Telling a story of mental health experiences

A guide

This guide has been produced by a group of people who have experienced challenging times.

They first started working together as members of an advisory group for the 'Narrative Experiences Online' study which aims to build an online collection of people's stories relating to mental health.

For more information, visit:

www.researchintorecovery.com/NEON

Why we wrote this guide

We feel that hearing or reading other people's personal accounts of what has happened to them can be useful for helping us process painful memories. We feel that sharing stories can be beneficial for the person telling them. We also think that the decision to share a story is a personal one and comes with certain risks. It isn't always a good idea to share a story, perhaps because the timing, context or audience might not be right.

Sharing stories about mental health, experiences and journeys is common. Nowadays, there are more opportunities for people to share stories than ever before. Many of us have been asked to (and have chosen to) present 'our story' in one form or another in the past. Some of us have spoken at events, written blogs, written books, recorded podcasts or videos online.

All of us have been asked to give some of our story to a health professional at some point. Many of us have shared our story in less formal ways, such as speaking to a peer support group or speaking to someone at a bus stop. We feel that the considerations in this guide are relevant for all these situations.

We wrote this guide for anyone who may be considering sharing a personal account of the times they have been through. It contains information that we might have found helpful before we shared our own stories. We hope it gives you some ideas about how to share your story, and that it helps you decide whether you want to share anything at all.

We believe that every story is a unique, important part of someone's life history. We know from our own experience that our stories change, just as our feelings about certain events are also likely to change over time.

Most importantly, your story is yours to share as you choose, at your pace, in your own way. There is no 'right' version of a story, only the one that feels right at the time you tell it.

On that hospital ward there were three of us who seemed to have a desperate need to share what had happened to us. Somehow, the other patients did not seem to have such urges, or they were able to contain themselves.

I was told I was suffering from 'pressure of speech', a symptom of my undiagnosed troubles. Staff kind of listened without listening. It was as if they listened because they were paid to listen while their minds were on whoever they had been told to observe. It was an 'Observation Ward', where we were all being observed.

Staff would knit, keep an eye on patients and talk with other staff while I desperately wanted to be understood. I did not think it through, it just became clear after a couple of weeks – there were only two places I felt listened to:

- **The smoke room**

  I've never been a smoker, but this was a place where we all felt safe sharing our stories, even the quietest seemed able to talk in the smoke room.

- **Walking in the grounds**

  This was where I healed. Whether walking with other patients or with staff I felt listened to, I calmed down and my own thoughts became more ordered.

To tell or not to tell

Wanting to share our experiences with others is part of being human. Most of us felt that sharing our experiences with others as a 'story' was useful, that giving voice to feelings and emotions could be cathartic and help us understand things that had happened. Those of us who had shared our story also described it as an emotionally challenging experience.

Turning Points...

In telling my story I remember several turning points in my life, that each involved listening to someone speaking of their recovery. I am sure others have benefitted from reading, watching videos or whatever, but for me it was being in the same room and hearing their account first-hand.

One time, it was hearing someone explain how he coped with just the kind of thing I was struggling with. He was about my age and as he told us about his life, I could relate to what he'd been through. I decided to take the same recovery course he'd been on and it helped massively.

Another turning point was meeting with a doctor who confided that she had spent time as a psychiatric patient and how she eventually figured out what was causing her troubles. This chat was more valuable, to me, than any diagnosis or medications she could have offered me that day.

If you want to tell a story based on your experiences, the most important decision is what you include and what you don't include. It is unlikely that you would want to tell every detail. Consider:

1. **What is the most important message?**
   The bit you'd never leave out. Perhaps sharing the entire story feels important but consider what you could leave out to help the story flow.

2. **What do you wish to achieve by sharing?**
   Why you want to share it, what do you want to get out of it, what do you want others to take away from it?

3. **What are you <u>not</u> comfortable sharing?**
   This is a good starting point when thinking about what to include.

4. **How will you feel once you have shared your story?**
   Spend as much time as you can on this. Sharing your story might not feel quite like you had hoped.

5. **Does your story have the potential to harm anyone?**
   This isn't necessarily a reason not to tell it, but it might change how and when you tell it, and whether you give any warnings in advance.

   One option is to exclude anything that identifies you (your name, the names of other people, places or events). Making your story anonymous works well in writing but is more difficult on camera. It is almost impossible if giving a talk in person, or when having a conversation with someone.

Each time I started to share my story I would stop. Eventually, I made a list of why I felt unable to continue. I found that for each reason I could put 'fear of...' in front of it.

Fear of rejection, fear of being misunderstood, fear of upsetting someone, fear of being attacked again (verbally and physically), fear of sounding stupid... There were a few more. Recognising these fears, I realised there was nothing to hold me back from writing what I need to say, sharing just the little bits I needed to share, and only sharing with people who want to hear – and most importantly only with people I trust.

It may seem sad that I seem to have to hold back, yet the reality for me is that I am now moving on, piecing my life together, page-by-page, and reaffirming friendships through sharing just enough.

One day, I may put it all together and tell all. I feel fortunate that I no longer believe I have to do that.

Before writing this, few of us considered how our story had the potential to harm others. After thinking it through, most of us agreed that some things were better not shared with everyone. Some things may upset someone we didn't mean to upset, or cause people to feel anxious.

Stories relating to mental health can be dark and full of imagery which people may find troubling (particularly if it reminds the listener/reader of things that happened in their own lives). Be aware of the effect your story might have on others, for your own wellbeing and for that of the listener.

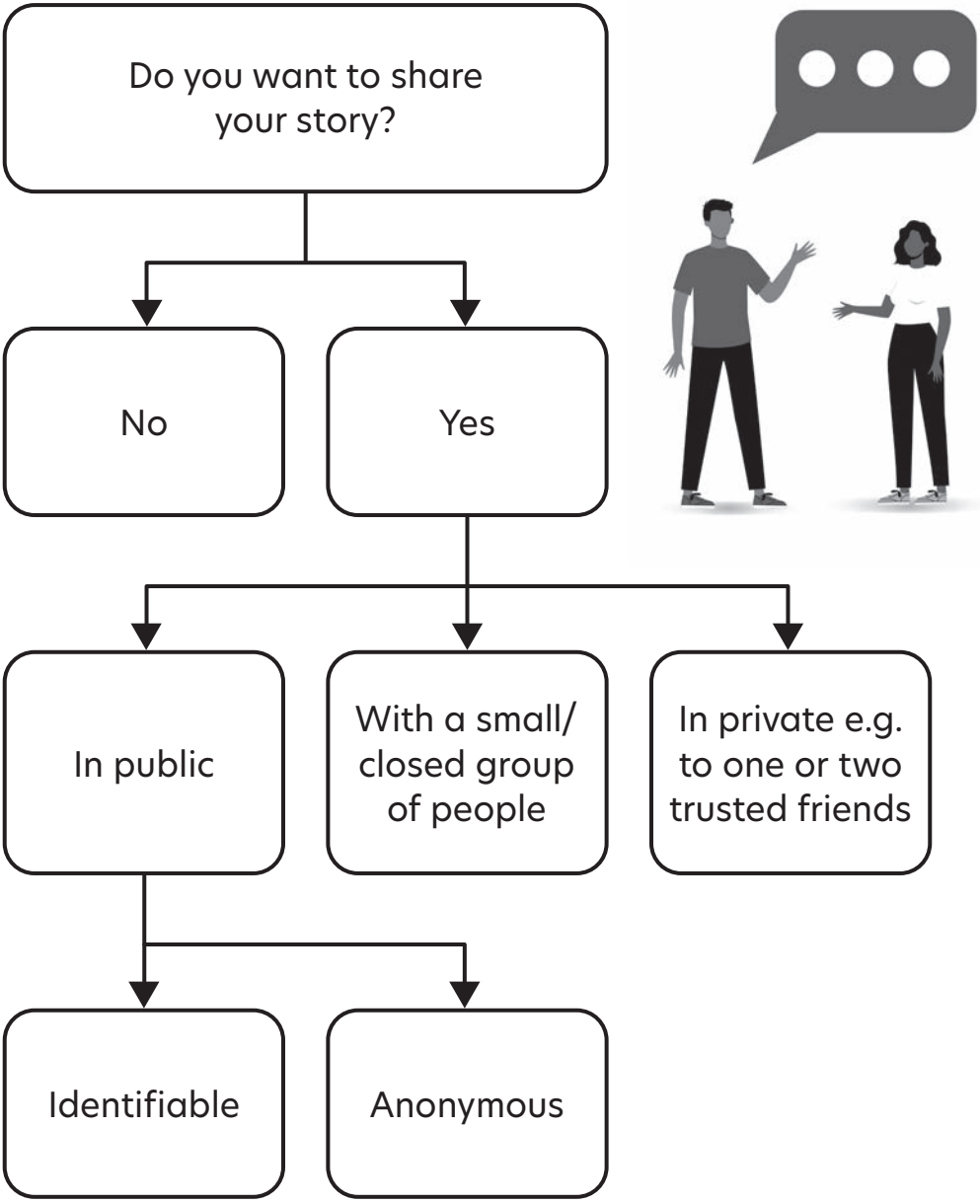
You will probably be familiar with 'content warnings' which are often given before TV programmes. Usually, they appear before a show begins to warn you of upsetting images, words and situations. In parallel, there is often information at the end of a TV programme about relevant organisations to contact.

Applying content warnings to a story might be useful so that people can decide whether to continue watching, reading or listening.

Some of us had already told parts of our stories privately to friends, family, neighbours, co-workers or mental health workers. Sometimes we found this helped us in a positive and cathartic way. Other times we found this experience disappointing, people did not 'get it' in the way we had hoped. We could use these experiences to help us decide whether to tell the story (and how to tell it).

After consideration, you may decide that you do not want to share your experiences after all. This is sometimes the best decision. You may decide that you would rather share your story privately, in a small (closed) group, or anonymously. These are all options worth considering (see Figure 1).

Figure 1: Decisions about sharing your story



I have a story in my head that I may never tell. It is a true story about what I experienced while I was (for want of a better term) 'out of my mind'.

I did not hurt anyone and nothing horribly embarrassing happened. It is just that I do not know how to explain what no one else is ever going to see, feel, hear, smell or taste. These were experiences that involved all my senses, and I can only explain them by describing a fantastical new world I had never known existed.

My story is in my head. I can tell it to myself and recognise every bit of it as real, yet so much of what I experienced was 'not of this world'. There are spiritual people who would understand.

My family would not, so for now and perhaps for ever, my story is just that, my story and not for sharing. Sorry guys.

Honesty

It was only recently that I grasped what might be meant by 'too honest'. I grew up believing honesty was always the best option, so how could there ever be too much honesty?

In my story, honesty is my accurate sharing of precisely what happened because I want the world to know the truth. Yet the more I shared the more I found people who did not want to hear the truth or the way I was sharing it.

To get across my message I needed to find the right balance between saying what was right for me and saying what was right for the situation; leaving out that which seemed to hurt even though I felt it needed to be told.

I suggest this balance will be different for everyone. It is always worth asking, "Do they really need to know this or would it be better if I keep back some truths I would love to be telling?"

I no longer believe I have to tell it all. I hope this will help if you are dithering as I was.

adidas

Who is the audience?

Every story needs an audience. This can be an imagined audience if you prefer. When we were compiling this, we considered an audience of people like ourselves; for example, people with similar troubles, who had been through the mental health system. Most of us had taken medications in the past or were still taking medication.

However, there may be other audiences, friends, family, people at work, people we meet, people in support groups, nurses, doctors, other health professionals, the general public, the media. These audiences are all quite different to each other.

To what extent will they respond differently to your experiences as told in a story?

In truth, you won't be sure until you have tried it, but it may help to know who your intended main audience is. Who are you really aiming your story at?

Good and bad experiences of sharing stories

My best experience of sharing my story was 100 miles from home with a small group who all had the same diagnosis as me. They were so appreciative.

My worst experience was after meeting with a newspaper reporter who recorded my answers to his questions. It seemed great at the time, yet when the article was published, I was horrified. So many errors! So many changes to what I said! Where was the hope I felt I was sharing? Where was the little diagram I drew that I was told would be included?

Ways to tell the story

One of the most important considerations is 'how' you want to share your story. You may decide that you only want to share your story privately, rather than publicly. The steps below may be useful for people who want to share their experiences publicly in the form of a story. This reflects things that we found helpful ourselves.

Capture your first thoughts
You could do this in a journal, notebook, on a computer or by recording your voice.

Consider the format
This might include text, video, painting, speaking/presenting, or something else.

Create it
This is the part which takes the longest and requires the most work.

Edit the story
Or find someone who you trust to help you with this.

Consider whether (and how) you are going to present the story
The most important thing is to share the story in an environment that you feel comfortable with.

Think about what happens afterwards
Is there someone you can talk to?

Capture your first thoughts

You could do this in a journal, notebook, on a computer or by recording your voice. It can be good to start by capturing the most important bit, rather than starting from the 'beginning'. Start with the main message.

Many of us found that our story changes while it is in our head. Writing it down can help us clarify details. This isn't necessarily because the memories in our head are changing. It is probably to do with the way the mind organises the memory of events, and the emotions attached to them. This can change over time. We may feel differently about things as time passes.

When sharing your experiences, consider what was happening for you at the time you are remembering. Were there any specific events that you remember? How did things start to deteriorate when you started to struggle?

Consider the format

How will you share your story? You may want to use one format or a combination of formats. This might include text, video, painting, speaking/presenting, or something else. Choose the format(s) that you feel comfortable using, or ones where you can find a friend to help.

Do you want to tell the whole story at once, or parts of the story over time? The answer to this question will help you decide which format is best for you. Will your story include pictures or imagery? Will others understand those pictures as you do? Will you start with pictures then put words in-between? Will you start with words and then insert pictures?

It is a good idea to start small and practice telling bits of your story. Perhaps talk with friends and agree on a sequence, tell it to them, read it out at some local meetings, change it, experiment with telling it in different ways, whatever suits you best.

- You may want to prepare a short, informal talk about your experiences for a local support group at their usual meeting place.
- Changing the hearts and minds of health workers around the world would be much more difficult. It will involve lots of effort and luck. You may need to share your story on YouTube, having your own channel and linking with others who have similar hopes.

Create it

This is the part which takes the longest and requires the most work. There are lots of guides on writing and producing stories out there. We focus here on the things which we found specifically important for these types of mental health-related stories.

The process of considering why we share, who we share with, when and where will influence how we share. Being flexible will ease the process. Perhaps you might 'test the waters' by sharing parts of the story online, for example as anonymous blog pieces presented in a series (rather than in one large chunk).

A story doesn't have to be straightforward, polished, nor does it need to end positively. Many of the best stories include contradictions and inconsistencies. You also don't need to think of your story as being the final word. Stories are not static. They change over time, evolve, as we gain new perspectives or have new experiences. There is no 'right' version of the story, just the one that feels right when you tell it.

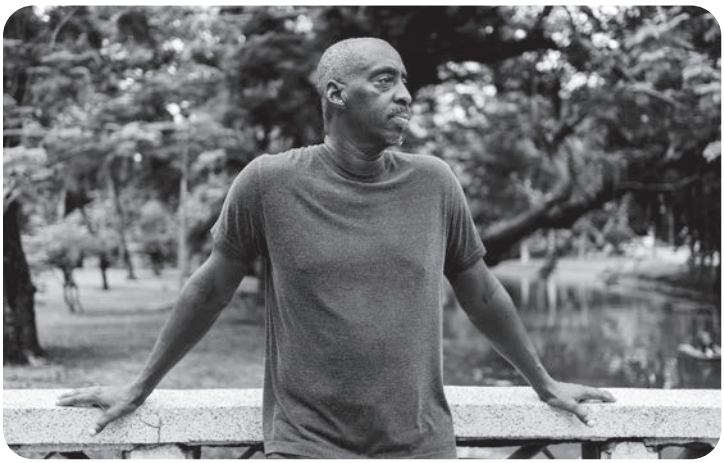
Does every story need a mixture of negative versus positive, in terms of events, thoughts and feelings? Stories will include bad times as well as good times, but does there need to be a balance? Perhaps there does, but that balance is going to depend on what happened to you, your interpretation, your audience and how you choose to share.

Edit the story

After you put together your story, it can be useful to check it through. Perhaps there are corrections to be made or bits that could be explained more clearly. It can be helpful to find someone you trust to look at it.

You may be uncomfortable with the idea of having someone else to suggest changes to your story. However, a good editor will be able to tell you whether your story makes sense or not. Tell them what the most important parts are that you want to keep. They will also make useful suggestions for improvements.

If you are editing the story yourself, leave some time (perhaps a week, probably more) between completing the first version and editing it. Writing and editing require different thought processes. You cannot do them both at the same time.



Consider whether (and how) you are going to present the story

We have talked about the different formats that you might want to use. The most important thing is to share the story in an environment that you feel comfortable with. The prospect of presenting the story in public may be distressing for some, for others the adrenaline can motivate us to publish and promote it. Remember that once shared, the story is 'out there'.

Conferences and events are often recorded and shared online these days (which can happen without the permission of either yourself or the conference organiser). This increases the likelihood of someone taking the story out of context or misunderstanding it.

If you want to publish it, consider how. These days, self-publishing does not necessarily mean you have to publish a book. There are lots of opportunities to self-publish your work online, such as setting up a blog, or through videos uploaded to YouTube. There are many free routes to share your content online. There are also many free resources available online (and at local libraries) which can guide you through the process of self-publishing.

Think about who is going to see, read, or listen to the story (regardless of whether they are your main intended audience or not). Think about how they might use it. Do you want to request that people contact you before they use your story? Nowadays, stories shared online can have a far greater reach than they ever had in the past. They can be shared around the world in seconds.

Think about what happens afterwards

If you do present your story in public, consider what you might need afterwards. Is there someone you can talk to about the experience? How did you feel when you shared your story, and did you get the outcome that you anticipated or wanted?

Finally, your story as you told it might not be how you would tell it again next month, next year or in five years' time. Stories change but publishing them or repeatedly presenting the same story can cement them at a moment in time, both in your mind and the minds of the audience. This isn't necessarily a good thing. Your story may become easier to tell, but it might no longer represent how you feel about things.

Remember, just because one version of your story is out there, it doesn't mean your story won't continue to evolve.

Have I finished?

I was talking about me, what happened to me, what was worrying me. Then I was writing a few words, drawing pictures and diagrams, picking out photos.

Even so, I had not really started, and I was never going to finish.

Then I realised I had a reason to tell – a point to my story, and telling it could help others to avoid some of the anguish I had suffered.

One morning I woke early with a little bit of a dream still in my head and stayed in bed wondering if the ideas in that dream might help me tell my story.

After this, all my thinking and writing happened in quiet places, in the bath, while walking on my own, on my own in cafés and in my own home while everyone else was out.

It was only when I added, "... and these are the things I want you to know" and "I believe it will help if you can remember these few things.", that I felt I had finished.

It felt good that I could move on with my life. My urge 'to tell' disappeared and that, for me, was a good thing.

Concluding words

In working together on the largest online collection of mental health stories, we have seen people share stories in many ways. There are more reasons to tell a story than we initially imagined. There are also more reasons **not** to tell a story than we have ever thought before.

If you decide to tell your story, this guide may have helped you choose the best method, place and time to share it, with those you want to let into your life in this way.

Limitless

I thought I had said it all. Fifteen years later and it turns out I am still wanting to explain about my pain and what I've been learning through the hardships I have experienced.

At first it seemed I'd been hard-done-by and that coloured my story. Now, I can better appreciate that there are many ways to explain what happened, why it happened, and who or what may have led to my troubles.

How many ways can I tell my story? The possibilities seem infinite.

This guide has been created by the Narrative Experiences Online Lived Experience Advisory Panel (NEON LEAP), including Roger Smith, Sylvia Bailey, Paul Davis, Donna Franklin, Julian Harrison, David King, Rianna Walcott and two people who wish to remain anonymous.

This document was published in October 2020 and can be cited as: Narrative Experiences Online Lived Experience Advisory Panel. (2020). *Telling a story of mental health experiences, a guide*. McPin Foundation.

This guide is independent work funded by the NIHR under its Programme Grants for Applied Research Programme (Programme Grants for Applied Research, Personal experience as a recovery resource in psychosis: Narrative Experiences ONline (NEON) Programme, RP-PG-0615-20016).

The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

McPin Foundation
Transforming mental health research

FUNDED BY
NIHR | National Institute for Health Research

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

University of Nottingham
UK | CHINA | MALAYSIA

Follow us:

McPinFoundation

@mcpinfoundation

@mcpinfoundation

Sign up to our newsletter:
www.mcpin.org/stay-in-touch/

Find out more about our work:
Visit **www.mcpin.org**
Email **contact@mcpin.org**

McPin Foundation Head Office: 7-14 Great Dover Street, London SE1 4YR
Company number: 6010593. Charity number: 1117336.