

Zintuigenverhaal



Sensory stories for significant life events

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This document is an English translation of the original Dutch publication and was produced using automated translation tools and AI. Every effort has been made to ensure the accuracy. However, errors, omissions, or unintended interpretations may remain. Readers are encouraged to consult the original Dutch version if clarification is needed.

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Introduction

Someone who has difficulty with language and communication, for whatever reason, has to deal with this every day. Communicating about everyday events is often complicated. But communicating about significant events is even more complicated^{3,5,6}. This guide is about a storytelling method designed primarily for people (young and old) with language and communication difficulties: sensory stories. In this guide, information is provided on how you can prepare for and facilitate these significant events yourself, as that is the first step toward creating an appropriate sensory story.

Sensory stories

A sensory story is a short story of 6–8 pages about a familiar topic. Each page features a photo and/or pictogram, and each page is paired with an object that offers a sensory experience—for example, something you can smell or touch.

With sensory stories, you can weave together stories about everyday events, such as playing outside or cleaning. Various instructional materials and sample stories have been developed for this purpose. Visit www.zintuigenverhalen.nl for more information. If you have no prior experience with sensory stories, it is recommended to start there; you'll also find two guides on how to read and create sensory stories^{1,2}.

Significant events

You can also use sensory stories to communicate about significant events, such as a move, a death, or a hospital visit. Emotions like fear, sadness, or anxiety can play a role in these events. That's why it can be helpful to get some extra information on creating these "significant" sensory stories. This guide was written for that purpose.

Contents

In this guide, first is discussed how someone might experience a significant event and why that can be difficult (or more difficult). Next, the focus is on communicating about significant events. Finally, it is described what is needed to create a sensory story about a significant event.

In this guide, background information and tips, a step-by-step plan, and a worksheet are provided. Three significant events are fully detailed, and you can also download a sample story for each of them online. These examples might help you to create sensory stories about other significant events as well.

Guiding questions

Throughout the guide, you will find guiding questions. These questions can help you think through the sensory story and tailor it to be as appropriate as possible. In the appendix, you can answer all the questions in a clear and organized way. You can use these guiding questions, but you do not have to.

Before you create a sensory story...

Experiencing significant events

Before you create a sensory story about a significant event, it is helpful to know a little more about how we structure our experiences. This can help you prepare for the significant event and create the sensory story.

There are many different theories about structuring and making sense of experiences. In this guide, the focus is on the Theory of Structuring Experiences⁷.

Structuring experiences

Everyone structures the world. We do this unconsciously at first, and gradually become more conscious of it. But that unconscious aspect is always present. When something exciting happens, we get flustered, and it is important that we feel okay. According to the Theory of structuring experiences, it is therefore necessary that we (unconsciously) be able to answer the following questions with “yes.”:

- Does my body feel safe?
- Is my environment predictable?
- Do I understand the context?
- Am I allowed to be myself?

All four questions represent a way of structuring of and making sense of experiences; from the perspective of your body, predictability, coherence, and whether you are allowed to be yourself. These ways are present simultaneously and influence one another. It is possible that one way comes more to the forefront than the others. Especially in times of stress, you often see that one way is particularly prominent. For example, you might notice that someone really wants to eat or be hugged (Does my body feel safe?), or that someone wants to know what comes next (coherence), or keeps asking the same question to check if the answer is still the same (predictability). By recognizing which question is taking precedence, you can better attune to someone.

To understand how someone is structuring their experiences at that moment, you can ask yourself the following questions:

- Do you see which way of structuring experiences is taking precedence?
 - What is the person doing with their body? For example, do you see them fidgeting, rubbing, eating, smelling, or touching? Do they talk a lot about food, drink, heat, cold, or pain?
 - Does the person want to know what is going to happen? Do they frequently check the daily schedule? Do they check things, such as whether something is open or closed? Is there something they always do the same way?
 - Does the person try to understand how things are connected? Does the person ask, “What happens then?”? Is the person thinking about previous, similar experiences? Do you notice the person trying to understand how things fit together in the situation?
 - What characterizes this person? How does someone show what they like, enjoy, or find unpleasant? How much leeway is there for that? How does someone react when something isn’t allowed or is not possible?
- How can you take those ways of structuring experiences into account?
 - How can you pay extra attention to physical safety?
 - How can you offer more predictability?
 - How can you help them understand the bigger picture?

- How can you help the person be more themselves?

For each significant event, this guide provides a number of tips on how to help the person make sense of their experiences.

Before you create a sensory story...

Communicating about significant events

When you are about to communicate about significant events, it naturally starts with knowing who you are dealing with: How does someone typically communicate and function? What are their preferences? The following guiding questions can help with this (see the appendix for all questions):

- **What are the person's strengths, preferences, and areas for attention?**
 - What are the person's interests and preferences?
 - What can someone do, and what can't they do? In what areas does someone often need support?
 - Are there certain sensory stimuli that the person finds pleasant or, conversely, unpleasant?

Next, consider what is already known about how the person handles significant events.

Perhaps there are already tips or points to consider based on previous situations.

- **How does the person usually handle a significant event?**
 - Has the person experienced this event before? What do the people in the person's circle know about how they react to a significant event?
 - What potential emotions and triggers are at play for the person in connection with the significant event? Is it anxiety-inducing, exciting, challenging, intriguing, etc.?
 - For example, does the person have difficulty with changes or transitions? Does the person understand the situation? Does the person feel safe?
 - Do you notice a particular question from the person's way of structuring experiences coming to the forefront when something significant happens?

Augmentative and alternative communication (AAC)

For people with language or communication difficulties, forms of communication other than spoken, written, or sign language can be helpful in understanding one another better. Some forms of communication are easier to understand and less fleeting than spoken or sign language. The use of other forms of communication in interaction—ranging from body language, objects, and photos to speech-generating devices—is called Augmentative and Alternative Communication (AAC). (For more information on AAC, see, for example, [Information \(online modules\) – Deelkracht](#) and the Zintuigenverhalen website, www.zintuigenverhalen.nl.)

When significant events happen, it affects how a person communicates. A person may temporarily communicate differently (for example, switching from spoken language to body language) or may not yet have learned certain words (for example, the word "stethoscope"). Or, due to nervousness, a person may need extra visual support to remember what is going to happen.

- **What AAC materials does this person need for this significant event?**
 - What signs, images, or aids does the person normally use?
 - What specific terms might you encounter during the significant event? Do you also have the corresponding gestures, photos, or other forms of AAC for these terms? (Think of Sclera/Visitaal pictograms, PCS symbols, Symbolstix, communication cards, speech buttons, tactile images, etc.)
 - Is it possible that the person will need more visual or tactile support because of the significant event? For example, preparation for what is going to happen, a step-by-step plan, daily routine cards, tactile images, a communication card, a communication passport, additional vocabulary in the speech-generating device, etc.
 - Can you take photos or videos of the event?

A sensory story about a significant event

How do you create a sensory story about a significant event? Using this guide, you can create a customized sensory story about an event that is relevant to you.

Is the event expected or unexpected?

There are three possible scenarios for significant events:

- the event has yet to take place but is unexpected (for example, a funeral or a sudden hospitalization)
- the event has yet to take place but is more or less planned (for example, a medical exam at the hospital, a move, or a birth)
- the event has already taken place, but you still want to create a story about it.

If the event is still to come, that gives you time to prepare. First, review what this guide says about structuring experiences and communication during significant events. You can also start gathering some materials that fit the event and will fit into a sensory story box (such as a doctor's kit or a moving box), print out AAC images, think about how the event will unfold, and arrange for someone to take photos of the event. Of course, whether there is room for these preparations depends on the emotions surrounding the event.

If the event has already taken place, the preparation is no longer necessary, but you can sometimes find some photos or materials retroactively.

Tip:

- When gathering materials, you can contact an institution such as a hospital or crematorium. They are often willing to cooperate and sometimes even have materials of their own that can help with the preparation or the story.

Preparing the sensory story

Creating a sensory story begins with attuning to the person for whom the story is intended; see Chapters 1 and 2 on the organization of experience and communication. You can also do this by asking yourself a number of questions about the person and the sensory story.

- **What is the purpose of the sensory story?**
What do you want the sensory story to help with? Do you want the person to be well-prepared, or do you want to alleviate anxiety or uncertainty? Or do you want to introduce or practice new concepts?
- **What will the person experience during the significant event (or what did the person experience), and in what order?**
 - How did the person experience the significant event—what exactly happened? The order is important because it increases the likelihood that the person will recognize the significant event. For events that have yet to take place, stick to the most likely sequence as much as possible.
 - What were/are the most important moments for the person? These may be something entirely different from the main focus of the event. For example, perhaps the little doll hanging from the car mirror was much more interesting than the moving truck itself.
- **Are there certain memories or elements of the event that are important to the person?**
 - Which memories resonate most with the person?
 - What made the biggest impression?
- **What sensory experiences are present or were present in the situation?**
 - What stimuli do you expect? What do you see, hear, smell, taste, or feel on the spot?

- Which sensory stimuli resonate with the person?
- What sensory stimuli can you add to the situation that will later fit into a sensory story box?
- Can you record sounds from the situation?
- Are there any distinctive materials in the environment that fit into the story?

People who are deaf or hard of hearing will hear less or no sound, but may perceive a vibration, for example. And someone might pay extra attention to details in the surroundings, or to smells.

People who are blind or visually impaired may not be able to see objects, or may see them less clearly, but they can smell, possibly hear, and of course feel. So pay close attention to how someone can navigate in an unfamiliar environment—for example, whether there are distinctive floors, doorknobs, or wall coverings.

Especially if someone has a hearing and vision impairment (deafblindness), it is important to engage their remaining senses as much as possible; for example, what does it smell like? What movements does someone need to make during the event? How does the chair or sofa feel?

There may be certain sensory stimuli that make the person feel uncomfortable. If this is the case, ask yourself whether these stimuli are necessary to incorporate into the story. It is; a story doesn't have to consist solely of pleasant stimuli but can also be a little suspenseful. But if that makes the story as a whole unpleasant, so that someone doesn't find the activity, then you are obviously missing the point of the story.

You can also add sensory stimuli on the spot that fit into the story later. Think, for example, bringing an extra teddy bear, a bottle of juice, bubble solution, a flashlight, or hand sanitizer. That way, you can be sure these elements can go into the sensory story box without having to rely on what is available at the location.

Putting together the sensory story

Once you know as much as possible about the event and the person, you can start putting the story together.

- **What content will be included in the final sensory story?**
 - Which moments will and won't be included in the final story? This requires making choices, because often much more has happened than can fit into 6–8 pages. In that case, it can help to consider which sensory experiences are most appropriate.
 - Where does the story begin and end? With the journey there or at the location itself?
 - What emotions were present in the situation or might arise? How can you incorporate those into the sensory story? Do not just fill in the emotions; instead, look at what was actually visible and describe that—for example: Mom had tears in her eyes, Jip had to laugh.
- **Which sensory stimuli are included in the sensory story?**
 - For each sensory experience, consider whether it can be integrated into a sensory story. If you can't use something (because it is too big, not possible, etc.), see if you can use a photo instead. For example, of the examination lamp in the hospital—in the story, you can then incorporate a flashlight.
 - Are there any distinctive sounds that can be incorporated into the story via a voice button?

You read sensory stories aloud using AAC. This involves using various forms of communication. This helps the person understand the sensory story. When reading a sensory story aloud, choose the form(s) of communication that the person uses in daily life. You can choose to add an additional form of communication that the person is currently learning. If you do not know which form(s) of communication the person uses, check with the speech-language pathologist or communication specialist involved.

- **What AAC materials are necessary and helpful for the sensory story?**

- What AAC materials are available on this topic (photos, pictograms, drawings, objects, tactile boards, tactile pictograms)?
- Have you taken your own photos? Photos provide a clearer picture of the situation and are a good idea to use, if applicable to the person. This can be helpful both in preparing for a situation and during a debriefing. You can also have photos made tactile; look online for companies that offer this service.
- Can you generate images using AI? (Check www.zintuigenverhalen.nl for appropriate instructions (prompts) on how to do this.)
- Which sensory stimulus (object, image, pictogram, button) will you use for the story?

This is how you structure the story: 6–8 pages, 1–2 lines per page, and a box with the sensory materials.

On the following pages, you will find key considerations for creating a sensory story about three significant events: a death, a hospital or doctor's visit, and moving. Sample stories for these events can be found at www.zintuigenverhalen.nl. There you will also find sample stories about, among other things, the dentist, the hairdresser, and the birth of a baby.

Death and loss

For many people, death is a difficult topic to understand. For people with communication difficulties or limitations it is often even more complicated⁶. It is an abstract and difficult-to-grasp concept that only truly takes on meaning when it personally affects someone—for example, through the death of a pet or a loved one.

First, you will find some *key points and advice* on how to generally address death of someone in relation to this target group. (This advice is, of course, also valuable when creating a sensory story.) Next, it is explained how the way somebody is *structuring experiences* can change following the death of somebody. And finally, you will get suggestions on how to use this information to create a *sensory story* about the death and the funeral.

Points to consider and advice in the event of somebody who died

As a parent, volunteer, or professional, you can make a significant difference in supporting someone through a death. The most important thing is to provide *clarity and a sense of security*. Below are some tips and advice on how to do this in practice.

Communication

People with communication difficulties may struggle to recognize and express emotions. It is normal for someone to repeatedly ask if a person has died. This is a way of seeking confirmation.

- *Use clear, concrete terms* to explain that someone has died, such as: they no longer talk, move, or walk; they are very cold and still.
- *Avoid* using *abstract statements or metaphors* such as “he is sleeping” or “she has become a little star.” This can cause confusion and even fear, for example, of going to sleep.
- Explain that death is *irreversible*: once someone is dead, they will never return and can no longer do anything.
- Mention a *meaningful aspect of the relationship* to make this clear:
 - “Mom is dead. She won’t be reading to you anymore.”
 - “Grandpa is dead. He’ll never be able to go biking with you again.”
 - “Jip is dead. He can’t play soccer anymore.”
 - “Boef is dead. He won’t bark anymore.”
- *Discuss the funeral or burial afterward*, for example using the sensory story, but also at other times if possible.
- *Keep repeating* things *calmly* and use the same words you think are most appropriate—don’t keep switching to different ways of saying it.
- *Ask questions*, such as “Do you miss your grandpa?”
- *Name* the emotion you see in the other person: “You’re finding this difficult (or weird, strange, exciting, sad),” but without filling in the details

Structure

The death of a loved one can disrupt daily routines. This can lead to anxiety or sadness.

- *Maintain the daily routine* as much as possible. This provides stability and a sense of control. After the funeral, return to your regular daily schedule (meals, bedtime, etc.).

Faith and rituals

If there is a religious belief, it may involve specific words, rituals, or symbols.

- Discuss together (parents and professionals) *which words, gestures, or rituals* are most appropriate and understandable.
- Take into account *the sensory experiences* associated with rituals (smell, sound, touch).
- Take into account the person's *personal experience*: what is already familiar to them, what feels safe, and what causes confusion?

Emotions and behavior

Grief is different for everyone. For people with communication disabilities, grief can manifest in different ways:

- Sometimes *no immediate emotion* is visible. Sadness may come later, or manifest as frustration, anger, or withdrawn behavior.
- The person may *miss a shared activity* (such as riding bikes together) rather than understanding the death of the loved one itself.
- Be alert to *sudden changes in behavior*. Behavior that is difficult to understand, or conversely, quiet and withdrawn behavior, can be an expression of sadness or confusion.
- *Don't project your own emotions* onto the other person. Someone may experience the death very differently.
- Feel free to show your own emotions, but *explain that these are your feelings*. This helps the other person recognize and make sense of their own emotions.

In summary

- Use simple, direct language
- Repeat information calmly and patiently
- Use AAC (photos, pictograms, objects, speech-generating devices, etc.)
- Maintain the daily routine as much as possible
- Be mindful of rituals and expressions of religious beliefs.
- Observe behavior and emotions without judgment.
- Feel free to show your own emotions, but be sure to explain them.
- Remember that grief can also be expressed without words.

Keep in mind that the grieving process is different for everyone. Not everyone views death as something sad. Still, it is important to remember that difficulty expressing emotions does not mean the person isn't affected by the loss⁶.

Death & structuring experiences



Does my body feel safe, even if someone I know well has died?

How can the death of a loved one affect the physical safety of the person?

The person may encounter unfamiliar sensory stimuli. At a funeral, for example, there are often many people present who are grieving. The space is also often unfamiliar. The room may be bright or, conversely, very dark, and there is often music playing in the background or during the ceremony. All of these sensory experiences (crowds, others' emotions, sound, lighting) can cause discomfort for the person.

- Whenever possible, prepare the person for the sensory stimuli they will encounter
- Allow space for physical reactions (fidgeting, withdrawing).
- Address any concerns they may have about their own body: "Grandma was sick. You're not sick."



Is my environment safe, even if I have lost somebody?

How can an environment be created before, during, and after a death in which the person feels safe and comfortable?

The death of an important and trusted person often brings about changes. For example, because the usual routine changes or because the deceased is being laid out at home. These changes can lead to uncertainty and a feeling of insecurity.

- Use AAC to clearly explain what is changing and what will remain the same.
- Provide familiar people or objects.
- Provide structure and predictability through familiar activities or by resuming the regular routine.



Can I discover the connections, even when someone is no longer here?

How can the person see or experience the meaning and connections surrounding loss, death, and missing someone?

The concept of death involves many abstract terms. This can make it difficult to make connections. For example, it may seem as though the person understands that someone has died, while they do not grasp that that person will not be coming back.

- Use simple language, visualize what is possible, and repeat the explanation.
- Use AAC (photos, pictograms, objects, gestures).
- Point out meaningful connections: "Grandpa is dead. He won't be coming to ride his bike anymore."



Can I be myself, including in how I say goodbye?

Can the person be themselves in how they choose to experience the death, express their emotions, and say goodbye?

It is important to involve the person in the memorial process. Everyone says goodbye in their own way.

- Involve the person in the farewell (flower, drawing, object)
- Respect personal choices, even if they seem unusual. Maybe someone wants to place a hamburger on the casket because they always ate them together...
- Allow space for emotions, without judging.

On the next page, you'll find suggestions on how to create a sensory story based on this information.

A sensory story about somebody who died and the funeral

The points to consider, advice, and information about structuring experiences mentioned above form the basis for creating the sensory story. The steps for creating a sensory story are always the same and can be found in the guide “Creating Sensory Stories”² and at www.zintuigenverhalen.nl.

When creating a sensory story about a death and funeral, there are a few additional questions that can help you:

- **What resonates?** Which memory of the funeral or cremation resonates most varies from person to person. For one person, it might be seeing the emotional family; for another, it might be coffee and refreshments.
- **What images?** It is a good idea to take photos of the funeral or cremation, such as a photo of the casket. These photos can be used later (in a sensory story). It is becoming increasingly common for a photographer to be present at the funeral, or you can ask someone standing a little further away to take the photos. People are usually very understanding of the importance of photos for someone with a disability.
If someone has difficulty perceiving photos, see if you can focus more on the sense of touch, using tactile materials and possibly raised-relief images.
- **A duplicate object?** You can bring something to place on the casket during the funeral—something of which you have a second copy. You can then incorporate that duplicate object into the sensory story.

Materials

The following sensory stimuli can be used in the sensory story. Of course, only if they apply to this person.

Sense	Sensory stimulus
sight & touch	• black clothing/the driver’s hat/pallbearers • photos of the funeral • photo of the deceased • lighting a (fake) candle • belongings of the deceased • sprinkling sand on the coffin • hearse • a coffin/urn—a piece of the same wood or a similar small jar. • liturgy booklet • handkerchief • feels cold to the touch, just like a doll
hearing	• music • church bell
smell	• incense • flowers • candle • coffee, soup, sandwiches
taste	• food served at the funeral (e.g., coffee and refreshments) • crying – (salt) water
do	• sign the condolence book • an activity the person can no longer do (together)

Note: Different religious beliefs may involve different sensory stimuli, such as wearing white clothing instead of black. Please keep this in mind.

A sensory story in memory of a person

The points to consider, recommendations, and information about the structure of the experience mentioned earlier form the basis for creating a sensory story. The steps for creating a sensory story are always the same and can be found in the guide “Creating Sensory Stories”² and at www.zintuigenverhalen.nl.

In addition to a sensory story about the funeral itself, a sensory story can also help keep the memory of a person alive. A sensory story allows someone to communicate about the person who has passed away, even if they have limited verbal ability. In this way, a sensory story can help shape and guide the grieving process. Consider the following points as well:

- **What suited the person?** What was characteristic of the person who has passed away? What did they look like? What did they smell like? What did they enjoy doing? What was their favorite mode of transportation? What kind of music, food, etc.?
- **What images?** Create a beautiful memory book based on the sensory story by selecting photos of the person who has passed away and the person for whom the story is intended. The central theme of the story is the person who has passed away, so the sensory story does not need to be about a specific event.

Materials

The following sensory stimuli can be used in the sensory story. Of course, only if they apply to this person.

sense	Sensory Stimulus
sight & touch	• beautiful photo • piece of clothing • household item • accessory or aid belonging to the person (necklace, bracelet, hearing aid, glasses, walking stick) • short video of the person
hearing	• favorite music • voice on a voice button • phone ringtone • A sound associated with the person’s hobby or home, such as a TV theme song, a musical instrument, birdsong, the ocean, a motorcycle, etc.
smell	• the person’s clothing • the person’s scent • the person’s personal care products (shaving soap, shampoo, body lotion) • specific foods the person liked to eat or cook • a scent associated with the person’s hobby, such as the scent of flowers, fish, or straw.
tasting	• favorite food or drink • something the person liked to bake or cook
Doing	• An activity the person enjoyed doing, such as a bicycle bell, a ball, colored pencils, a book, dice, Rummikub, needlework, crafts, pottery, gardening, etc.

A sensory story in memory of a pet

The previously mentioned points to consider, recommendations, and information about the structure of the experience form the basis for creating the sensory story. The steps for creating a sensory story are always the same and can be found in the guide “Creating Sensory Stories”² and at www.zintuigenverhalen.nl.

A sensory story can also help keep the memory of a deceased pet alive. It allows you to share together what the animal meant to you, and the sensory story offers support during the loss of the pet. Consider the following:

- **What was characteristic of the animal?** Think about what the animal looked like, smelled like, or sounded like. What did the person enjoy doing with the pet? What habits or sounds were characteristic of the animal?
- **What images?** Create a beautiful memory book based on the sensory story by selecting photos or tactile images of the pet, preferably together with the person for whom the story is intended. The pet is at the center of the story, so the sensory story doesn’t have to be about a single specific event.

Materials

The following sensory stimuli can be used in the sensory story. Of course, only if they are applicable.

sense	Sensory Stimulus
sight & touch	• beautiful photo • collar, brush, leash • fake fur, tuft of hair, or stuffed animal • toy • short video of the pet • the pet licking or cuddling
hearing	• animal sounds via the voice button (barking, purring, meowing, chirping, squeaking) • sound of a toy • sound of walking on the floor, the food bowl, the cage door
smell	• straw or wood shavings • pet food • favorite blanket or toy • fur or wool
taste	• water • vegetables, such as lettuce or carrots (if the animal was given them)
do	• favorite toy • the animal's favorite activity, such as running in the exercise wheel, hiding in the straw, fetching, digging, or swimming • greeting • caring for the animal (brushing, bathing, combing, trimming nails)

At www.zintuigenverhalen.nl, you’ll find the sample story “Grandma has passed away.”

Going to the doctor or the hospital

A visit to the doctor or hospital can be stressful or even frightening for people with communication difficulties. Some have already had many experiences at the doctor's office or in the hospital, which may have left them with negative memories. For young children or people with intellectual disabilities, fear often stems from a lack of understanding: they don't really know why they have to go to the doctor or the hospital or what is going to happen. Things like staying sober or anesthesia are also difficult to explain. The environment is different from home, the course of events is unpredictable, and the hospital is often busy, white, and sterile. That can be overwhelming.

That is why, in this chapter, first is focused on *general considerations and advices* regarding a visit to the doctor or the hospital. (These tips and recommendations also apply to the sensory story!)

Then you will find information about visiting the doctor and *structuring experiences*: what factors might play a role during a visit to the doctor? And how can you take those into account?

Finally, it is explained how you can create a *sensory story* about visiting the doctor.

Points to consider and advice for a visit to the doctor

Communication

- *Be clear* and direct.
- Also pay close attention to *when you* provide *which information*.
- Explain *step by step* what is going to happen, for example, "You'll put on headphones" and "Now you'll hear some beeps."
- Use *AAC* during preparation, at the time of the visit, and when processing the doctor's or hospital visit afterward.
- Try *to choose* your *words carefully*. Avoid words that might cause confusion; for example, for one person, anesthesia might mean "sleeping," but for another, you might say "lying still with your eyes closed" because "sleeping" brings to mind being in bed at home.

Preparation

- Good *preparation* can help prevent (some of) the fear or anxiety. So, for example, see if you can get a video or photos of the treatment room, or if you are allowed to come take a look beforehand.
- Think about a clear *start and a clear end* to the doctor's or hospital visit.
- In what ways can the person play an *active role* during the doctor's or hospital visit? Can they hold onto something during the exam, check off pictograms for each step, or perform the same exam on their teddy bear or doll at the same time?

Emotions and behavior

During a doctor's or hospital visit, emotions such as tension, fear, sadness, stress, or panic may arise. These are often only visible in the moment, because it can be difficult to communicate about things that aren't happening right here and now. Possible reactions may include: seeking attention through unwanted behavior, being quiet and withdrawn, resisting (not wanting to cooperate or actively opposing), and aversion or fear of anything related to the doctor or the hospital (even toys).

That is why here are a few more tips:

- Associate *positive experiences* with the doctor's or hospital visit, such as a special stuffed animal, coloring book, fidget toy, sticker sheet, or doing something fun together afterward or enjoying a treat to eat or drink.
- *Don't project your own emotions* onto the other person. Show your emotions, but explain: "I find this nerve-wracking; that is how I feel."
- Stay *calm and clear in your explanation*, even if you are feeling emotional yourself.
- If necessary, ask *someone* who is a bit more detached *to come along*, so they can provide support and a sense of calm.

Doctor's or hospital visit & structuring experiences



Does my body feel safe, even at the doctor's office or in the hospital? *How can you ensure physical safety during a physical exam or treatment?*

A visit to the doctor or hospital can feel physically unsafe. The environment is unfamiliar, and there are many stimuli (light, smells, sounds). Even being touched by doctors can be confusing or stressful. How can you take this into account?

- Prepare the person well using visual aids (photos, the sensory story)
- Explain what will happen and why, using simple language.
- Let the person bring something familiar (a stuffed animal, their own clothes).
- Allow space for physical reactions such as fidgeting or pulling away.



Is the environment predictable, even at the doctor's office or in the hospital? *How can you ensure as much predictability as possible before, during, and after the doctor's or hospital visit?*

A visit to the doctor or the hospital disrupts the daily routine. This can cause anxiety and uncertainty. Familiar people, familiar routines, and the use of AAC help make the environment predictable.

- Maintain the daily routine as much as possible both before and after the visit, preferably using a visual daily schedule.
- Use clear (supported) communication to explain what is different and what stays the same.
- Show when the hospital visit begins and when it will end.
- Ensure that a trusted person is nearby.



Can I make sense of the situation, even when I am at the hospital or the doctor's office? *How can the person understand the meaning and connections surrounding a hospital visit?*

Understanding what is happening and why can help them experience a sense of coherence, even at the doctor's office or in the hospital.

- Use simple words; say "picture" instead of "X-ray."
- Use AAC to show in advance where someone is going and who will be there.
- Repeat the explanation using the visual aid.
- Describe the steps: "First we'll sit down, then the doctor will come."
- Sometimes, as a way to prepare, a person can visit beforehand to look around or even try out some equipment (a stethoscope, a syringe, turning the big light on and off, etc.). This can help them feel a sense of coherence.



Can I be myself, even at the doctor's office or in the hospital? *What is a comfortable and characteristic way for this person to be?*

Various emotions can arise in the hospital. It is important that the person feels seen and is allowed to react in their own way.

- Respect their emotions and give them space to express themselves.
- Let the person ask questions.
- Let the person make choices whenever possible (for example, who comes along, what to bring).
- Associate something positive with the visit (a cookie, a balloon, doing something together).
- Try to set aside enough time for the visit so that the person can go through the exam or treatment in peace and quiet, ask questions, or take a moment to process what is happening.

A sensory story about a doctor's or hospital visit

The points to consider, advice, and information about the sequence of experiences mentioned above form the basis for creating the sensory story. The steps for a sensory story are always the same and can be found in the guide "Creating Sensory Stories"² and at www.zintuigenverhalen.nl.

When creating a sensory story about a doctor's visit, there are a few additional questions that can help. By going through the visit step by step, a person gains a better understanding of what is going to happen or what has happened. This can reduce anxiety and fear. Consider the following:

- *Visualize the steps.* If necessary, check with the hospital or the doctor to find out exactly what will happen. Try to collect photos of the treatment room or the equipment.
- *Be careful when mentioning pain in the story.* If there is a chance of pain (for example, during a blood draw), don't mention it until the moment it happens. Talking about pain too early might cause unnecessary anxiety. It can feel different for everyone; one person might not feel anything, another might feel a tingling sensation, and someone else might experience a lot of pain. If someone asks about it, give an honest explanation and discuss together what might help (for example, squeezing a hand or holding a stuffed animal).
- *Use real objects whenever possible.* Bring some items to or from the hospital that are used on the spot and can later be incorporated into the sensory story—for example, a napkin during a meal, a straw, a face mask, etc.

Materials

The following sensory stimuli can be used in a sensory story. Of course, only if they apply to your situation.

Sense	Sensory stimulus
sight & touch	• photos of the hospital, doctor, treatment room • calendar (... days until the hospital visit) • bright light • syringe (without a needle) • hospital clothes • headphones • headphone cord • white, sterile (clothing, comforter) • doctor's bag • eye patch/toy glasses • stethoscope (cold) • applying band-aids • anesthesia mask • ECG electrode stickers • get-well card

	• cotton balls • spit cup • IV bag • balloon • gloves • clown nose (clini-clown) • ear thermometer (toy) • blood pressure monitor (toy)
hearing	• beeps (loud/soft) • stethoscope (listening to the heart) • MRI scan sound • music or a song during treatment/in bed
smell	• alcohol wipe* • flowers • fresh scent (Dettol, alcohol wipe)* • hand soap • disinfectant lotion
tasting	• Is there anything you always eat in the hospital? • hospital meal, • juice • water • ice cube, popsicle
do	• activity in the waiting room/during the stay • open/close mouth, open/close eyes (depending on the type of treatment) • make a fist

*This has a strong odor that may be unpleasant. So let them smell it only briefly, and use this option only if someone isn't (too) sensitive to smells.

At www.zintuigenverhalen.nl, you'll find the sample story "Lynn Goes to the Doctor." (in Dutch 'Lynn gaat naar de dokter')

Moving

Moving is often a major life event. The familiar surroundings disappear, routines change, and the person must find a new sense of safety and stability. This can cause stress, confusion, or uncertainty. In this chapter first a number of general *considerations and recommendations* that are important when moving are given. You can also use these tips when thinking about your sensory story. Next, the focus is on *how experiences are being structured* during a move. How might this affect someone? And what should you keep in mind? Finally, you will receive some advice and suggestions for the *sensory story* about moving.

Points to consider and advice for moving

Communication

- Adapt your *explanation* to what the person understands.
- *Repeat* information calmly and use clear language.
- Allow time for *questions and emotions*.
- Use *visual aids* such as photos, a bed schedule, and, of course, a sensory story during preparation, while moving, and when discussing the experience afterward.

Preparation

- Involve the person in the move whenever possible: packing *together*, doing chores, making decisions.
- Let the person *get* to know the new space in advance.
- See if the person can move something *on their own*—a box with a few items, for example.

Structure

- Stick to *their familiar routine* as much as possible: eating, waking up, and going to bed at the same times.
- Use *familiar items* (unwashed bedding, familiar furniture) in the new environment. And give *favorite items* a permanent place.

Emotions and behavior

- Show them the *empty room*, let them say goodbye, and then move their familiar belongings to the new home together. Even if someone is at school or a day program that day, make sure someone still shows them that all their belongings are now gone from the old home.
- Help the person say *goodbye* to their old home, the people there, and the surroundings.
- Support them as they *adjust* to the new environment; a photo album of both the old and new homes can be helpful. Keep in mind that routines will require more time and attention at first.

Moving & structuring experiences



Does my body feel safe, even in a new environment? *How can you help someone relax physically amid so many new stimuli?*

A new environment brings many unfamiliar stimuli: different colors, sounds, smells, and materials. This can cause physical tension or stress.

- Consider whether the person can be present during the move. This can be nerve-wracking, but it can also be helpful.
- Allow space for physical reactions (restlessness, fidgeting, withdrawal, eating).

- Provide moments of calm and familiar sensory experiences. As mentioned earlier, it is actually nice if the bedding still smells familiar and you still have the same creaky bed even right after moving.



Is my environment predictable, even during a move? *How can you restore predictability when the environment has completely changed?*

Due to the change in environment, the person may temporarily feel less comfortable and secure. A sense of comfort comes from familiarity and predictability.

- Maintain the same routines as much as possible. Also, give the person time to rediscover and adapt to these routines in the new environment.
- Use familiar furniture, objects, and routines.
- Use their own unwashed bedding, stuffed animal, and familiar pajamas for the first few nights. These smell familiar and provide a sense of security.



How can I make sense after a move? *How can the person regain a sense of control over the situation?*

Things are in different places, and routes and routines have changed. That is why it is important to help them find a sense of coherence again.

- Walk through the new home together and point out what is the same and what is different.
- Pack and unpack things together. Show the person what happens to their belongings—where are they being placed or hung?
- If possible, introduce changes—such as a new bed or a new closet—later, once the person has had time to adjust.



Can I be myself, even during the move? *What is the best way for this person to experience the move?*

Everyone experiences a move in their own way. Allow room for the person's own choices and preferences.

- Whenever possible, let the person help decide on the layout of their new room.
- Acknowledge and offer support for emotions such as sadness, resistance, or enthusiasm.
- Also consider whether you can create a ritual together around the move, such as making something for the people at the old residence.

(Based in part on the “Moving guide” by Laan et al., 2013⁴)

On the next page, you will find suggestions on how to create a sensory story based on this information.

A sensory story about moving

The previously mentioned points to consider, recommendations, and information about structuring experiences form the basis for creating the sensory story. The steps for this are always the same and can be found in the guide “Creating sensory stories”² and at www.zintuigenverhalen.nl.

In addition to the points above, here are a few more questions regarding the sensory story itself:

- *Incorporate sensory stimuli into the move itself* that can be included later in the story, such as a wall paint swatch, special takeout food, a small moving box, bubble wrap, etc.
- *Take photos of every step* of the move, including the room in its original state and the empty room, as well as the boxes and the moving truck.
- *Try to stick to the actual order as much as possible:*
 - First, we will pack [personal item] together.
 - We wave goodbye to the old house.
 - The new house smells like paint.
 - We will have coffee at the new house.

Materials

The following sensory stimuli can be used in a sensory story. Of course, only if they apply to your situation.

Sense	Sensory stimulus
sight & touch	• photo of the new or old house • moving box • key to new house • moving truck • new furniture • personal stuffed animal • carpet (sample) • curtain (sample) • bubble wrap • tape • wrapping paper
hear	• construction noises (hammering) • ringing the doorbell at the new house • engine or horn of a moving truck • music while working
smells	• familiar laundry detergent • wall or acrylic paint (sample) • cleaning product
tasting	• coffee or lemonade • special “moving” cookies • easy meal (Chinese, pizza)
do	• Packing something in a box or bubble wrap, or unpacking it • Lift something heavy • turn the key in the lock • pressing the button on the moving elevator • hammering a nail/tightening screws

At www.zintuigenverhalen.nl, you’ll find the sample story “Lynn is moving” (in Dutch, ‘Lynn gaat verhuizen’).

Acknowledgments

The guide was developed in collaboration with parents and professionals. First, a survey was distributed. It was completed by 27 professionals. In this survey, they indicated which specific events in daily life cause the most communication problems. The most frequently mentioned topics were “death and loss” and “hospital or doctor visits.”

Next, 9 professionals and 2 parents were interviewed. The professionals work at Kentalis and hold various positions, including educational therapist, speech-language pathologist, spiritual counselor, occupational therapist, communication specialist, and clinical linguist. They work with children and adults of various ages who have a hearing and visual impairment (deafblindness) or a multiple communication disability (CMB). The participating parents each have a child with a multiple communication disability.

The interviews focused on the specific communication difficulties experienced during significant events (specifically, somebody who died and hospital visits) and the possible underlying causes of these difficulties.

The interviewees helped determine the third topic to be addressed in the guide, in addition to “death and loss” and “doctor or hospital visits.” Since many variations of “changes in the home situation” were mentioned (ranging from moving or divorce to changing classes), “moving” became the third theme for this guide. The authors are aware that this does not apply one-to-one to, for example, a divorce or a change of class, but the elements of preparation—such as looking at a new place, packing belongings, saying goodbye, and making a fresh start—are components that apply to many situations.

Finally, an expert interview was conducted, and a literature review was carried out on scientific theories and studies regarding communication surrounding significant life events among people with communication difficulties. Subsequently, in collaboration with three professionals, a co-creation session was held to consider the format of the final product. It became clear that a guide was the most logical first step. The final guide was reviewed by a researcher, a speech-language pathologist, and a family member.

The development process and the underlying literature review are described in detail in Laura van der Tuuk’s Final Report for her Applied Psychology program. A reference list can be provided upon request; please email zintuigenverhalen@kentalis.nl.

Note: Despite the careful process used to develop these tips and recommendations, including the scientific basis, the topics in this guide are highly personal and intended for a broad audience. Everyone will experience these situations differently. The tips provided should therefore always be viewed from this perspective and—where possible, in consultation with an expert—adapted to your own situation.

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Appendix – Worksheet on significant events

Communicating about significant events

What are a person's strengths, preferences, and areas of concern? What are their preferred senses? Are there certain sensory stimuli that the person finds pleasant or, conversely, unpleasant?

How does a person typically cope with significant events?

What communication support materials might this person need before and during the significant event?

Preparing the sensory story

What is the purpose of the sensory story about the significant event? (To prepare for, process, or communicate about the event?)

What will the person experience during the significant event (or what did the person experience), and in what order?

Are there certain memories or elements of the event that are important to the person?

What sensory experiences occur (or occurred) during the significant event?

Creating the sensory story

What aspects of the significant event are included in the sensory story?

Which sensory experiences and stimuli from the event will be included in the sensory story?

What AAC materials are necessary and helpful in and around the sensory story?