

Written guidelines for social workers and casualty officers on delivering difficult news to individuals with Intellectual and developmental disability, such as news of a family member's death in combat or their capture and abduction.

Written by: Hila Tamar Edri

Professional consultants: Dr. Dalia Nissim, Dr. Yael Karni Visel, Dr. Yael Shoval-Zuckerman, Dr. Eti Evlin

Background:

Delivering distressing news is always a difficult task. When it involves delivering bad news to an individual with an Intellectual and developmental disability, the task becomes even more complex, because it presents both a professional and human challenge for those working in the fields of caregiving, social services and healthcare. In such situations, the caregivers – the ones who have to deliver the news – are tasked with addressing the emotional challenges faced by those receiving the news and navigating their own emotional responses. Additionally, they must consider how to convey the information in a manner suited to the specific cognitive needs of the person receiving the news.¹

It is important to bear in mind that individuals with intellectual and developmental disabilities are sensitive to the atmosphere and mood around them, they sense the pressure, the sorrow and the difficulty experience by others who have received also the distressing news.

People with Intellectual and Developmental Disabilities (IDD) have a full or partial understanding of concepts like death. They perceive changes in their environment and are sensitive the varied reactions of those around them. That is why they require a verbal explanation of what is happening. They need a person close to them to mediate and convey the information to them in a manner suited to their cognitive abilities, ensuring that they can understand and process the events.

Recommendations:

- In order to adapt the delivery of the distressing news to the recipient's functional level, it is essential to have a primary caregiver, guardian, close family member or a multidisciplinary team that includes a family member, a casualty officer and a social worker present.

¹ From *Bad Tidings and the Individual with Intellectual and Developmental Disabilities* (2011), Training Kit for Professionals, Ministry of Social Services.

- The information should be adapted, based on the recipient's reactions. The person conveying the news should provide the information, attentively observe the recipient's responses and questions and respond accordingly.
- Ensuring the accuracy of information is crucial to prevent the spread of false beliefs and rumors, which can lead to increased anxiety and misconceptions.

In the explanation, the focus should be on helping the recipient of the distressing news understand the components of death. These include:

1. Lack of function – The person you knew is no longer breathing, doesn't feel anything and is not in pain.
2. Irreversibility – It is final, cannot be changed and the person will not come back to life, breathe or speak again.
3. Causality – The person you cared about went out to protect us and died a hero.
4. Universality – Everyone in the world dies.
5. Inevitability – Death is something that cannot be prevented, as it happens to all people.

In situations where a family member is missing or captured, it is important to consult with the family regarding the available information.

Attached are adaptations of the SPIKES model for professionals delivering bad news to individuals with intellectual disabilities.²

²From: Baile, W.F., Buckman, R., Lenzi, R., Glober, G.A., Beale, E.A., & Kudelka, A.P. (2000). SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *The oncologist*, 5 4, 302-11.

<p>Setting up</p> <p>Preparation and planning of a meeting</p>	<ol style="list-style-type: none"> 1. Notifying the person with Intellectual Disability requires the consent of a family member or guardian. 2. It is recommended that the team present when the news is conveyed consist of a senior therapist, a primary caregiver, the institution's social worker and a casualty officer delivering the message. 3. Those present must be prepared for possible reactions on the part of the recipient of the message, such as sorrow, crying, aggression, panic, as well as inappropriate responses such as laughter, ignoring the message or even indifference, associative speech not suited to the topic, such as "My roommates are bullying me," "Bring me a newspaper," or "My stomach hurts; repetitive words and movements, breaking eye contact, worsening of challenging behavior, a desire to leave the room, requests for a picture of the deceased or missing person. 4. If the individual is on the autism spectrum, it's essential to check with the staff beforehand for any sensory sensitivities related to touch or noise and to avoid triggers of this kind. It should be assessed whether using touch as a support is suitable for someone sensitive to touch, or if it's better to refrain from it. Do not ask a person who avoids eye contact to "Look at me."
<p>Perception</p> <p>Assessing the perception of the person receiving the news</p>	<ol style="list-style-type: none"> 1- Prior to delivering the message, the current level of functioning of the recipient of the news should be determined. 2- Past experience with death: Have they encountered an event involving death event before? How did they cope with it? Did they participate in activities related to grief processing following the loss of a loved one, family member or friend? 3- Ask open-ended questions: Do you recall hearing an alarm? Do you remember when we discussed the missiles? Do you know what death is? Do you know anyone who has died? What do you remember of your grandmother's death?

<p>Invitation</p> <p>Engaging the individual to receive information</p>	<p>After the initial assessment and in preparation for delivery of the news, check their reactions (anxiety/avoidance) and how much information they can absorb. If the recipient of the news is not interested in hearing details, suggest that they talk with a family member, caregiver, or someone close to them.</p>
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<p>Knowledge</p> <p>Providing information to the person receiving the news</p>	<p>The news will be delivered in an adapted manner by a family member or caregiver who is closest to the individual.</p> <p>Begin with an explicit expression of the death: For example, “There is a war happening.” You heard the sirens. In a war, the IDF, Israel’s army, fights our enemies to protect us.</p> <p>Your brother (mention the brother’s first name) was a soldier/was in the army and participated in the war. Unfortunately, he died in battle/in the war. That means that he was wearing a uniform and carried a rifle to fight to protect and safeguard us, but he was shot and killed.</p> <p>Pause and wait for the person’s response, and only afterwards ask: Did you understand what I said/Do you know what it means to be dead? Do you want to ask me anything?</p> <p>When a person is dead, it means that they are not breathing, their body doesn’t move, they don’t feel anything, they are not hungry, they do not feel pain or anything else and they cannot come to us and be alive anymore.</p> <p>Pause and wait for questions or reactions.</p> <p>The recipient’s questions about the content of the news will guide the depth of the discussion based on their understanding. For instance:</p> <p>If they ask: “What is a battle?” “What does that mean?” You should explain and make sure that they understand before proceeding at their pace.</p> <p>If the response is off point, such as, “I’m being bullied in the apartment,” respond and return to the topic without adding new information. For example, “It’s unpleasant to be bullied. Does your counselor know? They’ll deal with it.” Wait, and only then return to the news and make sure they understand.</p> <p>If the individual’s level of understanding allows for continued conversation, you can continue as follows: “What did you enjoy doing with your brother? Tell me about your brother. People who knew your brother mentioned that he was clever/funny.</p>
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	<p>You might miss him or feel sad that he's no longer with you. You won't be able to talk to him on the phone and he won't be able to visit you at the apartment or home."</p> <p>In order to help a person with IDD grasp the meaning of the news, it's important to repeat the information several times.</p> <p>Always provide truthful, honest, and authentic answers to the recipient's questions.</p> <p>Individuals with IDD may respond with questions, which may often be unrelated to the event, perhaps as a way to avoid feelings of sadness and to quickly return to their familiar routine.</p> <p>Even for individuals with limited cognitive abilities, it is important to state in words that the person is dead.</p> <p>For example: "Hello, I'm X, a casualty officer." Introduce those who are present. The primary caregiver who is closest to the person will show them a picture of the deceased and point to the picture saying, "S/he (use the name of the deceased), your brother, will not return."</p> <p>It's important to address them directly, noting the family context, and to emphasize the irreversibility of the situation and address the emotional aspect, depending on the individual's level of functionality.</p>
<p>Emotions</p> <p>Responding with empathy to the feelings of the recipient of the news</p>	<p>Emotional responses of people with IDD, especially people with Down Syndrome, can be very powerful, including intense crying or laughter to silence, shock, indifference or even apathy. It is important to show empathy to subdued responses too, such as "You're not alone," or "He still loves you."</p>

**Strategy and
summary**

It's very important to involve people with IDD in funeral and mourning rites, with the consent of the families and in an appropriate manner.

Explain: The funeral will be at ____ (time) in _____ (location).

A funeral means that the body of the soldier who was killed is taken to be buried in the ground in a cemetery. He will not feel anything and nothing hurts him.

Have you ever been to a funeral? Have you ever visited a cemetery? What do you remember?

During the funeral, many people who knew [name of the deceased] will come to say goodbye to him for the last time. Some of them might cry and feel sad because they're also sad that he's no longer alive.

You can write a few words about him, and you can also tell everyone how much you loved him and how much he loved you. This is called a eulogy (consult the family to see if the person with the disability will read a eulogy at the funeral). Afterwards, they will dig a hole, his body will be in a coffin and the coffin will be placed in the ground (if it's the death of a person that is close to them: They will place his wrapped body into the ground). And that's it. So, he will rest in the earth, he will feel no pain and will not feel anything.

After they place him in the grave, which is the hole in the ground, it will be covered with earth, and you can place a stone there. The family will go home and be together for a few days. For Jews, this period is known as "Shiva" (or 3 days for Christians Muslims and Druze). During this time, family and friends will come to share stories about him and what a good person he was.

You can light a memorial candle at home with your parents or in your apartment with the staff. You can ask for a picture of [deceased's name] and keep it to remember him always.

If you feel sad during the funeral or during the shiva, you can hold an object that he gave you and remember him.

For individuals with IDD, it's important to allow the expression of feelings through alternative channels, for example, to write a letter, talk to

	<p>someone who is close, have someone at your side when you miss them or tell your friends what he meant to you.</p> <p>When preparing for the funeral and the shiva, for individuals with autism, it is important to maintain order, in other words, to connect the upcoming funeral service as much as possible with things that regularly occur in their daily routine.</p> <p>You can offer a transitional object, a printed picture or an item from their own space that provides a sense of stability.</p> <p>People with cognitive disabilities, especially those with Down syndrome, need emotional support and comforting words during the funeral and shiva. Say things like, "I am with you, you are not alone," "He still loves you," and "He will always love you."</p>
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It is also important to suggest options for after the funeral, for the apartment or room: to hang a picture, create an album, collect mementos, pray (attached are links to the books "Dear Nathan" and "Bad Tidings" for more ideas³).

It is important for a staff member or family member to be attentive to the reactions of the individual with IDD. There may be delayed responses, feelings of anger, emotional outbursts, withdrawal and even symptoms of depression.

The individual should be given the opportunity to express and release their feelings. It is a good idea to encourage meaningful activities and a return to their regular routine.

Translated by Rachel Avital.

For any question and further explanation on this topic please contact with:

Hila Tamar Edri - hilatamar@gmail.com

³ For Jews: attached is a link for a study unit and personal prayer to honor the memory of the deceased:
<http://mishkanapp.landsite.co.il/public/>