profile people (like politicians and football players) who may have been diagnosed with 'mental illness' but have few connections with other consumers, and may not have experienced the (social class-related) realities of life for many consumers, including poverty, powerlessness, forced treatment, homelessness and public hospitals. Such people are brave in their own way, but they don't tend to draw on the wealth of collective experience of other consumers, and so while their stories have value, the community misses out on hearing the many other important stories. There's room for many more stories to be told.

In New Zealand, the national *Like Minds Like Mine* project (see www.likeminds.govt.nz) trains consumers to tell their stories effectively to counter the stigma and discrimination associated with mental illness. They understand the power of storytelling at a grassroots level as a way to fundamentally change societal attitudes and discrimination. We reckon this would be a wonderful model for Australia to follow!

Who speaks for whom?

"For centuries people with an experience of mental illness have been spoken and written about, often in derogatory ways.

"In many cases people are still speaking about or on behalf of people with an experience of mental illness.

"Yet people have a right to tell their own story. They have the right to withhold participation in another's story about them. The recent catch-cry in consultation has been: 'nothing about us without us'."

(From Like Minds Teaching Kit: Teaching Strategies to Counter Stigma and Discrimination Associated with Mental Illness, p.32)



Laying the Foundations



SOME COMMON CULTURAL MYTHS

STORIES ARE ...



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* **What is storytelling?**

A different way of knowing

"Storytelling reveals meaning without committing the error of defining it."

Hannah Arendt

Most cultures have a history of storytelling as a way of passing on information to the next generation or introducing themselves to people from other mobs, societies, communities and nations.

Australia has many long and proud histories of storytelling, from the strong storytelling traditions of Australia's Indigenous peoples, to those brought by early European convicts and settlers and other waves of migrants from Europe, Asia, the Americas and Africa, to the parables imparted by religious texts such as the Bible, the Koran and the Mahabharata. For many communities, story is life and life is story. For others, stories powerfully communicate important life lessons.

Methods of storytelling can include dance, music, poetry, prose, fiction, fables and illustrative proverbs or parables. Different cultures have different stories (although it is quite interesting to see how often the same themes re-appear in very different circumstances). In this booklet we focus on storytelling mainly in the written or spoken form, because this is where most of our experience is, but most of the principles would apply to any form of storytelling.

For consumers, storytelling provides a powerful way of imparting our experiences, including our considerable knowledge of the services and systems that serve the people diagnosed with 'mental illness'. It can help us to inform and educate friends, family and communities, as well as clinicians, academics and even other consumers about our rights and needs and those of the consumer community as a whole.

Through storytelling, people diagnosed with 'mental illness' have also found commonalities with other communities that have experienced prejudice and discrimination, such as Aboriginal Australians, from whose own storytelling traditions we (the consumer community) have much to learn. Most Australians have now accepted Indigenous storytelling as intractably entwined in the knowledge not only of medicine but of all sorts of scientific and other knowledges.



Indeed, it is important to note that the understanding that comes from the passing down of knowledge through storyline is just as significant as the knowledge that comes from the more widely acclaimed 'sciences' of the 21st Century. Stories are not the opposite of science. They are a different way of knowing.

Not everyone is comfortable using the word 'storytelling' to describe their 'illness' or experiences. That reluctance may be exacerbated by some of the judgmental ways this term has been used:

- **Stop telling stories!** *You're making it all up.*
- **I'm not listening to your silly stories anymore!**
You're not telling the truth or saying anything of value.
- **When are you going to grow out of this habit of telling stories?** *Storytelling is only for children.*
- **That's just an old wives' tale!** *I don't believe you.*
- **He tells a great yarn!** *His stories are entertaining but he embellishes the truth.*
- **Where did you get that story from?**
Your information comes from an unreliable source.

Despite these connotations, we continue to use this term because we believe that stories can be reclaimed as valuable, as many cultural traditions attest. We acknowledge that some people prefer to use other language that doesn't carry as many negative connotations – e.g. *narrative, experience, history, biography, etc.*

Even if you are comfortable with the term, you may not be entirely comfortable with the act of storytelling itself, for yourself, at least in certain settings, or to certain people, or ever. And that's OK too.



* Telling your story from a consumer perspective

Speaking in ways that support other consumers too

“On some positions, Cowardice asks the question, ‘Is it safe?’ Expediency asks the question, ‘Is it politic?’ And Vanity comes along and asks the question, ‘Is it popular?’ But Conscience asks the question ‘Is it right?’ And there comes a time when one must take a position that is neither safe, nor politic, nor popular, but he must do it because Conscience tells him it is right ... This is the challenge facing modern man.”

Martin Luther King from ‘Remaining Awake Through a Great Revolution’, 1968

Obviously we cannot (and don’t wish to) dictate what you say and how you present your story. After all, your story is *your* story. This is *your* view of the world.

However, no story, no language, no attempt to communicate, takes place in a political vacuum. Some consumer history will give you a context to consumers telling their stories.

A bit of history

Twenty years ago, mental health consumers – those people that mental health services are designed to serve – had very few chances to tell our stories publicly. Sometimes our stories contributed to the education of mental health professionals but, typically, if we were involved at all, we were wheeled in at the eleventh hour of the eleventh week of an eleven-week course, and then wheeled out again, giving students time to talk about and (sometimes) diagnose us afterwards!

This sort of scenario is now seen as abhorrent by many consumers and unacceptable by academics and professionals in many disciplines, though it does still happen sometimes.

In general, though, the territory has changed. We are no longer just stories added in to illustrate content. There are now many consumers teaching clinicians, defining our own roles, using ‘story’ when we choose, not using story at all if we don’t want to, making decisions about curricula, marking assessments and coordinating other consumers to teach particular sessions where they have greater experience and expertise.

The whole idea of moving from being just a “walking story” to being legitimate educators is an important one. However, it does not negate





the role of story – storytelling remains a very useful tool in the consumer’s kitbag. We’re just aware now of how our stories can be used *on our own terms*.

Speaking from a ‘consumer perspective’

‘Consumer perspective’ is a way of looking at mental health that values the lived experience of those who have been diagnosed with a ‘mental illness’ as a crucially important source of insight.

It’s based on a belief that, in the words of The Lemon Tree Project, “as individual consumers we are the experts about our own life and carry the wisdom to best articulate our own needs if we are accorded the time, space and means to do so” and that collectively we have an important and valuable understanding of ‘mental health.’ Sometimes consumer expertise is described as ‘lived experience.’ Our expertise and knowledge are often under-recognised and even undermined by society and social institutions.

As mentioned earlier, while everyone must of course be free to tell our stories in our own individual way, there are ways of approaching storytelling that respect ‘consumer perspective’ storytelling. This tends to mean that the storyteller:

- will be in some way linked with other consumers or the consumer community/movement;
- will not automatically and unquestioningly use the language of psychiatric experts – instead reflecting on whether or not this language makes the best sense of their own experience;
- will avoid making themselves look good by making other consumers look bad (e.g. by pitting one diagnosis against another, or making it seem as if they worked harder than other consumers to ‘recover’);
- will not pretend that there is a magic wand, simplifying a complicated situation to “inspire hope”;
- will not adopt the judgmental and divisive language of mental health services such as ‘high functioning’/‘low functioning’, ‘dependent’ etc., or adopt the mystifying language of the bureaucracy unless there is a very good reason for doing so;
- may choose not to speak in forums where they know their contribution will be tokenistic or where they have just been invited to tick the box which says ‘consumer participation’.



Conversely, less *consumer perspective* ways of presenting our stories include:

- automatically and unquestioningly using the language of psychiatry such as; “I’ve been a schizophrenic for 14 years”;
- stating or implying that “the real experts” in mental health are non-consumers;
- using terms that put ourselves or others down;
- trying to amuse the audience by emphasising existing divisions.

On this last point, while it’s gratifying to make an audience laugh and it can be easy to achieve this – for example, if talking to a group of mental health nurses it is relatively easy to get them on side by throwing into the mix jokes about psychiatrists – as consumers, it’s important to resist this urge. Deepening these divisions is in no one’s interests. Doing so simply reinforces the very reasons why clinicians often fail to communicate when they are expected to work in multi-disciplinary teams. It also simplifies genuinely complex problems (making it seem like ‘the problem’ is just ‘those people’).

There are also two particularly unhelpful ways that consumers sometimes position themselves in relation to other consumers, which we suggest you be wary of:

- *“Once, I too used to ‘behave like that’/‘act out like that’/‘not be compliant’/‘resist the help I was being kindly offered’, but now I have seen the light, ...” or*
- *“Once, I too was trapped within the mental health system which kept me dependent and taught me to see myself as a diagnosis instead of a full human being. It taught me to be compliant and unable to take charge of my life. But now I have broken away from the dangerous medical model and you will, too, when you think hard enough.”*

Both these approaches position the storyteller as better than other consumers and presume that other consumers should follow the same path as them.

We think it’s important that when we tell our own stories we are mindful of the broader consequences of what we are saying and how we are saying it.

* Going public

Stop! Before you do anything, think carefully

*"Promise me you'll always remember: You're braver than you believe,
and stronger than you seem, and smarter than you think."*

Christopher Robin to Pooh, A.A. Milne (author)

Remember that how you talk about your story (and to whom, and in what venue, and when, and how frequently – and if!) is entirely up to you. No one can tell you how to tell your own story.



Telling our stories in public

Of all the things we may do to enhance the community's understanding of 'mental illness', telling our own story is one of the most powerful. But, while it may seem relatively straightforward, it's often the hardest thing we can do, bringing with it an unprecedented level of exposure.

There are a number of considerations to keep in mind, particularly if you are thinking of telling your story in a public or semi-public forum.

Everyone likes to be heard and this is particularly pertinent for consumers, who may feel that they have been silenced – by family who are embarrassed by us, members of the general public who don't know where to look in our presence, and a mental health system that often fails to trust what we say. To be invited to hold the stage, even if it is only for 10 minutes, can be seductive – but think carefully before you commit yourself.

There are consumers who do other things to promote changed attitudes to 'mental illness' but who draw the line at telling their own story. One of the main reasons for this is because they believe that consumers should be seen as experts, with important information to impart to the community, not just the emotive human interest story which usually comes at the beginning or end of a forum and can be seen as fundamentally less informative than what the 'learned professionals' have to say.

Still, stories can be incredibly powerful; even more so when they come from a very personal place.

If you do decide to go ahead, the next step is to think about the boundaries and protections that you may want to put in place.

Realistically consider the exposure

Tongues wag and stories can be embroidered. Once you launch yourself, particularly into the public domain, there is no going back. Of course, you can ask your audience for respect, but be aware that whatever you say may remain in the public domain long after your presentation has concluded.

Remember too that telling your story may well be an emotional experience for you, especially if you are speaking publicly about yourself for the first time. Check with yourself if you are ready for that exposure.

Decide what's off limits

For all of us there are some parts of our lives and histories that are too close to the bone, too embarrassing, too revealing. Work out beforehand where your boundaries lie.

It's OK to have some parts of your story "off limits". Everyone will have a different line in the sand. Similar to when you go to an auction, work out your upper limit in terms of divulging personal information. Do this well in advance and certainly before you get to the venue.

Writing down the aspects of your story that should remain off limits helps because on the day it can be easy to get caught up in the event and divulge very intimate and sensitive material that you later regret.

If you do say more than you intended to, take care of yourself. It can feel very vulnerable or embarrassing. Take note and reassess your boundaries. It's also OK to experiment with these limits – you'll discover your boundaries by going over them sometimes!

Consider how you will talk about others

Everyone's stories are interwoven – it may be difficult to tell your story without talking about others.

If you are going to talk about others, you should get their permission or rigorously conceal their identity. Part of this is actually about protecting yourself from accusations of defamation or breach of privacy, as well as shielding others from unwanted exposure and embarrassment.

On the other hand, some people will be open to being part of your story (especially people who come out looking good!).

Decide what name you want to use

It's worth putting some thought into what name you want to use. You might be completely comfortable using your full name, or you may have a version of your name that you keep for this context (or keep away from this context) – e.g. a maiden name or particular form of your name, e.g. Bob/Robert.

You may not want to use your surname at a public event for privacy reasons, but this has an unexpected downside – it can reinforce a common community impression that people diagnosed with 'mental illness' are child-like (because it's common for children to be referred to



just by a first name). Some people create a fictitious surname. You can be upfront with the audience about these issues if you want.

Another alternative is to make up a name. In fact, you may consider 'making up' or obscuring parts of your story as well – altering details, names, venues or even states can allow you to speak from a little distance. Many people do this in written materials especially. Of course, dishonesty is not generally desirable but small changes in details can allow you to retain an essential honesty to the experiences you are speaking about, while also being self-protective. Again, you may wish to disclose to your audience what has been changed and why.

If you are willing to use your full, real name, it is a gift to other consumers – suggesting that you are willing to face the prejudicial attitudes without shame. But like any form of public exposure, the decision is completely up to you.

* The power of the parable

Working out what it is that you really want to convey

"All that passes is raised to the dignity of expression; all that happens is raised to the dignity of meaning. Everything is either symbol or parable."

Paul Claudel (1868-1955), French poet and diplomat

There are many different ways of telling our stories. The most obvious model in the context of mental health seems to be:

"I was very sick (or I suffered enormously or I acted very strangely), then I accepted help, and now I am better (or coping better)."

This style of storytelling can be appealing because it is chronologically ordered, culturally legitimated, conveys a sense of hope and often is met with positive feedback – especially if we had fallen to a very low point and can construct our story as one of heroic 'overcoming'.

But it's worth stopping to consider what people get out of hearing such stories. Unfortunately, the take-home messages of stories like this are likely to be (a) how dreadful your experiences were, (b) that the path you took is the path other people should take, and/or (c) that you are particularly brave or special.

It's worth considering that there are many other, often more powerful, ways to use our stories that honour the complexity and diversity of our lives.

One way is to tell our story as a **parable**, with a clearly thought-out message. There is an important difference between telling your story mainly as a truth-telling exercise, which can feel extremely cathartic and valuable for your own personal growth, and telling your story in a way



WE ALL TELL OUR STORIES DIFFERENTLY...



"MINE ARE REFLECTIONS OF MY EXPERIENCES, MY PERSONAL JOURNEY"



"MINE ARE OFTEN ABOUT MY GARDEN, THE FOOD I GROW AND THE MEALS I SHARE - KITCHEN TABLE STORIES."

"MINE ARE ABOUT FORCED 'TREATMENT' SURVIVOR POLITICS"



"MINE ARE FABLES, PARABLES, SYMBOLS OF OUR DEEP INSIGHT IN THE WORLD"



"MINE ARE ABOUT THE EFFECTS OF TRAUMA ON OUR EMOTIONAL WELLBEING"



"MINE ARE ABOUT FRESH AIR, MAGICAL PLACES, HOLISTIC MEDICINE AND..."



"MINE ARE 'WHO-DONE-ITS' BASED IN A PSYCHIATRIC HOSPITAL, WHERE I CONTROL THE PLOT!"



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that is conscious of the audience and what you want them to understand and learn. This is explained in more detail below.

The power of the parable

A parable is a short story that is used to illustrate a moral or ethical point. A parable doesn't have to be religious, but it must have a clear message.

Any good story should have elements of a parable – a sense not just of getting your story off your chest, but of a carefully considered message (more complex than “I suffered a lot. Mental illness is really awful!” or “I really have come a long way!”).

Parables are extremely useful tools for consumers because often part of the motivation for telling our story is because we want things to change – whether it is attitudes towards ‘mental illness,’ a discriminatory or disrespectful behaviour that we have witnessed, the inaccessibility of a valuable service, or the attitude of mental health professionals in certain contexts.

Below are some tips for writing a powerful parable.

Who is your audience?

Clearly define who the audience for your parable will be – e.g. the general public, psychiatrists, social workers, other consumers, etc.

Try to be really specific – for example, if you will be talking to psychiatric nurses, are these new nurses or veterans, or a mixture? This will influence both your message and how you choose to convey it.

Start with the moral

What is it that you want the audience to learn? Write or type out the moral of the story. This is your starting point. Examples might include:

- *You have to listen to people with ‘mental illness’ if you want to be supportive. If you don’t listen, you will make terrible mistakes.*
- *If you treat me like I am a 10-year-old, I will resent it and I won’t be ‘co-operative’.*
- *If you ask me 10 minutes before my interview with you in the acute unit whether I would mind students coming in I am most likely to say I don’t mind when I mean ‘yes, I do mind’. Power relations in acute units get in the way of good communication.*



Develop your story

Now it's time to start pulling all the threads together. Keep it simple. Concentrate on the parts of your story which best lead towards the message.

Parables work best when they are short so try to tell your story in 400 words or less. If you are delivering your story in a setting that requires something longer, try to knit together two or more parables (though this will work best if the stories you tell complement each other and they each reach, in sometimes quite different ways, towards the overriding moral).

There are strategies you can use that will allow you to stay honest to the spirit of the story while fudging details, either to protect people's privacy or to make the story 'work' more smoothly. Refer to the 'going public' section on page 21 for more on this.

An example of a sophisticated story:

Mary O'Hagan is a very experienced consumer leader from New Zealand who often uses stories in her public speaking.

A few years ago, Mary presented one part of her story at a conference in Melbourne. She divided up different roles in her story. Mary herself spoke as the commentator. Another consumer played the role of a younger Mary as a terrified teenager in an acute unit – this text was taken straight out of the diary Mary had kept at the time.

A second consumer played the voice of clinicians who were 'caring' for her – she obtained the text for this part from her clinical files (which she obtained through Freedom of Information legislation). In the storytelling, Mary melded together the voices of several individual clinicians into a "clinical voice."

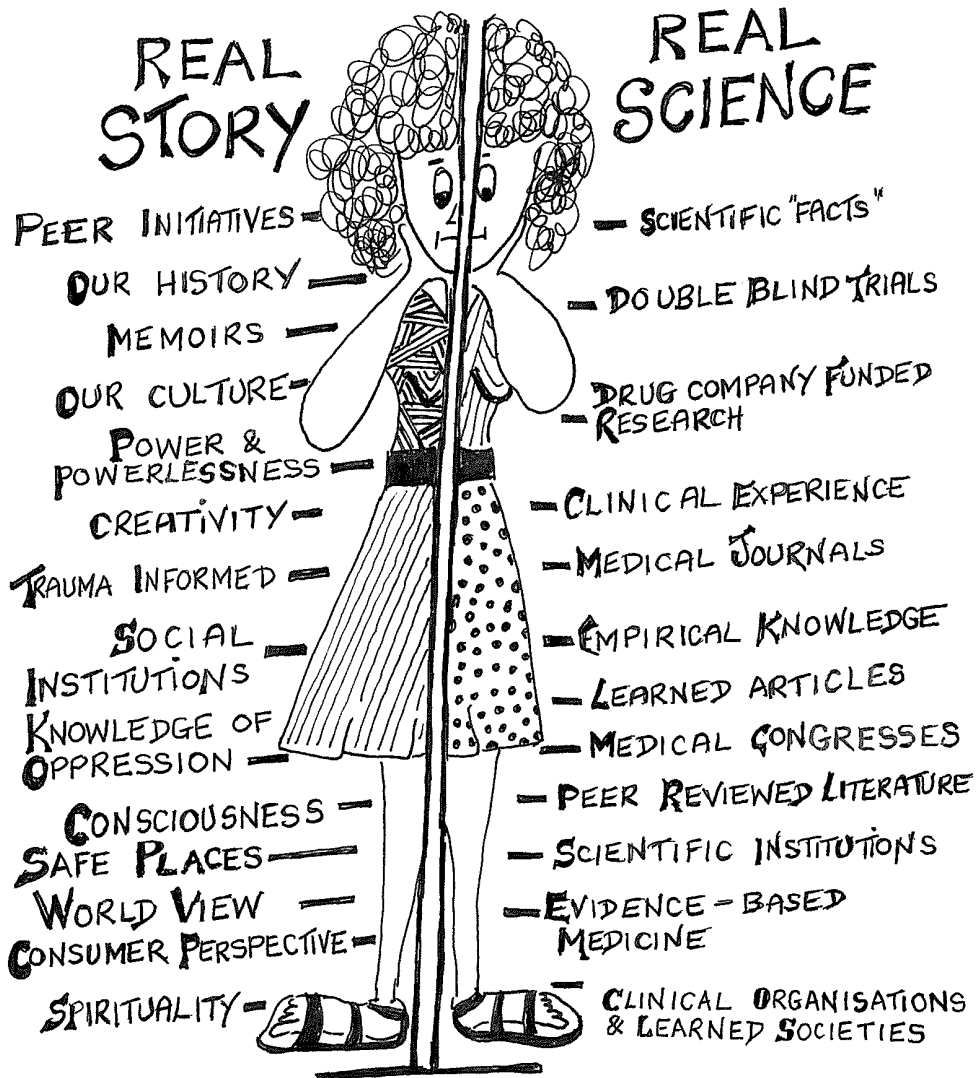
The point of Mary's story was to demonstrate the profound difference between the way she understood what was happening at the time and the way clinicians and the service understood it. In this way, the audience was able to experience how disempowered and misunderstood Mary was in that acute unit, and how clinical practices contributed to that.



REAL KNOWLEDGE

REAL STORY

REAL SCIENCE



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* Some examples of parables

We tell our stories by the way we live, create, love and die

"Until lions have their historians, tales of the hunt shall always glorify the hunters."

African Proverb

There are many recurrent themes that run through consumer storytelling. Here are some of them:

The walking dead: Pervasive hopelessness is one of the stories that the community seems only too willing to accept and expect. However, this can be turned on its head by a skillful storyteller. For example, Patricia Deegan (who has lived experience of being psychiatrically labelled and is also a practicing clinical psychologist) often writes about people whose lives have been reduced to absolute hopelessness by mental health systems and services that spread hopelessness and helplessness. However, Deegan tells these stories in ways that politically challenge community acceptance of this hopelessness.

Re-awakening: Finding hope and a capacity for joy in small things and small changes we ourselves make is another common story – one that certain people with power over us both want to 'hear' and also not 'hear' because they are afraid. Often, they are more comfortable hearing how our lives have been improved by how they helped us.

Canaries in the mine: This is a story which tells the community of our unique capacity to interpret early warning signs of a society that is deeply distressed. It suggests that we have sensitivities that we can start interpreting as important gifts we can give our communities, reading warning signs, a skill that is respected in many smaller-scale societies.

Creativity: There are many clichés about people with 'mental illness' and creativity. There is also truth in many of them. As we offer creative solutions to illness talk and find life and stature from creating we weave another new chapter to the community story about 'mental illness'.

Searching for a better world: Many of us plait stories together as we, in many different ways, start fighting for a better world. Sometimes these stories are told through our daily lives: bartering for what we need, finding cheap and wholesome places to get a meal, managing pensions



creatively, growing our own food, meeting with others, some of whom have experienced 'mental illness' and increasingly those who have not

Spirituality: Many people tell their story through their spiritual beliefs and actions. These are not always organised religions. Through their spirituality, people's way of living with emotional distress changes and new stories emerge, with a stronger core system of values and beliefs. Spiritually driven stories often speak of acceptance and grace.

Real Community: Some people tell their stories through community – real community. Knowing we belong can dramatically change the way we live our stories. The communities might be consumer communities but are not necessarily. Peer support helps us to change our stories from dependence to supported independence or interdependence, from isolation to empowering commitment to each other, learning how to challenge and be challenged.

Fighting for freedom: having a 'cause', whether it be fighting for our rights as people with 'mental illness' or fighting for new policies to tackle environmental destruction, fundamentally change our stories and the activities we undertake that tell the larger community who we are.

Consumer initiatives: As we become increasingly involved with others who have traversed similar journeys our stories start to change and gather communally. Together we can forge stories of success rather than stories of failure, moving towards new ideas rather than away from old shame.

Leaving services behind: It is amazing how often our stories cling (often longer than is necessary) to therapeutic interventions in our lives. Moving on from this can be hard but the new stories that emerge can transform us and even create totally new beginnings.

* Knowing when to say no

When it's not a good idea to use your story

"History is a symphony of echoes heard and unheard. It is a poem with events as verses."

Charles Angoff: Journalist and author (USA), born 1902 died 1979

Your own personal story is a precious gift which deserves to be treated with respect. Yes, you might play with it, teasing it to produce a bountiful supply of anecdotes and wisdom to share with others. However, every



person draws a different line in the sand about when, where and how they use their own experiences.

When and what to disclose, to whom, and under what circumstances is a major, extremely personal decision. Nobody has the right to question your decision or push you one way or another. Don't force yourself out of your comfort zone just because you think you should. But, do push yourself out of your comfort zone if you want to!

It's best not to talk about things that continue to cause you great pain. Though some consumers rely on storytelling as an important tool, many even very experienced consumers never use story. Some try it and get burnt. Some try it and find that it feels right.

Are you afraid that telling your story in public will embarrass your family, reveal too much to your colleagues/friends, or injure your professional relationships or career? You have to assume the possibility that everyone in your life might someday get to hear about everything you say in public. You must remember that once the words leave your mouth they become public property and can be manipulated by others or retold with different emphases.

Stories and meetings: can they mix?

There are 'formal' places where storytelling is seen as non-professional and inappropriate. An example is non-consumer meetings – meetings that, for example, might focus on issues that are important to bureaucracies and service providers, rather than service users. We have coined the term 'other people's meetings' for these contexts.

As a consumer, you may well be a tokenistic inclusion in these meetings; the other participants may not **really** want to hear from you. Unfortunately in 'other people's meetings' using story often works to further silence us because other participants may believe they are far too important, too 'efficient', too purpose driven and time limited to listen to 'mere stories'.

If you want to get messages across in these settings, as they presently exist, it is sometimes best to play the game and pick one or two points and argue them in the same sort of ways as other meeting participants operate. Save the stories for places where they will be appreciated.

That said, there are some important research projects that have demonstrated how meetings could be transformed into much more powerful vehicles if they were reshaped so they could embrace our stories. Anyone who is interested in the ideas of consumer stories and meeting practices might wish to have a look at *The essential U&I*, a compilation of three years of consumer evaluation of acute psychiatric

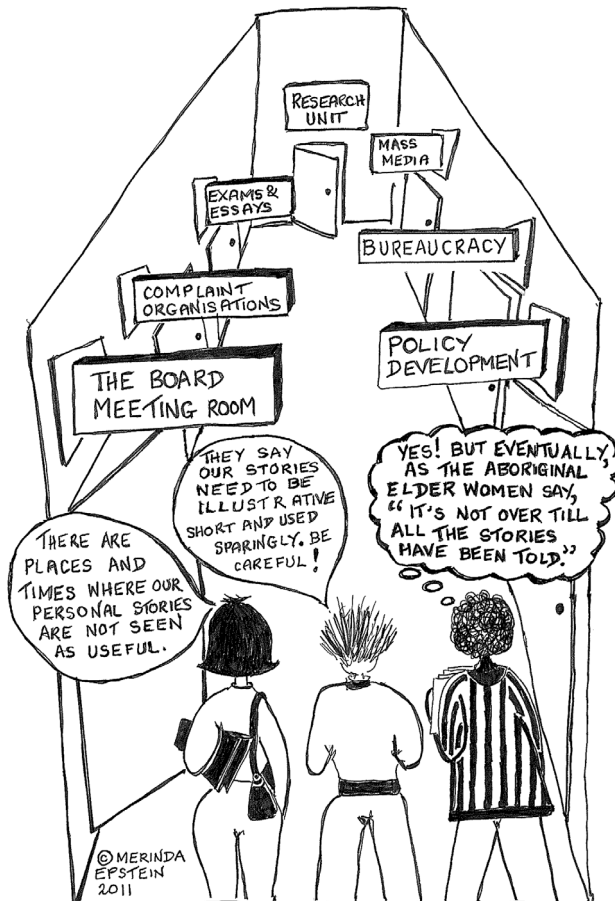


hospital practice. The author describes the transformation of a Project Planning Committee into a Collaborative Committee, precisely because it became evident that losing the stories from the meetings would leave the committee impotent. Instead, each meeting was taped and transcribed and the stories became part of the data that was collected for the research. Decisions were also made in the meetings – storytelling and decision-making can co-exist!

Later, the idea of 'Deep Dialogue' emerged from the Collaborative Committee. Structured exchange of stories between staff and consumers was facilitated. There were strict rules which were designed to enable everyone's stories to be honoured.

For more information, see:

- Wadsworth, Yoland, ed. (2001), *The essential U&I* Melbourne: Victoria Health Promotion Foundation.
- Epstein, Merinda and Helen Lee, *Deep Dialogue Project*. An evaluation of the Deep Dialogue Project and a paper, *The Chocolate Cake Factor*, can be found on Merinda's website: www.takver.com/epstein



Storytelling Settings





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* Telling your story to yourself

My Story, Myself

“History is a symphony of echoes heard and unheard. It is a poem with events as verses.”

Charles Angoff: Journalist and author (USA), born 1902 died 1979

This section was written by Hobart-based consumer Ann Tullgren. It is an example of quite sophisticated storytelling – Ann uses both her own personal story and a storytelling approach to tell a much larger story. Ann is co-author of the textbook ‘Social Work Practice in Mental Health’, (Allen and Unwin, 2009) and an Honorary Associate of the School of Sociology and Social Work at the University of Tasmania. She is passionate about developing the role of consumers as educators.

When I was born, I was whole and full of promise; a Rubik’s Cube still packaged for sale, before anyone twists, turns and distorts the colour pattern only to find it near impossible to get it back to ‘normal’.

At least that’s what I thought.

Looking back, the stories I told myself as a child resembled fairy tales: I was Sleeping Beauty, or Snow White, or the Ugly Duckling, or the girl child in the story of the gingerbread house and the wicked witch. It was no great leap of imagination to think I was the eighth member of The Secret Seven, always ready for adventure. Whatever the trials and tribulations, the ending always came good.

In a similar manner, as I grew older, I embraced the plot-lines others had for me: work hard at school, keep the Faith, go to uni, travel, find work which is meaningful. Then, get married and have kids

But when I was in my mid to late teens the storylines became fractured and I no longer had words for the evolving plot.

This was the onset of mental illness.

I embarked on conventional treatment: I consulted a psychiatrist and spent a lot of time in hospital. I learned a new language to describe this radically reshaped life; it was the language of diagnosis and treatment.

It was useful to have words and concepts to make some sense out of my experience and to explain it to others. And, at the same time, I felt rather clever that I had learned so quickly (and could spell and



pronounce) the labels, concepts, names of the medications, and the sad prognoses. Embracing science, I cast aside those quaint and comfortable colloquialisms: 'a touch of the vapours', or 'a kangaroo loose in my top paddock', or 'fairies at the bottom of my garden'. Instead, I had endogenous depression, and later on, bipolar disorder.

Looking back, I was imprisoned by a web of jargon and ideas. Michel Foucault says that the postmodern use of power isn't about manacles or walls. He says we learn to become our own jailors by using the official discourses of failure and brokenness – a far more effective confinement.

In the end, the language of medicine was the language of disease and deficit, not the language of strengths, possibilities and transformation.

Yet, to think about it another way: did the dog (myself) wag the tail, or did the tail (this madness constrained, contained and replicated by the jargon and ideas of medicine and science) wag the dog?

It was much later in life that I learned other ways to story my life, ways informed by literature, poetry, sociology, religion and philosophy. Alongside biomedical understandings of madness sit other meta-narratives – class, gender, poverty, religion, family, sexuality – which layer the storying, making it more subtle, opening up possibilities. But, in the end, the language and stories of possibility, of redemption and change, come most poignantly from poetry and art.

Hope comes in a Haiku.

I have moved beyond the facile fairy book construction of childhood where I thought that I could only reach 'heaven' (a better place) by keeping the Rubik's Cube of self unsullied and safe from harm. I am content to keep the books of science and psychiatry on a shelf, where I can consult them when I need to. My pills are in the dosette box next to a glass for water (they help).

But, I have learned that my route to 'heaven' (what is possible) is through the back door: what really matters is how I story for myself my suffering, my heroism and my humour. The language of poetry is indeed fit-for-purpose. It can heal the wounds left by reason.

* Telling your story to mental health worker(s)

Where your story meets your ‘case history’

“A meeting with a psychiatrist need not be a confession!”

From *Reclaiming your power during medication appointments with your psychiatrist*, By Patricia Deegan, consumer and clinical psychologist, National Empowerment Centre, Boston, USA

For many of us, one of the most common situations in which we ‘tell our story’ is to mental health workers – often many times, to different professionals, in different contexts.

Some of these people – a GP who schedules patients in 15-minute blocks, staff at the emergency department of your local hospital – work under massive time pressures. In such settings, there’s often not enough time to share as much of your story as would be needed for real understanding.

At the other end of the spectrum, in many ‘talking therapies,’ the telling of your story – in intimate detail – is central to the process. However, even in these contexts, there are ways in which storytelling is complicated by issues of power, clinical orientation, and different styles of relating – ranging from very intimate to quite remote.

It is important to be aware of some of these issues because it’s possible to get hurt trying to tell too much of your story to people who are not employed to listen in the way we may want, but instead are expected to act swiftly, diagnose, prescribe and look for signs of stress in our voices and body language rather than really listening to what we are actually saying.

Many clinicians are taught that ‘through science and study they must know’ – to them, story is not science.

Turning our stories into ‘a history’ – the inevitable medicalisation of our stories

The difference between ‘taking a history’ and ‘sharing our story’ is a matter of perspective. When a mental health worker ‘takes a history’ the perspective is clinical – they listen, ask certain questions and record what they understand from what we are saying, using clinical concepts, medical jargon and sometimes judgment.

Even when we try to emphasise those parts of our story that are important to us, the clinician may be listening for different information that they’ve



been taught to listen for as part of their history-taking recipe. While this can be both necessary and helpful, it can also feel like they're not really listening, because *they are not listening in the way we might want to be heard!*

This can also be a form of co-option – not only of the content and language we use but also of the emphasis: what is important and what is not. Some of us challenge this, some of us find the predictability deeply reassuring, while others have no idea what's going on (or don't care). None of these approaches is right or wrong. However, the emphasis here is for those of us who want to keep as much control of our stories as we can.

Here are some systemic issues that might impact on your experience of telling your story:

'Observation': clinicians are taught to *observe* and sometimes do not *listen* very well, especially in acute psychiatric settings. It's also worth bearing in mind that *we can observe too!* Some mental health clinicians will be thinking about other things and may not be listening to us when we tell them our stories (beyond getting an initial 'history').

'Venting': this is a term used, usually in acute settings, to dismissively describe our actions when we talk about important aspects of our story which might not seem relevant (to a strictly medical interpretation of our circumstances). Some of us just put this in the box of thoughtless language and try not to take it too personally, and make sure we don't use it ourselves. Others feel angry about the disrespect it implies.

'Compassion fatigue': Remember that many people working in the psychiatric system, no matter what their qualifications and roles, spend their days working with many consumers. This can be hard emotional work. Some of the very best clinicians acknowledge their responsibility to understand and deal with their own 'compassion fatigue.' This may mean they need to take breaks from listening, which many of us find hurtful. If this is your experience, you're not being odd! It's the strange nature of clinical relationships – they are lop-sided and artificial in many ways, even though they may feel very important to us.

'Safety': Despite community assumptions that psychiatric services, therapy and other clinical interventions are there to 'help people,' they are sometimes unsafe places. Be careful about how and where to reveal parts of your story that are particularly traumatic or private (e.g. abuse histories) – especially if you haven't revealed this information before. The busyness in acute units and the crisis-driven, in-and-out admissions of public psychiatric hospitals make disclosure to crisis team members or contact nurses, for example, sometimes hazardous. Some respond well

but others don't have the skills or the time to be helpful and this can be psychologically dangerous. It is OK to withhold any parts of your story you want with any clinician. No mental health worker is a priest and they have no right to demand a confession!

There are clinicians and then there are clinicians!

Different clinicians have different skills. Obviously, there are big differences between individual clinicians and it is not uncommon for 'good' clinicians to be chastised by senior staff for "wasting time" or "allowing themselves to be manipulated" by those of us who need our stories to be heard with regard.

Others find it impossible to find the time to listen properly. Some are just plain inexperienced and are not getting enough supervision to develop the skills they need.

In some circumstances, we can try to find a different person with whom to share our story. Unfortunately, in the public system, we rarely have a choice over who our 'case manager' is.

Case workers can come from different clinical backgrounds, including social work, psychiatric nursing and occupational therapy. Some disciplines give a better grounding in genuine listening than others.

It can be difficult to find out which clinicians have what training in multi-disciplinary teams. It is OK to ask questions about their qualifications, or what their inclinations are in terms of therapeutic approaches. Some might tell you what they think you want to hear rather than what they actually do. Nonetheless, it is worth questioning if you are confused or unsure.

Talking Therapies

In the various forms of psychotherapy (or 'talking therapies') there can be an opportunity for us to really share our stories with clinicians.

Firstly, there is more time! Secondly, certain talking therapies understand the relationship between 'therapist and client' as central to the therapeutic process, and there is more place for storytelling here. However, there are still issues to consider in the way we tell our stories in these contexts.

- **Talking therapies are not all the same.** For example, 'narrative therapy' – in theory at least – is one that honours story and has formed a central place in some indigenous ways of social, emotional and spiritual renewal. However, some consumers argue that the whole idea of 'narrative therapy' colonises our stories and relies too much on interpretation and clinically driven re-working of our stories, taking from



us something as basic as our understanding of our own lives. Not all consumers think this, however – there are many who find this type of therapy refreshing and powerful.

- **Despite any touchy-feelies, power is at play.** There is a huge power differential between a client and a therapist. The reality is that the clinician's interpretation of our stories will be the one mental health services, and other social institutions, are more likely to believe. In most relationships, it is the person with least power who can see the power dynamics – often the people with power don't even realise that power is a factor! There are many ways we might react to this power imbalance – it can be tricky to maintain our self-confidence; we might try to 'please' the therapist and tell them what we think they want to hear; or 'rebel' and get angry with them, partly for their power; or we may become passive and allow them to dictate what avenues are explored and what is 'important'.
- **"The point is to change it."** Many therapists see part of their role as helping us to re-think our stories. Many of us find this incredibly powerful and transformative. But if the clinician is not upfront about what they are doing, this can lead to us feeling unheard and manipulated. Sometimes talking therapies involve finding 'new, more positive scripts' to tell our story through. Others push us to focus on the 'here and now' and leave behind our (hi)stories, focusing instead on changing our 'wrong thinking' and 'dysfunctional behaviour'. These are really helpful strategies for some people, and infuriating and pointless to others. In either case, it's best to know your options (when choice is possible).



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- **Listening (only) for certain things:** Therapists are taught to listen for certain things determined by teachings about pathology. This can be quite damaging for some people who end up feeling that everything is fixated on the 'bad' things about us, or on details that just aren't that important in our experience. There can be a fine line between useful and transformative professional insight and frustrating professional tunnel-vision.

A final note about “confidentiality”

Although we should have a reasonable expectation of professional confidentiality – that our personal stories will not be aired and shared outside clinical boundaries – not everyone has the same ideas about exactly what this means. For example:

- **How do you feel about your story being used as a teaching tool?** Some mental health workers participate in writing, teaching or speaking at conferences, and they may want to use examples from the 'case histories' in their professional experience. Sometimes they pick parts from different stories and integrate them into a new story, de-identifying the information and presenting a 'case study' that is not identifiable as one particular consumer. Some of us are happy with this, so long as we are not identifiable. Some appreciate being part of making things better for others in the future. Others intensely dislike being re-interpreted and treated as a 'case study'. For many of us, we need complete confidence that our stories will not go outside the consulting rooms – including to other medical professionals – feeling that any use of our story elsewhere is a violation of trust. Others strongly want our stories to be told, but are adamant that only we can tell our stories, on our own terms.
- **Sometimes an over-emphasis on 'confidentiality' can feel oppressive:** Conversely, there is sometimes a hyper-vigilance amongst clinicians about 'confidentiality' without asking us whether we would like part of our story told, to whom, by whom and for what purpose. This hyper-vigilance can feel patronising or insulting, as if our story is so shameful that we couldn't possibly let anyone know about it.

If you have any concerns about confidentiality or privacy, you might consider thinking about what you're comfortable with and make this known to anyone to whom you tell your story.

Some of the material in this section was adapted from:

www.psych.uic.edu/uicnrtcl/raisingissues.pdf

We gratefully acknowledge their great work!



* Telling your story to friends/workmates/ family/community

Disclosing to the people close to you

The universe is made of stories, not of atoms."

Muriel Rukeyser (American Writer, 1913-1980)

For some people, telling their story to family and friends is more difficult even than telling their story to an auditorium full of complete strangers!

Perhaps this is because the stakes are higher – people we care about can disappoint us or hurt us terribly. A parent may react by becoming meddlesome and controlling, or by disengaging, acting obviously



QUOTE FROM A YOUNG HOMELESS WOMAN
CIRCA 1993. FROM "IN A NUTSHELL"

uncomfortable (but adamantly not wanting to 'talk about it'); a friend you assumed would be open minded might stop trusting you with her kids, or may start becoming overly 'helpful,' offering unwarranted advice and doing things 'for you'; a trusted sibling may pass on to other family members private information that you really didn't want passed on. Or worse.

There are many risks in 'coming out' to our nearest and dearest. For most of us, though, it's important that some people close to us understand what we are going through, or that they know our history.

Many of us also find that sharing our experiences with people who already know us beyond our 'mental illness' has a huge impact on de-stigmatising and encouraging better understanding more generally.

Unfortunately, though, it's not entirely possible to predict how different people will react – someone we expect to be prejudiced will genuinely surprise us with their warmth and understanding, whereas other people who are outwardly 'cool with it all' will actually be struggling to come to terms with it, or may be downright hostile.

Many different stories

Remember, you don't have to tell anyone everything (or anything).

It can be tempting to feel like you're being 'dishonest' if you don't tell friends and family 'the whole story' about 'what's happened'. Or you might feel the opposite way, like no one needs to know anything about 'it'.

Ultimately, only you can decide how much you want to disclose, and how you want to do it.

It's worth developing different versions of your story that feel appropriate for different circumstances, each of them as honest and revealing as you want them to be. Often, it's appropriate to gloss over or fudge details to protect you or other people – perhaps Grandma only gets told that "you have some ongoing health problems so you aren't able to work anymore," while your favourite niece may be open to hearing about the suicidal experiences you've been having or your recent psychotic episode, because she can sit with these conversations. Perhaps it's appropriate to tell your old mate that you "have had a brush with 'mental illness'" (with no mention of how it currently affects you) while another friend will chat in detail with you about the struggles you've been through, without any diagnosis or even any idea of 'mental illness' necessarily being mentioned.

No one has a right to know what you've experienced. Some people may probe and ask questions you are not willing to answer – in these cases, it's good to have thought beforehand about what you are comfortable disclosing and what you might either fudge over or possibly even be



untruthful about – you might have an almost-truthful story to cover over an episode you're not comfortable sharing (e.g. gaps in your employment history, or particularly difficult experiences).

Like any kind of lying, there is the danger that you will be found out and lose trust and credibility. You might also feed a stereotype that people with mental illness are untrustworthy. But for some people the stakes are just too high to be completely honest in every single context. It may feel more appropriate to clearly state, "I'm not comfortable talking about that".

Some people will surprise you – you might find yourself pushing a bit further and sharing more information with someone who has asked a particularly thoughtful question, or discloses their own history, or shares a story about a similarly difficult personal experience. Sometimes sharing this vulnerable, tough or truly remarkable part of ourselves can take relationships up to a whole new level.

It's up to you to weigh up the pros and cons of telling particular people specific information. Remember, it's always easier to add details later than to subtract them once they've been shared!

When a story just happens

Sometimes, we tell our story without planning beforehand that this is what we are going to do – it may be that we feel safe in an environment, or for some reason it feels appropriate to do so.

While this may work out just fine and may even open up wonderful or important conversations that might otherwise not have been had, it can alternatively (or simultaneously) lead to us feeling ashamed, embarrassed, or distressed. Perhaps we've ended up sharing more than we intended to share; for example, a part of our story that is especially painful, shameful or confusing.

These things do happen and it's good to get support if needed and to take the time to reflect on the situation later – maybe we've gained a clearer idea about what feels safe/unsafe to disclose; or maybe we realise it's time to go back and reassess our boundaries!

It's important to be aware that many of us work out how much we feel comfortable sharing by pushing our comfort zone, or over-sharing, or experimenting. These are all normal experiences.

* Telling your story at public forums/conferences

Some hints if you're going to go public

"As long as there are human rights to be defended; as long as there are great interests to be guarded; as long as the welfare of nations is a matter for discussion, so long will public speaking have its place."

William Jennings Bryan (American politician and orator, 1860-1925)

There are many different contexts in which you might have an opportunity to share your story in public – either by invitation, or by putting yourself forward. There is increasing public interest in the issue of mental health, and many people are interested to hear personal stories.



Public speaking is difficult for most people. It's nerve-wracking to stand in front of a big audience and speak, especially when you're speaking about yourself. It's extremely common for people – even seasoned public speakers – to get very nervous. When the subject is 'mental illness' and we have chosen to talk about our own experiences – not *his*, or *hers*, or those people down the street's, but *our own* – then we get into even more nerve-wracking territory.

Mental health consumers, as a group, are often the recipients of negative community discrimination, prejudice and oppression. Public audiences most likely have unconsciously absorbed these dominant cultural beliefs.

To speak in public to such a group is therefore extraordinarily brave; you may feel as if you are putting your head on the chopping block. For those who do accept an invitation to speak publicly as a consumer, the dangers are usually outweighed by their drive and passion to help others understand 'mental illness', to talk about psychiatric institutions from a first-hand, consumer perspective, and to demand that things improve for those coming after us.

It's important to understand who your audience is and what they might want, need and demand from your presentation. Ask the organisers what they think the audience will want. Try to cater to that, while also staying true to what it is that you want to convey.

People in a community setting will not understand medical acronyms or jargon, so don't use either. If you have a written speech, road-test it on someone without the specialised knowledge that you have to make sure it makes sense to them.

Even people who come to a public forum with quite prejudicial views about people diagnosed with 'mental illness' might be genuinely keen to learn. In a community setting it's important to try not to jump too quickly or heavily on people who are naïve and say silly things (or things that seem silly from your perspective). Seasoned consumer speakers have learned to let some language and comments go without commentary, believing that if people have made the effort to come along, at least they are thinking about the issues.

If you know you are going to get really angry about the language that others use or specific attitudes that they may have, think about choosing, say, two things that you will comment on. Let the rest go. You are much more likely to have your point heard.



A note about ‘carers’

Public community events frequently attract ‘carers’. Many of us understand that both consumers and ‘carers’ have a right to be heard and that ‘carers’ also have a large investment in what happens to people diagnosed with ‘mental illness’.

However, it’s not uncommon for such groups to offend each other, usually without any intention to offend. We just often have different priorities, experiences and messages. Be prepared for that if you are speaking to an audience that may include ‘carers’.

Sometimes consumers and ‘carers’ are both on the speakers’ program. This can be tricky. You may need to weigh up the need to ‘correct false impressions’ (as you see them), with the need to recognise the ‘carer’s’ right to speak and to have their experiences heard.

In such circumstances, if a ‘carer’ says something that seems really offensive, it is probably the consumer speaker’s responsibility to gently question it. Bear in mind, though, that the less often you do this, the more impact you will have when you do. The same issues apply to other speakers on the program, including clinicians.

A final word

Over the past few years, there seems to have been a shift in the community’s receptiveness to hearing personal stories about ‘mental illness’. Much of this interest is real curiosity, and a desire to be part of making progressive changes to how people with ‘mental illness’ are treated.

All too often, though, isolated consumers are expected to “speak for all consumers” or speak with very little support. Other times, stories are encouraged, but they are considered supplementary to what the ‘experts’ have to say. Sometimes, the only storytellers who are encouraged to speak are those who will present a comfortable story of how the mental health system, who will say that the current system is fundamentally fine, it just needs more money to help more people.

We hope that more consumers will share their stories from a consumer perspective and with clearly considered messages. There’s so much room for more of our stories to be shared, and we would like our stories to be treated as real knowledge.



* Telling your story to the media

The media can be a powerful tool (but are notoriously fickle)

"What is laid down, ordered, factual is never enough to embrace the whole truth: life always spills over the rim of every cup."

Boris Pasternak (Russian poet and novelist, 1890-1960)

The media are often extremely interested in consumer stories – we can be used to add colour, personal flourishes and drama to their material.

Consumers may be involved in magazine or newspaper articles, radio interviews or stories, and occasionally television broadcasts. Of course, these days consumers are often producing and participating in our own media –the radio, TV and especially in cyberspace are all now full of articulate, passionate consumers speaking on our own terms.

This section is about telling your story to the sections of the media that aren't controlled by consumers.

All too often, the media seek out consumers to tell their stories to give an article a human interest angle, while the rest of the article is based on information provided by 'other experts'. This context isn't always apparent when you are asked to be interviewed, and it always pays to ask questions (although, don't assume you'll be told everything that you want to know!).

The media can be such a powerful vehicle to get a story and a message across, and so it's worth considering getting involved. Just be aware that the experience can be damaging, since the journalist's or media outlet's interests are not always the same as consumers' interests.

As with all storytelling, it's important to consider what message you want to convey, what your intention is, regardless of what the journalists' intention is. Journalists will often ask questions that probe into areas you haven't prepared for or that reflect their ignorance about the issues.

Most of the general tips for public speaking apply equally to speaking with the media. However, the media are often interested in particular qualities in a speaker – seeking someone who is fluent, friendly, flexible and confident. No matter how worthy your content, the media tend to be interested in style as much as substance.

In the context of mental health, they may also be looking for a particularly 'good story', which isn't always the same as 'important' or 'revealing'. Often it means sensational, amusing or (conventionally) physically attractive.



It's (unfortunately) vital to be vigilant with what you say to the media. However friendly you think you are with media contacts, however lovely they may seem as a human being, if you say something controversial and it's a good story, chances are they will run with it.

These are some common pitfalls. Journalists and other media professionals may:

- Sensationalise details that are not actually that big of a deal to you (e.g. dwell on a particularly visible self-injury or on some passing comment you've made about making your kids suffer);
- Delve into aspects of your personal experience more deeply than you are comfortable with – journalists are trained to probe. They are often skilled at asking questions of their interviewee in a relaxed way that builds trust, as a strategy to get more information! Many of us have found ourselves becoming relaxed and disclosing more than we had initially intended to. This is especially hazardous when the material is then going to be made very public!
- Cut and paste quotes or information in a way that conveys a different meaning than was intended (this is terribly common, as anyone who has been interviewed will attest);
- Cut the interview very short (e.g. only include two short quotes from an hour-long interview), so that the interviewee can be left feeling that what they said is not important, boring or in some other way unworthy.

Be aware that this is how the media works, and that it's not a personal failing on your part. Natural storytellers need to be especially careful. Most journalists see themselves as the storytellers. They won't just retell your story, they will reinterpret it! Instead of telling a story, you might want to pick out three important points and keep coming back to them. (Don't be shy about this – politicians do it all the time!)

Media exposure breeds more exposure

It's also worth knowing that media exposure tends to lead to higher recognition, which then makes it more likely that you will be called on again.

It's not uncommon for an 'out' consumer to become 'the voice' of, for example, a particular diagnosis or experience (e.g. suicidality, hearing voices, or seclusion), and you may find yourself becoming a spokesperson not only for your particular experience, but for the field.

While this is flattering, you might want to consider if this is what you want, if you would prefer more diversity of voices being included, or if you've moved on to thinking about other things!





JUST WHO **IS** THE STORYTELLER ?

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* Telling your story in the new social media

An easy way to share stories?

“Miracles are a retelling in small letters of the very same story which is written across the whole world in letters too large for some of us to see.”

C. S. Lewis

‘Social media’ – YouTube, Facebook, Twitter, LinkedIn, blogs – use online and mobile technology to facilitate interaction. In this way, it contrasts with the mainly one-way flow that exists in traditional media such as newspapers, radio and television.

New media has made it much easier and faster for anyone to create and share material. On the one hand, this is exciting, freeing and democratising; voices that are not often heard in the mainstream media (like consumers’ voices) have more space, and we can express ourselves on our own terms.

On the other hand, this comes at a price: there are often no constraints on content and no editorial support. This means that content can range from insightful to ridiculous to offensive – many people, perhaps buoyed by the anonymity that is often permitted, make spontaneous contributions (including comments and feedback) that are poorly considered or even abusive.

Sometimes material is spread far beyond the contributor’s control. They may later regret sharing it or wish they had exercised more forethought.

Social media is a mixed bag, but if you use it mindfully, it can be an incredibly powerful tool.

Many people point to the role of social media in contemporary political revolutions and disaster responses; on a more modest scale, social media has radically reshaped how people can network – which in itself can be revolutionary for consumers sharing our stories.

Issues to consider

Because social media can be so easy to participate in, it’s tempting to jump in with less forethought than if we were contributing to other forms of media that have an inherent time-lag, or where financial cost is involved.





IF PEOPLE DON'T COME TO US,
WE MUST TAKE OUR STORY
OUT TO THE PEOPLE.

Here are some things that other consumers and consumer groups have found are worth giving consideration to before jumping in (or perhaps once your toes are in the water and you're wondering how to step back a bit).

1. What's your intention?

Before you start, it's always worth thinking about who your audience is and what you are using social media for: Is it to raise the profile of your group or organisation? Is it because you need to *speak your truth*? Is it to promote intellectual debate? Is it as an advocacy tool with a particular audience and purpose in mind? Is it to help others; and if so, how exactly? Is it a combination of all of these or something else altogether?

There are different venues for different types of conversations, and sometimes confusion or antagonism can result from competing ideas about the purpose of a space (including a "virtual space" like a website), or how the space is kept 'safe'.

You can get started in social media without fully understanding your intention, but having a clear intention will help to better shape the project and probably reduce stress in the long run.

2. How much exposure (and/or criticism) are you willing to tolerate?

This is particularly important to consider in the context of consumers sharing our stories. It's possible (and, unfortunately, not uncommon) for misunderstandings and distress to arise when someone bares a part of their soul, or for the first time begins to express their experiences verbally, only to be faced with a passionate intellectual or political critique, or a thinly disguised attack.

These kinds of situations might arise because of different ideas about what the space is intended for: One person might believe it's especially important for people to be able to honestly and openly share their lived experiences (including, for example, experiences of trauma or terrible suffering) in a safe space, while another might be passionately committed to vigorous political discussion and debate.

To give a different example, one person's focus might be to spread awareness about effective treatments, or to encourage more people to seek help from the mental health system, whereas for others the focus might be about abolishing or critiquing existing treatment regimes.

And some people are just plain rude.



These different perspectives can lead to vigorous and enlightening discussions, but they can also generate more heat than light!

It can be helpful if the person or people setting up a new group or site states their purpose clearly, and returns to it, possibly expanding or reinterpreting this purpose over time.

3. What's important?

It's also worth thinking through what's important as these things might not 'just happen' organically.

For example, perhaps you want to update a blog at least once a week, but what happens if you get sick or go on holidays? Perhaps you want your YouTube videos to include a range of diagnoses, but most of the people in your network (or who are willing to share their story) have the same diagnosis?

What about money? Is there anyone involved who should get paid?

Because of the ease of creating social media, some important questions can get forgotten along the way, as we become heady with the experience of creating without traditional constraints (such as expensive equipment, funding or months of waiting for a finished product).

Case study: An under-maintained website

One consumer activist has her own website, created by a technologically savvy friend. This website has been a wonderful way to share stories, conference papers, cartoons, experiences and social analysis. However, because she is less technologically savvy than the friend who set up the site, it doesn't get a great deal of maintenance.

In some ways, this is not a problem, since most of the analysis and all of the cartoons are enduring in their relevance. The site is a wonderful resource, so why does it matter if it's not constantly 'updated'?

BUT, there is an occasional pang of "I really should update that thing" related to the general perception that online content should always be fresh.

4. Do you want to leave a permanent mark?

Once something has been shared on the internet, there's always going to be a trace of it out there, even if you later remove it.

This can become an issue for consumers who are 'out and proud' for part



of their life, but later decide they no longer want this part of their life to be public knowledge. This might range from (often legitimate) fears about discrimination or prejudice, to simply a desire to 'move on' to other things.

Not everyone decides to remove all traces of their story, even if they do decide to focus on other things in life. One consumer who has 'moved on' to other pursuits reflects on his decision to keep up his blog about his personal experiences of depression:

"I find it a way of fighting the idea that I should feel stigmatised by depression ... being public about depression helps me feel that I don't have anything to hide."

Many of us weigh up the benefits of being 'out', which can be personal or altruistic, with the potential for discrimination, misunderstanding and a lack of control over how information may be used.

5. Do you really have enough time?

Much of the electronic media requires updating, maintenance and continual input – once you have set up a blog, for example, it can take commitment to keep updating it regularly, and it can feel a bit silly to have lapses.

There is no actual reason why this should be a problem, beyond social convention, and many people contribute as much as they can/feel like.

But it's worth keeping this in mind from the outset so you can be sure that you're able to keep up with your own (and others') expectations for your site.

Case study: A Webforum that gets minimal traffic

One consumer group has a moderated 'message board' area (a 'moderated' site means that a person – called a moderator – reads and approves each contribution before it is publicly accessible).

This area has occasional flashes of activity, and then months of silence. The group is reflecting that perhaps the forum is more frustrating than useful!

They have also reflected that it's difficult to know whether the space should remain 'moderated' – it takes constant attention to check if anyone has posted a message that needs to be read and approved (or rejected), and although the idea is to stop spam and 'flaming' (i.e. inflammatory posts), it's possible it might be better to just deal with such issues as they arise.



Specific types of social media (for the uninitiated):

I. Facebook

Facebook is a social networking site. People create a personal profile which includes a personal photograph (which doesn't have to be of themselves, it can be a symbol, or an interesting image) and basic information about themselves. People vary in how much identifying information they share – some don't provide anything beyond their name or a nickname. The privacy settings allow you to limit who can see which pieces of information.

Once you have a profile, you can ask other people who have a Facebook profile to be your “friend.” Facebook friends can exchange messages, photos and event details, spread the word about causes and issues, make recommendations about films and restaurants and websites, and, most importantly, provide details of what they ate for lunch or are currently excited or irritated about!

Groups, businesses and events are also now using Facebook, either to raise their profile or to provide a space for discussion and networking (or all of those things).

Consumers are now also sharing stories on Facebook in various ways. Status updates, for example, could themselves be seen as mini-stories – some of us are sharing our lives with those in our networks one small status update at a time.

The power of these small stories should not be underestimated, especially when you are sharing stories that are otherwise relatively silent. Many of the issues around privacy, forethought, and disclosure are relevant here, though.

Facebook also facilitates group discussions, enabling consumers to share our stories as part of an online forum, connecting with others or using our stories to make political points.

Facebook can also be a part of how we tell our stories to ourselves – in fact, some people have argued that Facebook (and blogs, see below) has replaced the use of paper diaries, with people broadcasting their most private thoughts, albeit mediated by the ‘public’ nature of this writing.

Facebook isn't everyone's cup of tea – some people dislike it because they prefer ‘real’ social interactions, while others express concerns about the lack of control, including privacy issues. Some problems associated with social networking sites like Facebook have included bullying (most commonly amongst young people) and other, more subtle forms



of comparing and shaming. But, especially for younger generations, Facebook is now an important element in the social landscape.

2. Blogs

A blog – short for ‘web log’ – is a kind of online editorial or diary, comprising a series of entries, posted online.

Blogs might be focused on one topic, or include everything and anything on the mind of one person, or they may be written by a group of people.

Some blogs attract a major following and (once paid advertisers become involved) can become a full-time job. However, most blogs are a side-line for everyday people to share their thoughts with anyone who cares to read them.

As well as reading a blog, you’re able to comment on most of them too. It’s common for conversations to emerge among readers, particularly in the more high-profile or controversial blogs.

In the context of mental health, many blogs share personal stories. Unlike a book, a blog can chronicle the changes in someone’s life and be shared as they are happening. For example, some consumers have blogged about their recovery journey or their experience of coming off a psychiatric drug.

Blogs are also used by groups, but despite the hype, many have found that maintaining a blog for the purposes of promoting their group is time-consuming and only of limited effectiveness. The main problem is that you need to have good writers who have the time to post frequently, which is beyond the resources of many groups. An infrequent blog can become a problem (if the purpose is to be promotional), becoming stale and outdated.

3. YouTube

YouTube allows for videos to be uploaded by anyone, without cost or the need for specific video production expertise.

Many consumers are discovering that videos are a powerful way to ‘put a face’ to a story, though your audience is usually only as big as the number of people you direct to your clip (despite the excitement, there are still very few examples of spontaneous, worldwide YouTube hits).

YouTube videos vary enormously in quality. People can respond with comments (not always nice ones) or indicate that they ‘like’ or ‘dislike’ the video. You can also see how many people have viewed the video.



Case study: Video stories

A consumer organisation created several videos of consumers telling their stories. What began with a simple idea and a “let’s just do it!” approach has become an important collection of consumer stories that are used internationally as a lobbying and educational tool.

Some logistical lessons:

Planning: While it was very easy to load material on YouTube, it was much more difficult to think through the issues that came up during the planning phase.

Strategy: The number one lesson was the importance of strategy. Ask: Who is our audience? What is the purpose? What is it that we want to be portraying as our overall message?

Participation: Because there was a tight time-frame and some money was available for the project, the group engaged an outside company to create the material. This helped to ensure that the ‘message’ was clear. But there was a difficult balancing act between respecting consumer participation processes and maintaining a tight message, especially in the editing process. Consumers were remunerated for their participation as casual employees.

Diagnostic bias: The group realised once they had the finished product that they had ended up with an unconscious diagnostic bias (too much depression and no representation of schizophrenia at all). This highlights the importance of careful planning, especially where strong barriers of prejudice and discrimination keep people from feeling comfortable disclosing certain diagnoses.

Promotion: The material was launched as a DVD then uploaded onto YouTube. This two-layered process was important, because even though the electronic version would be free and highly accessible, it’s often desirable to have a physical product, even if just so there is something to launch!

4. Twitter

Twitter can be seen as a kind of cross between a social networking site like Facebook and a blog – it’s a micro-blogging site that allows users to post (or ‘tweet’) instant messages of up to 140 characters at a time.



Users 'follow' other Twitter users (i.e. receive their tweets), and are followed in return.

The use of Twitter is becoming increasingly common in Australia, buoyed by its adoption by many high-profile celebrities and its incorporation into mainstream media programs such as the ABC's Q&A (which generates tens of thousands of tweets during each one-hour episode).

You can restrict who sees your tweets to only those people you have permitted to follow you; however, Twitter is generally seen as an extremely public form of new media.

Twitter's ability to broadcast an idea in an instant makes it a great tool for communicating with a large number of people quickly and cheaply – but it has led to the undoing of a number of hot-headed users. The mantra of the modern age may well be “tweet in haste, repent at leisure”.

When is a website a blog? How is a Facebook group different to an email list? And what's all the Twitter about?

Technological change is rapid. At the time of writing, Twitter is the fastest growing form of social media, but who knows what will have emerged by the time you read this booklet?

Many websites are now based on blogging software, blurring the boundaries between two forms that used to be different media. Our computers used to be the only places we could access web-based tools; these days, our phones make it possible for us to send a tweet or make a blog entry or update our Facebook status from virtually anywhere.

Most forms of social media interface with others in various (constantly changing) ways. Universal updates can mean that your privacy settings might be changed in an instant.

The best way to find out how these new tools work – and if they will work for you – is to give them a try, though do be aware of some of the possible pitfalls, including (but not limited to) the potential for overexposure, online bullying or abuse ('flaming').

Remember that as ubiquitous as they now are, these are new tools we are dealing with. Some commentators have suggested that as 'natives' to social media are born and mature, clearer social rules associated with these forms of technology will emerge. But we're not there yet. In the meantime, play cautiously and stay safe.



* Using your story to educate mental health workers

Turning personal experience into useful teaching material

“Experience is one thing you can’t get for nothing.”

Oscar Wilde

Storytelling can be a powerful educational tool. Consumers’ stories can be extremely useful for educating mental health professionals, especially stories that are developed with clear intentionality.

In fact, storytelling can be especially useful in this context because (a) it connects us on a personal, human level, which can mitigate against the distancing that professional training can create, and (b) it specifically draws on what makes consumer knowledge unique – our lived experiences. Stories connect on a human level, while being based on what gives us specific authority to speak.

Most of what has been said so far about other storytelling contexts is relevant to this context too. The main difference is cultural – clinicians are often (unfortunately) reluctant to recognise the educational value in our stories. On one level this is understandable – they have been trained to be ‘the experts’, so it is a cultural shift for clinicians to recognise that we too have expertise.

Also, storytelling is not always accepted as a legitimate educational tool, even though it is important for many oppressed groups, including consumers. It may take a lot of hard work before some clinicians ‘get it’ – although there are a few wonderful exceptions and we can support these people to act as ‘culture carriers’ to help spread new understandings.

When using storytelling as a consumer educator you need to decide before you start what message you want to convey. Even more so than in other contexts, it’s really important to think through the pedagogical (teaching) value of your story.

Avoid the urge to use your story just to make people laugh, or to like you, or to feel sympathy for you, or to think you’re a better speaker than others. Bear in mind at all times the reason for your presentation. What’s the lesson? That’s not to say you can’t use humour and other storytelling techniques to illustrate your point!

Take the example of a consumer who wanted to talk about the effects of nurses locking themselves in the Nurses’ Station, leaving her knocking at



OUR STORIES WERE GREAT. YOU COULD HEAR A PIN DROP.

BUT WILL IT CHANGE THEIR PRACTICE?

WE NEED TO INQUIRE, DO RESEARCH ... GET PROOF

MANY DON'T SELF REFLECT! THEY BELIEVE OUR STORIES DESCRIBE A FEW ROTTEN APPLES - NOT THEM!

I WANT IT TO BE OK THAT I FEEL I HAVE ACHIEVED SOMETHING BY TELLING MY STORY.

I JUST THINK WE MIGHT BE ENCOURAGING VOYEURISM

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the door for 20 minutes. This consumer used all the tools of storytelling, including humour, suspense, drawing pictures with words and emotive language in order to connect the audience with her embarrassment, frustration, lack of understanding, and lack of capacity to be assertive. It was a good story, an entertaining story – but there was also a lesson. The point is that your story must lead somewhere. See page 24 for more on how to write a parable, a story with a message.

Considerations

Some of us find it seductive to be offered an opportunity to tell our story to clinicians. Suddenly – finally – we have the stage, the microphone, the attention, the knowledge of what is going to be said next: we have the power. These are rare experiences for many consumers.

Often our previous attempts to be heard by mental health professionals have met defensiveness, cop outs, white washing and betrayal. Many of us have spent years with no one listening to us or believing our story. It is a bold step to say to an audience of clinicians, “you will stay and you will sit and you will listen to what I have to say!”

The same sorts of pitfalls inherent in any type of consumer public speaking (see page 21) apply equally to storytelling to a group of clinicians.

An additional consideration in this context is to ensure that you are clear at the start of your presentation how you would like your story to be used by the clinicians in your audience. If you are happy for your story to be used as a tool by others, do make that clear. Most (though not all) clinicians will assume you want anonymity unless you indicate otherwise – often mental health professionals are hyper aware of issues like confidentiality and protecting our anonymity, assuming we don't want anyone to know about our mental health problems, even when we are very open about our experiences and speak publicly often (this 'protectiveness' can feel insulting, actually).

Remember too that an audience of clinicians is different to an audience comprising members of the general public. It is possible that there will be some skepticism, defensiveness, or even questioning of your status as a 'real consumer' or the value of your story. Some clinicians will just 'switch off' – no matter how compelling the story or how superbly woven the parables. Some professionals just don't think we have anything to teach them.

Try not to be offended or discouraged by this. In the end it comes down to not just the power and relevance of the story, but also the make-up of the audience, how they have been prepared, and (unfortunately)



whether it counts for anything in terms of exams or points for professional education.

Students may be more receptive, on a human level as much as on a professional level, than qualified clinicians as they have been less acculturated.

All of that said, it can be truly incredible to be part of the formal education of clinicians. Consumers have worked hard for many years to create this opportunity, and those of us who have engaged in this work often find it deeply satisfying.

If the particular audience isn't generally receptive (which happens sometimes, especially if you are teaching just before lunch, or in a stuffy room), it's good to remember that even if you connect with one person in this audience, your story has been worthwhile.

Many involved in the education of clinicians use storytelling either ourselves or include guest consumers, judiciously mixed with other teaching methods and skills. Some of us prefer not to use our own stories, using other ways of drawing on our lived experience. As always, it's important to resist any urge to create hierarchies, or assume that 'more experienced' consumers 'move on' from telling stories.

Some examples of techniques for using story creatively:

- The stories we use to educate don't have to include us at all if we don't want them to. Neither do they have to be about mental illness/mental health. The message is often a universal one.
- Sometimes it is pedagogically expedient to avoid personal story and familiar mental health contexts. For example, stories about power might be heard more effectively if we put clinicians into places where they may have been disempowered themselves.
- Stories told in ways that invite clinicians to listen and process rather than react and defend are useful. Staying away from the mental health sector and using stories of bad practice judiciously will help.
- Interactive storytelling often works best. There are ways that experienced consumer educators can draw clinicians into participating in evolving story-making see page 10 for more information on this).





Public Speaking Tips





* Preparing to speak

Some things to think about before your audience is in front of you!

“According to most studies, people’s number one fear is public speaking. Number two is death. Death is number two! Does that sound right? This means to the average person, if you go to a funeral, you’re better off in the casket than doing the eulogy.”

Jerry Seinfeld, comedian

While some people seem to have a natural knack for public speaking, far more have a major fear of the experience. Many break out in a cold sweat at the very thought of public speaking, even if it is something as short as introducing another speaker at an event.

As with so many things, preparation is the key to success.

Know the purpose

Part of proper preparation is to know the type of presentation you are expected to provide, and the reason why you are providing it. The content and structure of your presentation can vary greatly depending on its purpose. Is your speech aiming to:

- Inform?
- Advocate?
- Garner support?
- Instruct?
- Lobby?
- Entertain?

This will shape its tone, content and structure.

Similarly, your presentation can vary depending on how it will be delivered. For example, a straight speech delivered from the front of the room will differ in structure and style from a more interactive – or more intimate – workshop session. A presentation to a larger audience should, for the most part, aim to convey a bigger picture, broader themes and general observations. A workshop or presentation to a smaller audience might cover fewer points in more detail.



24 HOURS TO GO...



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Know the context

Ask for a list of speakers and a copy of the official program (and maybe the internal running sheet) well in advance. If you are the only consumer, you might want to consider where you'd like to go in the running order – you might like to speak early so the consumer voice doesn't seem like an after-thought, or you might want to speak later so you have a chance to respond to what other speakers have said.

Ask for some guidance on what the audience is likely to expect from your presentation. In isolation, your prepared speech might be stunner. But if it is aimed at the wrong audience, wrong situation or the wrong purpose, it may fail to connect.

Know your audience

Find out how big an audience you will be speaking to. Is it to be a small gathering, a medium-sized crowd or a large number of people?

The size of the audience can alter the way you approach a public speaking task. For example:

- It might help or hinder any interactivity between you and your audience.
- It might mean you are unable to use charts, graphs or other displays.
- It may mean you will need to use a microphone which could possibly limit your movement around the room.

Ask organisers if they can give you an idea of the types of people attending, what sort of organisations they are from, and if there are any VIPs expected to attend. Will it be inside or outside?

This information will help you tailor your presentation for maximum relevance and will help you prepare for any expert questions or encounters with VIPs you might have during or after your presentation.

Know the venue and its technology

Try and find out in advance what the venue is like. How big is the room? How many people does it hold? How will people be seated? What's the light like? Will the speakers be on a stage with a lectern? Are there stairs up to the stage that you will have to negotiate?

If you have a disability that needs accommodating make this known very early on, and check again a few days before, and on the day as well, to make sure it hasn't been forgotten.

Will there be a fixed microphone or a clip-on one, or will you get the choice? We all have our own preferences. Some of us opt for the lectern to disguise raw signs of terror – like shaking hands. Even experienced consumer speakers can find the lectern increases their feeling of self-belief and self-worth. Others prefer the freedom of a lapel microphone.

If you don't have an opportunity to stake out the venue before the day of your speech, don't worry, just try to get to the venue early and do your 'preparation' before things get under way.

If you are going to be using props of any sort, you will need to find out what's available before the event. Can Blu-Tack be used? Is there a pin board or white board available?



If you are planning to use some form of technology as part of your presentation (a PowerPoint presentation, for example), make sure you are comfortable with it, and – maybe most importantly – can get by if it malfunctions.

Check with the event organisers or the venue to see which technology you can use as part of your presentation. The venue might have technology on-site or you might have to bring your own equipment.

If you are going to be using a computer, who will control the slides – you (on the stage) or someone else? How (and when) will you need to upload your presentation? Will there be a wireless ‘clicker’ or will you have to move back to the computer each time you need to move to another slide?

Don’t think that you have to use technology. When used well, a PowerPoint display can be useful in engaging the audience and emphasising key messages; but when used badly – when it merely repeats what’s in the speech, for example, or includes far too much information on each slide – it can be terribly painful. Many fabulous speakers never use PowerPoint!

Know your time limit

While the length of your presentation doesn’t have to be spot on, at least ensure it is close to the time you’ve been allotted. If your presentation is scheduled for 45 minutes, don’t prepare a 60-minute presentation, or a 30-minute one (unless you wish to allow for a question-and-answer session at the end).

Rambling on past your scheduled cut-off time can bore or irritate your audience – even worse if you’re keeping people from their lunch! It can also be unfair to other speakers, if you are cutting into their time. On the other hand, a presentation that is too brief might leave attendees feeling short-changed.

A key step to ensuring you get this right is to check with event organisers on how long you will be expected to speak. There’s a big difference between a five to 10-minute presentation and a 45-minute talk. Know how long you’re expected to speak so you can prepare accordingly.

Know your material

The factors listed above will all play some part in shaping the material you present. Once you have prepared your speech you should review it – repeatedly, if possible – before delivering it to your audience. Practicing



aloud is a good idea to ensure you're familiar with your content and that the timing is right.

It also allows you to edit, remove difficult words and clumsy sentences, and to grow more familiar with the rhythm of your presentation.

You might want to practice your speech in front of other group members, friends or family to gain feedback on where it could be improved.

Prepare your supporting material and handouts

If you have extra material or handouts to give to your audience, have them prepared well before the day of your speech to avert any last minute rushing around which will leave you stressed out for the actual presentation.

Liaise with the organisers on the best way to distribute them.

Prepare your introduction

You will probably have been asked to give a title for your talk and a brief introduction about yourself. Usually, organisers will want this information submitted several weeks before the event.

If you haven't been asked, provide this information anyway. This will avert a last-minute scramble, or (worse) a situation where you're introduced in a way you don't approve of. It will also allow you to think about how you want to be introduced. Providing a bit of a background about the mental health-related parts of your life can be useful but it's also good to provide some information about other aspects of your life. As a consumer it's important that you reinforce the idea that we are real, multi-faceted people, not just a walking mental illness.

Make sure the biographical information you provide is short. People mainly want to hear from you not about you from someone else.

Prepare your support base

It can be very useful to have supporters in the room when you deliver a speech, particularly if you are new at it. Ask if you can bring along a friend.

Prepare your notes

Don't feel obliged to speak without notes! Using notes is fine, and it's also fine to read your talk. Some of the best and most passionate and informative talks are read. Often it adds to the atmosphere because it is an acknowledgement that this is the real story of a real person and the



written version is there to get them from the beginning to the end in one piece. People admire the pluck in such a person.

At the same time, some people feel better able to communicate without using notes or reading – it's up to you to present however feels most comfortable.

If you do read from notes, someone may ask for a copy. Think carefully before giving your story in written form to someone else because you have no control over how the written copy might circulate.

Prepare for questions

Brainstorm beforehand possible questions you might be asked and how you would like to handle them. Other supportive people might also be helpful to think up possible questions. Maybe you won't want to answer questions at all – it may feel too tricky, particularly if you're not a seasoned public speaker. Don't be embarrassed to say you don't want to take questions – as we've said several times in this booklet, politicians do it all the time!

Talk to the person chairing the event. Tell them whether or not you will be taking questions and, if you will, which questions you wish to avoid. By telling the chair what you will and won't talk about, he/she can negotiate with the audience – sometimes it is difficult for a speaker to say, "I don't want to speak about that" but easier for the chair to sensitively steer the conversation in a different direction. On the other hand, some of us have experienced chairpersons who are overly "protective" of us. These are all issues we learn to negotiate in our own ways.

Tips for preparing content

How and what you say in telling your story is up to you, but here are a few tips for structuring your presentation:

- **Be clear about what you want to achieve** from your speech. Write down a one-sentence summary before you write anything else. Keep referring back to that as you write your speech to make sure you're staying on track.
- **Set out the five or six most important points** and think about how you can frame them to ensure your outcomes are achieved.



- **Put some effort into the opening.** Try to find a hook that will attach people's attention straight away.
- **Put some effort into the ending.** The last thing audiences hear is often the part they remember.
- **Divide your speech into sections** so that there is a natural beginning, middle and end to the speech, and that it flows rather than jumps from one point to another. Sometimes people tell their story chronologically, starting from when they were diagnosed or from when they were young. This can be useful in creating a clear path for your story. You still need to have a message, however. Very good speakers often impart this message very subtly and thread it through the story.
- **Speak from the heart** and try to infuse your speech with a sense of hope. Everyone wants to be part of a solution. This doesn't mean you need to make it terribly saccharine though!
- **Say what you want to say, not what people want to hear.** Beware of people's voyeuristic tendencies. It is easy to get caught up in this cycle. The more sensational your story becomes, the more the audience becomes involved and the more they provide positive feedback, the greater is the tendency to feed them with information that feeds their voyeurism. It's important to keep this in mind when planning and delivering your talk – the main danger is that you will say more than you later feel comfortable with.
- **Decide how you want your story to be told.** Revisit your boundaries and be clear how much of your own story you want to reveal to this particular audience. Some storytellers amalgamate a number of different stories to produce a non-identifiable consumer through whom more difficult parts of our own story can be told, and to which aspects of others' stories can be introduced (with permission, of course!).
- **Practice. Practice. Practice.** Stand in front of a mirror, practice in the car or in front of your dogs or your friends – ask them (well, maybe not the dogs) to suggest improvements in style and content. Read what you have prepared to other consumers. Ask for honest feedback.

In short, experience builds confidence, which is the key to effective speaking.



* Delivering your speech

The big day is here...

"The most precious things in speech are the pauses."

Sir Ralph Richardson (English actor)

If you have prepared well, then on the day it is just a matter of getting the message across. Getting the message across is aided by a good understanding of how your body, visual cues, voice and controlled emotion work together to engage the audience.

On your mark

On the day of your presentation, make sure you've got everything you need – your notes (two copies, carried in different spots, just in case), your USB stick (if you're bringing your own PowerPoint), and any other props you need.

Don't assume something will be provided if you are relying on it – for example, there might not be whiteboard markers (or a whiteboard!), or butcher's paper. If you need to use it, ask in advance for it to be provided, or bring it with you, along with Blu-Tack, drawing pins, marker pens or whatever else you need.

Get set

Arrive at the venue early. This will allow you to familiarise yourself with its size, layout and where you are going to speak, as well as set up and test any of the technology you're going to use. It also gives you time to meet the people you need to meet and read over your presentation one last time. Depending on the occasion, you may need to register when you arrive. Even if you don't have to register formally, do let the organisers know that you are there.

Ask if you can see the room you will be talking in if you haven't been able to do this previously. Make a general inquiry about the technology if you are going to use it and arrange to get your USB stick to the technical staff.

If you're using PowerPoint or video, ask them to test that everything is working before your speech is due to start. If things aren't working well, try not to panic! They will almost certainly be able to fix the problem

RISK MANAGEMENT!



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(whatever it is) before your speech starts, and if not, it's no big deal if you have to abandon the visual aspects of your presentation. Some of the best and most inspiring talks have used no technology at all.

Always check on the availability of water. Those on psychiatric drugs that cause your mouth to be constantly dry must be particularly vigilant because nerves dry mouths out as well. The combination is not good.

Try to find a quiet spot to relax for a few minutes before you speak. Have a sip of water and take a few deep, head-clearing breaths before facing the audience.

Being introduced

When you are being introduced, look at the chairperson, acknowledge the introduction s/he is giving, and then have a quick look around the room to identify any people you know are your supporters. They will be a great reference point throughout your presentation.

There is nothing as encouraging as a smiling face and nodding head of a comrade. Sometimes you get this from someone you have never met before and this is an amazing feeling.

Making sure all is in order

Once you're ready to begin, check you can be heard at the back of the auditorium. If not, try moving closer to the microphone as a first step. If there are any technical problems, try not to panic. Ask if there is a technician who can help.

Really big technical problems can be stressful but remember that they are not your fault, and most people in the audience will totally understand! Consider having a few jokes or anecdotes ready for just such occasions to help fill the silence and warm up the crowd. Another technique is to ask the audience to have a chat with the person sitting next to them, or to take the opportunity to stand up and have a stretch.

Last minute alterations

This is one for the experienced hands. On the day of your speech, listen intently to the other speakers. Edit or highlight aspects of your speech so you can refer to what has already been said. This is powerful but can be tricky for beginners.

Many speakers type up their talk with double spacing and/or some big margins, specifically so they have room to add new thoughts or changes on the day.



Read/speak slowly

This sounds too obvious to mention, but most people need to be reminded of this, even when they are experienced. Partly this is because you have practiced so many times that your brain computes that the audience has also heard it dozens of times! It might also be partly because you are self-conscious and just want to get it over and done with, and partly because of the tendency many of us have to fill silences (bubbling out words as silence-stoppers!).

Actually, silences can be very poignant. Teach yourself to hold them.

Use your voice to maximum advantage

Don't worry too much if you have no headspace to think about things like your voice and body language – very powerful speeches have been given that break all the conventions! But if you do want to work on these things, here are some tips.

Pitch is about how high or low your voice is, and is controlled by the vocal cords vibrating. The greater number of vibrations per second, the higher the pitch. The pitch of our voice is not entirely beyond our control. Allowing ourselves to really feel the story raises the pitch by contracting the larynx. This attracts the attention of the audience but it must be used sparingly otherwise you will sound shrill. Try to balance your presentation with moments of calm deliberation, which will have the effect of bringing the voice down.

Inflection is a change of pitch. Natural speech changes pitch and doesn't just stay on the one level. Usually an upward slide or inflection expresses a question or an incomplete thought, and a downward inflection expresses a completed thought. Without changes in pitch we end up speaking in a monotone, which is a turn-off for an audience.

You can also control the **volume** of your voice, and can use it strategically. Speaking quietly when you are talking about something really important is a clever use of volume (though do make sure you can still be heard). Sudden changes in volume are also useful but practice it first or you may risk sounding too contrived.

Tone is the mechanism we use to tell the audience what judgements we are making with the words we are using. You can use tone effectively when quoting someone you disagree with or something you are excited about. Examples of tone might be using our voice to express excitement, disagreement or cynicism.



Your body is an important communicator. Some of us don't use **body language** enough and some use it too much, flailing arms around all over the place. Practice is the key to getting this right. Film yourself delivering a speech and watch it back with a critical eye. Ask trusted friends or family if you have any annoying habits when you're on stage (unconscious acts such as adjusting a bra strap, playing with your hair, or swaying from side to side can be fairly easily controlled if you are aware of them).

Timing

Try to keep track of timing during your speech. Remember it's rude and unfair to go overtime (there are other speakers who might be just as nervous as you coming up). With increasing experience, you can lengthen or shorten your story, depending on the mood of the audience (e.g. if they seem restless or deeply engaged).

If you are running over time, try to skip over part of your speech rather than speeding up your voice. A rushed presentation can be very difficult for an audience to follow. It's good to know beforehand if there are parts you can skip if time becomes an issue.

If you think you will find it hard to keep track of the timing yourself, ask the chair to give you a reminder five minutes before your time is up.

Emotions

It can be an acutely emotional experience for mental health consumers to tell a personal story publicly. If you start to cry or can't go on for a few seconds don't worry. That's completely understandable and not uncommon. And it can actually add to the impact of the story. Don't feel that you need to apologise (even if that's your natural tendency).

Making sure you have some tissues is sensible; all the better if they are thrown to you by a friend in the front row!

It is more difficult if the emotions that are stirred during the telling of your story are anger or fear. People sometimes find it hard to listen to anger. Maybe they just have to. If you know when it's coming, you can allow it to have a place and then try to move on if you want to keep the audience with you.

Fear is another common emotion when telling your story publicly. This is another reason why you need your pals in the front row. Taking deep breaths and keeping one or both hands on the lectern are also useful strategies for keeping the symptoms of fear (quaking voice, trembling hands) in check.



Reading the audience

For better or for worse it is usually quite easy to 'read the audience'. As you progress through your presentation you will learn the signs that people are with you or not. Take advantage of the energy if it is in the room. Comrades are essential if it doesn't feel so good.

People say 'speak to the back of the room', but on occasions when it feels like the talk is unraveling, direct the story to your 'friends' – both those you've planted and others that you might not know but who are giving you non-verbal cues of encouragement.

Taking questions

Even if you haven't set aside time for a specific question and answer session, it is more than likely that audience members engaged by your presentation will ask questions of you – either during your presentation or afterwards. And of course if your session is more interactive, then the questions can fly thick and fast.

You can be more prepared for these types of questions by trying to anticipate half a dozen that might be asked and coming up with responses beforehand. If you can't answer a question on the spot – or can provide a better answer later on – ask people to pass their contact details to the organiser so you can get back to them (it's often best not to give out your own contact details; it's useful to be able to retain some distance and control, though of course this is entirely up to you).

Sometimes there will be a very long silence before anyone asks a question. The audience has just been exposed to an uncomfortable topic and might be afraid to embarrass or offend you, or they might be just sitting with the new material. Maybe they've been moved by what you've said and don't know what to say.

As a speaker, it can feel excruciating waiting for questions, but don't take it personally if there are just a few or none – you may be competing with a very much needed lunch, or you may have been very thorough and left no obvious unanswered questions. People may also feel more comfortable approaching you one-on-one at a later opportunity (if there is one).

If the organisers have scheduled a question-and-answer session at the end (rather than directly after your speech), you might need to stay longer than you want to. Fill in the time by listening to the other speakers and taking mental or written notes to act as prompts. Adrenalin will usually get you through the rest of the session and you can sometimes surprise yourself with your capacity to remain 'on task' till the end.



If you do not want to take questions (and you shouldn't feel obliged to do so) let the organisers know beforehand.

* Phew! It's Over!

The aftermath

"Sometimes it feels like I have emotional haemophilia or God forgot to put on my emotional skin."

Consumer

It is vital that you plan for what you do after your presentation. Remember, many consumers have an exquisite sensitivity and capacity to 'feel' beyond levels which mainstream society considers 'normal'. This can be a wonderful asset but can also need to be nurtured, especially after you have laid yourself bare.

Sometimes you finish speaking glowing. Someone official says thanks and tells you you're brave to have talked about having a 'mental illness' in public and they give you chocolates or a bottle of wine and you feel like you've really achieved something (if maybe a bit patronised as well).

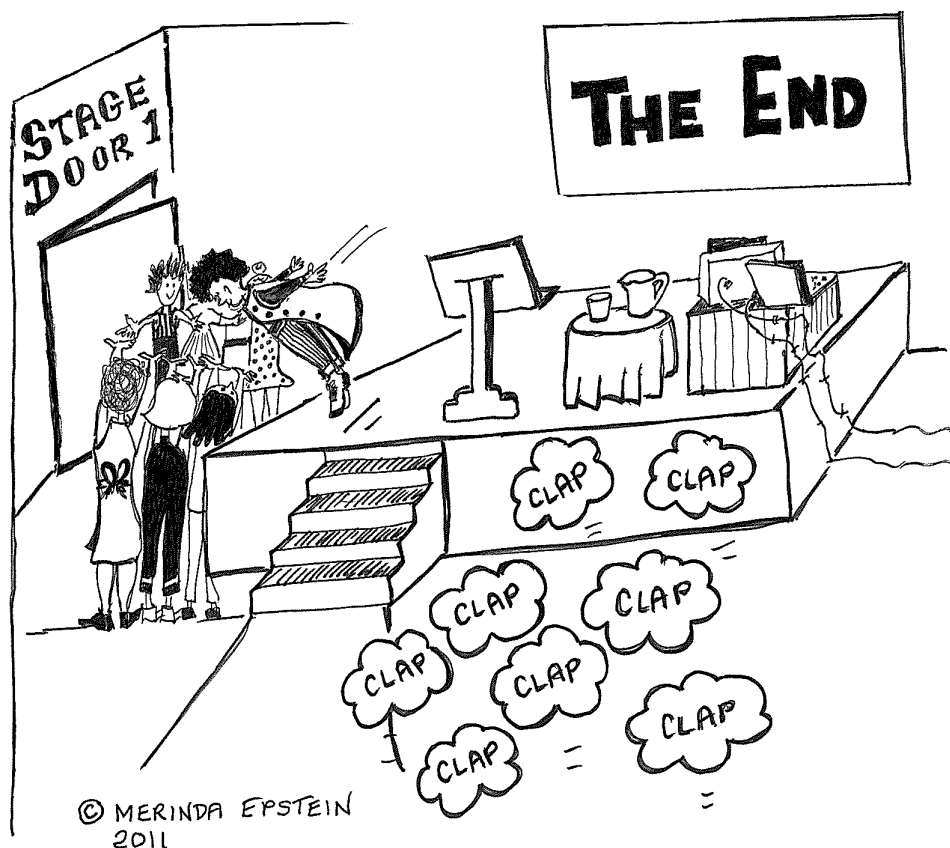
If things have gone particularly well, you might get swamped by audience members. This can be exhilarating, but also challenging. It's always difficult to talk to a number of people at the same time, or move quickly from one emotional conversation to another, particularly when you are already physically and emotionally drained. It's useful to have a loyal buddy with you to help you manage this and steer you away from the crowd if need be.

There may be other consumers who are hovering on the outside of the circle who really want to speak to you. You may sense that they do not have the confidence to come forward. You may feel as if you 'should' suggest meeting at lunch time or during a break. Be guided by your own capacity – remember how emotionally tired you may be later.

Be careful too about promising things in the future. Directly after a speech is not the right time to be making promises. If you have many people hovering who want to continue the conversation, or if you need to leave, ask people to provide their details to the organisers for passing on to you later. If you're comfortable letting people know how to get in touch with you, have some contact cards on hand.



SAFE LANDING: CONSUMERS IN THE WINGS...



Of course, if people don't come up afterwards, it can feel like you've failed to impress anyone. Try not to take it to heart. It may just be that people have got all they needed from your talk while you were on the stage, or are so impressed that they are shy to speak to you!

Handouts and extra material

If you promise extra material or handouts to those listening to your presentation, make sure you deliver on the day or soon after the event.

This is particularly important if people have come to your presentation intending to take notes but do not do so because you assure them



that notes will be distributed on the day or appear on a website at a later date.

If your audience doesn't find your material when they want, or where they expect to, they will soon forget your presentation and may even become critical of your 'broken promises'.

Making your exit

If you think you may need to leave directly after your speech, let the next speaker know this in advance. Make sure that they know that your exit does not reflect your opinion about their contribution, rather that you need to get to another appointment (or that you might need to get away to collect your nerves).

Ask the organisers to seat you somewhere where you can leave unobtrusively.

Coming down

Even if you feel on a high after your speech, be conscious that after two or three hours things might start to change. You may begin to worry that you have divulged too much personal information, or that you've done a bad job, or remember something important you forgot to say.

To some extent, almost everyone who is inexperienced at public speaking (and many of those who are experienced speakers) goes through this, but consumers may be particularly vulnerable. Low self-esteem and self-confidence can play havoc with your post-speech emotions.

It's always a good idea to plan to have someone you can trust to be at your side during the talk and after it. Going out for a cuppa with trusted friends (and away from the finger food where you can get cornered) is sometimes imperative. Trusted friends will know if you're likely to be fixated on the talk ... they'll cope with you getting stuck on one thought. They may be able to provide you with some reassurance that everything went fine.

If you are likely to suffer from post-speech terror, it can be a good idea to get some coping strategies in place. For example, it can help to tell a few trusted people not to assume that you will automatically know when you have done a good job. Don't be ashamed to tell them beforehand that you will need them to give you positive feedback (or nothing at all). Let them know that constructive negative feedback will be destructive feedback until you have recovered – maybe in a few weeks time.

It can also be a good idea to ask someone to check that you're OK 24 hours, 36 hours, or a week after your speech. People who are finely tuned



to negativity and community prejudice can find it hard to recover quickly after an emotionally exhausting experience such as speaking at a public event. You might need to take it easy for a few hours or a few days or a few weeks.

Above all, you should be proud of what you have done. Treat it as a gift to other consumers, and to the community at large.



Some Concluding Words

Storytelling is both a craft and a gift.

Stories explore meaning and expand our thinking, often with enormous subtlety and skill. They can touch deep parts of our humanity. When developed with care and reflection, they can be incredibly powerful vehicles for communicating messages, and for changing the world.

And – as we have explored in this booklet – stories can be much more sophisticated than what is often framed as ‘the personal story’ that details a chronology of suffering, treatment and recovery, without any other kind of conscious message. Stories can be extremely powerful and they deserve thought and time.

Not everyone connects with storytelling: some people just aren’t very good at telling stories, or prefer to use other skills or other ways of knowing.

But we hope that stories can take their rightful place in how we as a community make sense of ‘madness’, ‘mental illness’, emotional distress and other deeply human experiences.



