

# Sensitive Stories

A guide to creating and sharing sensitive multi-sensory stories with people with profound and multiple learning disabilities.

## Introduction

This guide has been developed by PAMIS and Mencap's Treat me well campaign to celebrate Profound Impact Day 2019. It is intended as an introductory resource to help and support people to design and develop a sensitive multi-sensory story that may help people prepare for a visit to the hospital. It will provide a very brief overview of multi-sensory storytelling but will focus on designing, developing and creating a sensitive multi-sensory story about going to the hospital.

No one looks forward to a visit to the hospital and if we do have to go for an operation or procedure we like to prepare as much as possible. We can read the leaflets supplied by the hospital if we choose to, we can speak to someone, or look online for information about what to expect on our admission. This is not the case for people with profound and multiple learning disabilities (PMLD) where the hospital ward can be a busy, confusing, noisy and often scary place to be. There may be a range of reasons that people with PMLD are afraid to be admitted to hospital so how do we prepare them for their hospital visit or admission?

How many times have you read and reread the hospital leaflet to familiarise yourself with the hospital admission processes or procedures? Or perhaps you put the leaflet in a drawer until nearer the time, as you are anxious and don't want to think about it until the last minute. This is the same for people with PMLD. They are all individuals who will all react differently but nevertheless they should all have the same opportunity to prepare for a hospital visit as everyone else does. Sensitive multi-sensory stories offers them this opportunity.

## What is the difference between multi-sensory storytelling and sensitive multi-sensory stories?

Storytelling is an age old tradition that connects individuals, groups and communities. For people with PMLD connecting with the world around them using their senses is their way of navigating their everyday experiences. Multi-sensory storytelling offers so many opportunities for people to engage and connect with each other in all sorts of situations. They can be created for the individual or shared with a group, they can be educational, raise awareness, incorporate exercise, enable access to culture and heritage and they are fun. Multi-sensory storytelling also opens up opportunities to connect with other people, share stories and be a part of their communities. Multi-sensory stories created for groups to engage with at festivals and events are very different to structured multi-sensory stories created for teaching and learning where specific individual learning targets may be built into the stories.

## What is a sensitive story?

Sensitive multi-sensory stories are a great way to support people to prepare for the more difficult or sensitive situations in their lives. A sensitive story is one that is developed by the people who know the person best or in partnership with those who know the person well.

A sensitive story is a multi-sensory story that is created and personalised for an individual to help them with their learning and understanding of sensitive topics such as going to the dentist, transitions, growing up or experiencing a visit to the hospital etc. The story contains words, sentences and sensory stimuli appropriate to the person that the story is being designed for. The story space is a safe space to explore the experiences, emotions and challenges that might arise when working with the experience.

Learning together through multi-sensory storytelling can help people with PMLD to make sense of some of their more difficult and challenging life experiences but it can also help the creator of the story to think more empathetically about how the person with PMLD might be feeling at that time. Through creating and sharing the story together in a safe space a shared connection and understanding of sensitive situations can be explored, created, adapted and amended over time. A sensitive story is a very personal and special story that explores sensitive topics in a practical but sensitive way.

## **What to consider and be aware of when creating sensitive multi-sensory stories?**

There are some things to consider and be aware of when creating a sensitive multi-sensory story and these may vary depending on your relationship with the person you are designing the story for.

Firstly, depending on the relationship between the story creator, the listener and the topic of the sensitive story, the story maker might be surprised with the personal emotion that creating the story might unexpectedly trigger in themselves. This sometimes happens and is something to be aware of. So give yourself time to factor in the recognition, acknowledgment, processing and integration of any emotion you might experience while preparing a sensitive story.

Consider the story space and the environment you choose for telling the story. Remember it's a sensitive story you are working with, so creating a safe, nurturing space that is calm, quiet and one with as little distraction as possible will enhance the experience.

The key to designing and developing an effective multi-sensory sensitive story is knowing the person well and working in partnership with others who can assist you with the relevant information to enable you to create a story that suits the person and the situation that you are designing the story for.

## Steps to creating a sensitive multi-sensory story

Begin by gathering information and developing a personal sensory profile that will help you choose the best stimuli for the story. You can do this by thinking about what you know about the person and what their likes/dislikes are.

Then working together in partnership with the relevant practitioners you can begin to plan the most effective way to structure your story, using stimuli that will engage the person appropriately and effectively in a fun and exciting way:

- What does the person like/dislike to touch?
- What sounds does the person like/dislike?
- What smells does the person like/dislike?
- What is the person's vision like? **How does the person respond to light? Has the person had a functional vision assessment undertaken? Speak to the people who can give you this information, e.g. a visual impairment teacher/ specialist.**
- What tastes does the person like/dislike?
- What movement does the person like/dislike?
- What multi-sensory experiences does the person like/dislike?
- Does the person use Canaan Barrie or Body Signing?

If the person is seen by an Occupational Therapist, Physiotherapist or Speech and Language Therapist, gather any relevant information they have such as a sensory profile or communication and visual passport to help you embed the correct stimuli into the story.

Use all this information for your planning of the story, together with the intimate understanding and knowledge you have about the person to shape the story. After all if you care for the person 24/7 you will know the person better than anyone but working with practitioners to gather additional information will enhance the success of the story.

**Remember:** It does take time to gather all the necessary information but it is an important part of the story making process.

Once you have collected all the information you have a great framework for putting together a sensitive multi-sensory story that will fully support the person you are creating the story for. Allow plenty of time for reading the story to the person, as it is the repetition of the story that informs the understanding of the experience. This can take up to eight, ten or twelve readings, depending on the individual.

## Choosing the stimuli

Robust information gathering will help you to more easily identify appropriate stimuli for the sensitive multi-sensory story. Firstly you should identify what the purpose of the story is and what you want to achieve with the story. Then you can begin to carefully plan the stimuli in the story that will be relevant for the person you are designing the story for. In other words the stimuli used has to be accessible to the person you are creating the story for and relevant to the planned situation.

Below is an example of what all this means practically.

### Planning a story for Tom's hospital visit

*As Tom's mum how would you make a sensitive multi-sensory story to support Tom's hospital visit?*

Tom is a young man with profound and multiple learning disabilities and a number of health related problems. He has a cerebral visual impairment and uses some on body signing, he is not tactile defensive. Tom is being admitted to hospital for some tests and is very anxious.

The first step would be to build a general framework of understanding by identifying and incorporating the standard hospital journey into the story, then think about the more specific detail depending on what you think Tom would cope with. By framework of understanding I mean how would Tom travel to hospital, who will he meet at the hospital, and where will he go once he gets to the hospital. It might begin something like;

Tom is going to the hospital. He is going in the car - (show appropriate stimuli such as a toy car)

When Tom arrives at the hospital the doors open - (use Tom's arms or something he is familiar to indicate open and say the hospital doors open)

Once he reaches the ward, the nurse says, "Hello Tom" and opens the door to show him his room - (show appropriate stimuli- e.g. show something you have designed to simulate a door opening)

"This is your bed Tom"- (show appropriate stimuli such as a doll's bed)

In the above example the story begins by simply explaining how Tom is going to get to the hospital, who he might meet and then introduces him to the room. Only then would you begin to add detail such as stethoscope and various pieces of equipment that might be used during Tom's hospital stay. (You would have already previously identified what tests Tom was being admitted for). Building up the story in this way his would enable Tom to have some understanding of what was going to happen once he was at the hospital.

Next you would consider what you felt was an appropriate level of detail given Tom's high anxiety. It might be appropriate to support his understanding of the actual procedure and this could be done through exploring the equipment that might be used. However it is important to think about the emotional impact that a sensitive multi-sensory story might have on the person that you are creating it for. It might be that you create the whole story but introduce it gradually, starting with the trip to hospital then adding pages and increasing the interaction with the more complex elements of the story as the person's confidence builds. Tom sounds very anxious about his hospital stay, so the story could be created using familiar hospital items such as stethoscope, equipment noises such as beeping and hospital smells. Then once Tom became familiar with these you could begin adding the more complex sections of the story slowly. It really does very much depend on the individual and your knowledge of them. The sentence structure is important in these stories. Short sentences are best and not too many of them.

**This guide is a basic introduction to developing and creating sensitive stories but it should be noted that everyone is different and everyone's hospital experience will be different therefore no one story will be the same.**

For further information: <https://bit.ly/2JFC3fP>- link to 'Multi-sensory storytelling as an aid to assisting people with profound intellectual disabilities to cope with sensitive issues: a multiple research methods analysis of engagement and outcomes' by Hannah Young , Maggi Fenwick , Loretto Lambe & James Hogg, 2011 or visit <http://pamis.org.uk/services/multi-sensory-storytelling/>