

TALKING TO CHILDREN ABOUT DISORDERS OF CONSCIOUSNESS

Many families have questions about how to talk to kids or teens about brain injury and disorders of consciousness (DoC). The tips below can help families feel more prepared to have these hard conversations.

- Give true information using age-appropriate words. (See examples below)
- Expect that kids will ask questions. Younger kids will likely have more basic questions such as, “Can I catch what they have?” Older kids and teens will have more questions about their loved one getting better and the future.
- Answer questions as best as you can. If you do not know the answer, it’s okay to say, “I don’t know.” The medical team (therapists, neuropsychologist, social worker, or family counselor) can help. There may be options for kids/teens to meet with the team for support and education.
- If there are several kids, talk to them together using words for the youngest child. Then, spend one-on-one time with each kid to support them individually. Have these discussions often. Children’s books are also helpful resources about brain injury and recovery.

Examples Of Age-Appropriate Information

Words in italics are defined below. Use these definitions when talking to kids and teens.

<p><u>Ages 3-5:</u></p> <ul style="list-style-type: none"> • Mom got a boo-boo on her head. It made her sleep for a long time and now she is starting to wake up. • Right now, it is hard for mom to stay awake, talk, and move. • She is with doctors who are helping her get better. 	<p><u>Ages 6-8:</u></p> <ul style="list-style-type: none"> • Mom’s brain got hurt. Our brain helps us think, talk, and move. When she got hurt, it was like her brain was sleeping for a while. Now her brain is starting to wake up, but this will take time. • Right now, it is hard for mom to stay awake, talk, and move. Sometimes her eyes are open, but her brain needs more time to heal. • She is in a hospital and is working on getting better.
<p><u>Ages 9-11:</u></p> <ul style="list-style-type: none"> • Mom had a brain injury. Our brain is like a muscle that controls lots of things. It helps us think, talk, and move. • Doctors call what’s going on with mom being <i>unconscious</i>. When she first got hurt, it was like her brain was asleep, but now is starting to wake up. Right now, it is hard for mom to stay awake. She can’t talk or move like before. Sometimes her eyes are open, but it’s not like how it is when you and I are awake. Her brain isn’t understanding what’s going on around her. • She is in a hospital and working on getting better. She sees doctors and therapists who help her body and brain. 	<p><u>Ages 12+:</u></p> <ul style="list-style-type: none"> • Mom had a brain injury and was in a coma. Now she is out of the <i>coma</i> but still <i>unconscious</i>. • She may have trouble staying awake, and the injury makes it so she can’t talk or move like before. Even when she is awake, her brain does not understand what’s going on around her. • Recovery can take a long time. She is in a rehab hospital where she sees doctors and does therapy to heal her brain and body.



COMMON TERMS AND CHILD-FRIENDLY EXPLANATIONS

- **Unconscious:** When someone is *unconscious*, they are not aware of what is happening around them. They may look asleep or awake depending on how much healing has happened.
 - **Coma:** A coma is one stage of being unconscious. When someone is in a coma, it's like they are asleep and cannot wake up. They do not react to sounds or what's going on around them. Their eyes are closed, and they cannot move.
 - **Unresponsive Wakefulness:** This is another stage of being unconscious. Doctors used to call this the vegetative stage. People in this stage can be awake and have their eyes open, but they are not aware of what's happening around them. They may move or make sounds, but they are not doing these things on purpose. These movements/responses are called reflexes. The following behaviors may occur:
 - Arms/legs may move randomly, but they are not moving their body on purpose.
 - Turning their head in the direction of a sound.
 - Making moaning sounds.
 - **Minimally Conscious:** This is the last stage of being unconscious. When someone is minimally conscious, they will start to respond to people and interact with their surroundings more on purpose, but they cannot do it all the time. When they do not respond, they are not avoiding the activity or refusing. Their brain gets tired and cannot be consistent during this time. The following behaviors may occur during this stage:
 - Following simple commands (ex: give a "thumbs up" when asked).
 - Following a person or object with their eyes.
 - Grabbing onto or reaching for objects.
 - Starting to talk or communicate.
- **Conscious:** When someone goes from being *unconscious* to *conscious*, they are more aware of what's happening around them. Doctors and therapists measure this by seeing if they can communicate (example: giving a thumbs up to a simple question like "Am I clapping my hands now?") and/or use objects correctly (example: bringing a cup to their mouth).
- **Emerged/Emergence:** This is the word used when someone goes from *unconscious* to *conscious*. When someone regularly shows they are aware of their surroundings and can respond on purpose (either by communicating or using different objects correctly), they say that person has *emerged* from their disorder of consciousness. Even after emergence, people still need a lot more time to heal and do therapy. Confusion and difficulty speaking or moving is common after emergence.



PREPARING FOR VISITS

Families often have questions about how and when visits should take place. While a visit might be hard, it may also take away children's worst fears, such as "Is mom still alive?" The following tips can help families prepare.

- Work your way up to a visit by helping kids know what to expect.
 - Start by talking about how their loved one looks and what they can/can't do. Let kids know that their loved one can't always stay awake, speak, see, move, or hear because of the injury. Talk about changes in appearance (scars, breathing tubes, a shaved head, wearing a helmet, etc.).
 - Next, show a current picture of their loved one. Answer questions/concerns as best as you can and discuss how the child feels.
 - If possible, show a video or have a video call between the child and their loved one.
 - Ask kids if they are ready to see their loved one in person. Let them know they won't be alone. Remind them that they can change their mind about the visit at any time.

- When ready to plan the visit, keep these tips in mind:
 - Children may need to "warm up" to being in a hospital. Show pictures or give a short tour of the hospital so they feel more at ease. If possible, have the first visit in a more "neutral" place like the family lounge, therapy room, or outdoor area.
 - Keep the visit short and your plans flexible. Plan for no longer than 15-20 minutes, and sometimes as short as 5 minutes is best.
 - If possible, bring multiple adults so one adult can be with the patient and one can be with the child/children.
 - Avoid over-stimulating your loved one. Remind kids to talk using an "indoor voice" and to avoid jumping around and on top of your loved one.

- No matter how the first visit was, remind yourself that you did a hard thing!
 - Ask them what they would like to do after the visit. Do they want to talk? Need some quiet time? Want to go out for ice cream? Try your best to meet their needs.
 - Remember that with more visits, kids will likely feel more comfortable over time.

SUPPORTING CHILDREN AND TEENS

- Encourage kids and teens to talk to you without pressuring them. Give them your full attention during this time.
- Sometimes children feel more comfortable talking to a counselor, other adult family members, or family friend. Give them these options.
- Keep routines as much as possible. Help them stay busy with schoolwork, sports, activities, and time with family/friends.



- Tell important adults like teachers and coaches that the child’s loved one had a serious injury. Ask these adults to let you know if they notice anything different about the child’s mood/behavior.
- Help kids/teens know that feelings are okay. They may feel sad, confused, worried, or even angry. These are not “bad feelings” – it is normal to feel these during hard times. Help them know it’s also okay if they feel "okay" or happy at times.
- Guilty feelings are common after a loved one’s injury. Let them know the injury was not their fault.

WATCHING OUT FOR MOOD AND BEHAVIOR CHANGES

Major changes in mood/behavior may be a sign to seek professional support. If you notice the following, consider talking to a pediatrician. You can also work with a school counselor or child/family therapist.

- Major changes in sleep patterns or nightmare frequency
- Loss of interest in activities once enjoyed.
- Withdrawing from family or friends
- Loss of age-appropriate skills like speech, toilet training, or feeding themselves
- Anger or behavior outbursts.
- Getting shaky, sweaty, hyperventilating (breathing very quickly), or getting sick to their stomach when talking about the injury or their loved one
- Avoiding conversations about their loved one, such as running from the room or “zoning out” in such a way that you cannot re-engage them.
- Making comments about suicide or self-harm. If self-harm is actively occurring or you fear the child/teen is in immediate danger, call 911. In a crisis, call 988 for the *Suicide and Crisis Lifeline*.

RESOURCES FOR CHILDREN AND CAREGIVERS

Children’s Books	Caregiver Resources
<p>Get Well Soon Balloon Available on https://lapublishing.com</p>	<p>BrainLine https://www.brainline.org/dchub</p>
<p>The Brain Is Kind of a Big Deal Available on https://www.amazon.com</p>	<p>Curing Coma www.curingcoma.org</p>
<p>Think Tank! The Human Brain and How It Works - Anatomy for Kids - Children’s Biology Books Available on https://www.amazon.com</p>	<p>Headway https://www.headway.org.uk/about-brain-injury/individuals/brain-injury-and-me/supporting-children-visiting-a-parent-in-hospital/</p>
<p>Why Did It Happen on a School Day? Available on https://www.biausa.org</p>	

Additional Comments:

