How to help a child or an adult with a severe disability?













Introductory note: Supporting children and adults with disabilities during COVID-19

What

- Get up to date information and resources on COVID-19.
- Visit when possible in country regulation.
- Conduct phone consultations where visits are not possible.
- Instruct family members how to enable their children to be more functional and independent.
- Raise awareness about COVID-19.
- Educate family members on COVID-19 related local regulations. Provide contact information of people or agencies related to COVID-19.

Where

• Conduct the care and rehabilitation work preferably in open areas.

Remember to

- Wash your hands as you enter and leave the compound.
- Avoid touching the child during home visits.
- Ensure to maintain appropriate physical distancing.
- Use hand sanitiser.
- Use gloves and face masks appropriately.
- Avoid touching materials in the house, including assistive devices the child is using.
- Bring your own instructional materials and protect them from getting contaminated.
- Monitor family members' health situation; report COVID-19 related symptoms, if any.

Introductory note: Conducting your work

How to conduct care and rehabilitation work?

- Prepare a specific rehabilitation plan.
- Use the provided materials (written, pictorial, or video) or prepare your own.
- Help the family to identify resources at home and in the community.
- Encourage family members to use their own materials.
- Encourage family members to observe the specific needs of their family member with a disability and explore ways to adapt the activities to the child's and family's daily life.
- Instruct a family member to follow these steps:
 - Clearly discuss the rehabilitation plan with a family member.
 - Instruct the family member to perform each steps for at least two weeks.
- Visit or call at least once in two weeks.
- Report challenges, if any, for further actions and learning.

Required steps to follow during a visit

- Ask if the family is healthy (no cold, cough, fever).
- Start by proper handwashing practise.
- Demonstrate proper handwashing to family members .
- Encourage family members to sanitise all the toys used during the rehab work.
- Use your own materials to demonstrate the activity (don't share it with the child).
- Always explain the changes to the child.
- Greet the child warmly (maintain appropriate physical distancing).
- Encourage the child to participate in the rehab work actively (become their own best therapist).
- Educate the child about COVID-19 and prevention methods.
- Always teach family members why physical distancing is needed.
- Provide current information on COVID-19.
- Wash your hands before you leave.

About epilepsy and nodding syndrome

Seizures can be caused by a condition called 'Epilepsy'. These are not contagious, it is not a spirit that possesses the person. Medication might be needed to control the seizures. Ask a doctor for advice.

Symptoms prior to a seizure are:

- Shaking
- Confused speech
- Fumbling
- Blank staring
- Wandering
- Chewing and biting

Seizures can also be a result of a condition called 'Nodding Syndrome'. Seizure-like activity is often accompanied with repetitive nodding (dropping down) of the head, and/or staring spells. Unlike Epilepsy, however, Nodding Syndrome is infectious. This condition can cause stunted physical and intellectual growth, and injuries or death related to seizures. **In case of Nodding Syndrome symptoms, consult a doctor.**

About epilepsy and nodding syndrome



SHAKING



CONFUSED SPEECH



FUMBLING



BLANK STARING





CHEWING & BITING



WANDERING

What to do in case of a seizure

- 1. Make sure the person is safe. **Block** hazards.
- 2. Loosen tight clothes.
- **3. Don't** put anything in the mouth.
- 4. Roll the person to the side.
- 5. Cushion the head with a pillow or clothes.
- 6. Time the seizure with a clock or watch. Most seizures should end in a few minutes.
- 7. Do **not** hold or grab the person
- 8. Speak calmly
- 9. Explain to others what is happening
- 10. Stay with the person until they are awake and alert.

Take the person to a health centre to see a doctor immediately when:

- Seizure lasts longer than 5 minutes
- When seizure repeats
- Person is injured or sick

- Difficulty breathing
- Seizure occurs in water
- First time seizure

What to do in case of a seizure



1.Block Hazards



2. Loosen tight clothing



3. Don't put anything in the mouth



4. Roll the person to the side



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VISIT A CLINIC TO SEE A DOCTOR

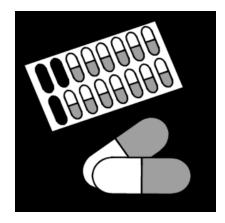
Medication

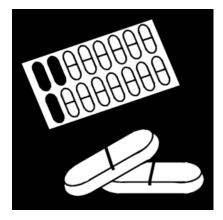
Medication is sometimes needed to control the seizures. With appropriate medication, a person can function normally, go to school or work, play and be included in the community.

- ✓ Give appropriate, prescribed epileptic medication at the right time
- Make sure to refill the epilepsy medication in time so there are not gaps in taking medication
- ✓ Keep the medicine in a safe and dry place
- Keep an eye on changing behaviour of the person with epilepsy this might mean there is a problem

Medication



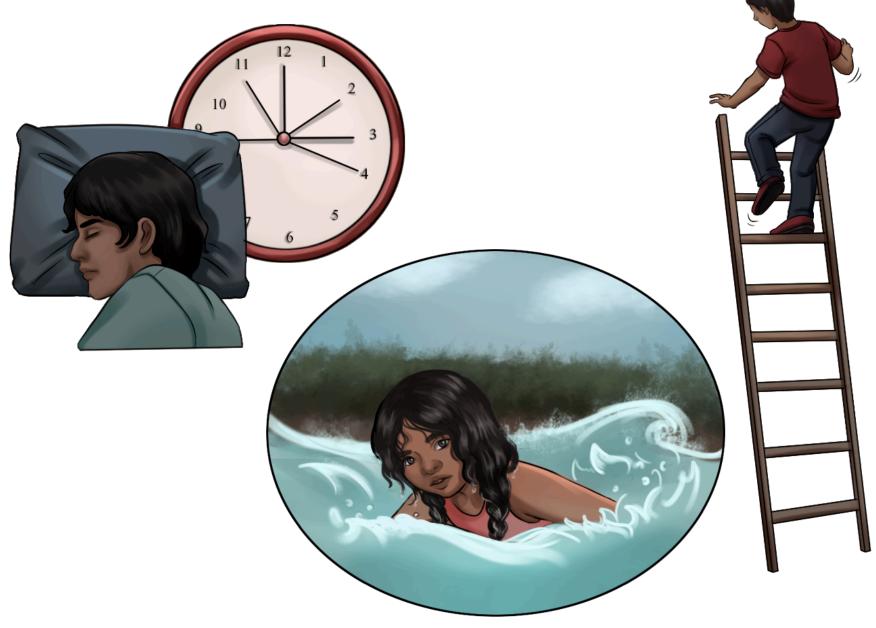




Behaviours to avoid

- ✓ Keep an eye on changing behaviour of the person with epilepsy this might mean there is a problem
- × Irregular bed time
- X Swimming alone
- X Climbing high things

Behaviours to avoid



About eating and drinking

Appropriate eating and drinking, in a good supported position, is essential for the child or person with severe disability, and helps them:

- Prevent choking
- Prevent illness
- Energise
- Socialise
- Develop
- Sleeping

Safe feeding requires: good sitting position, giving enough time to chew and swallow, communicate to introduce a new bit.

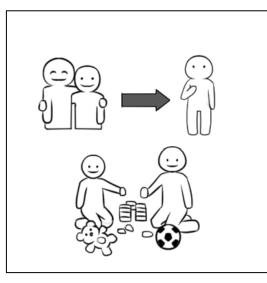
About eating and drinking













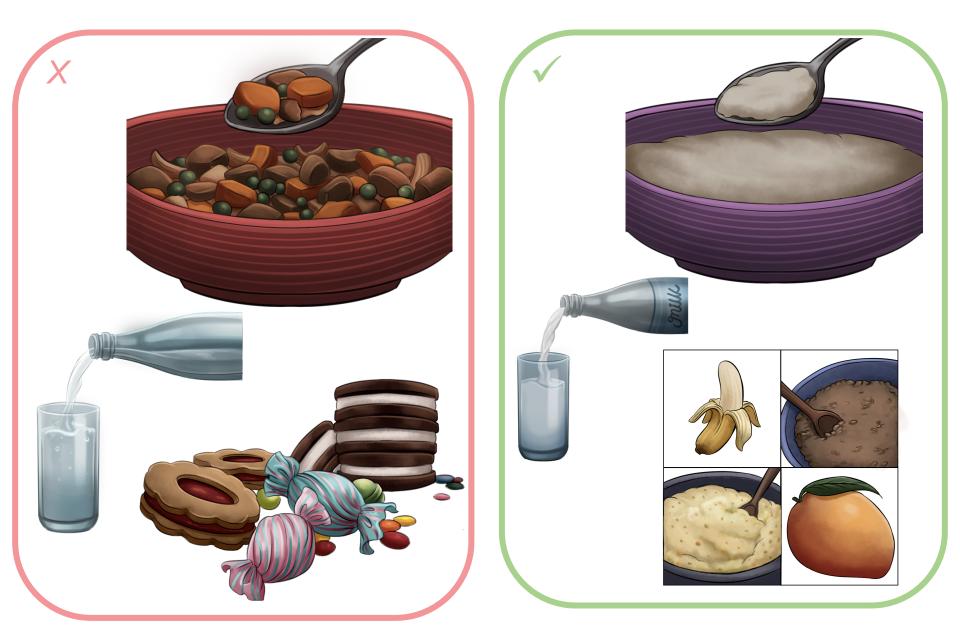
Types of food

- Give mushy food and thicker liquids that are easier to swallow and less likely to make a child cough and or choke
- ✓ Give healthy, colourful food with a lot of calories

Avoid giving candy and biscuits as main source of food, since are not healthy nor nutritious options

Food with lumps and water are more difficult to swallow and may lead to choking

Types of food



Good positioning in eating and drinking

- ✓ Tell the child what you are doing while helping them eat
- ✓ Give time to chew and swallow
- ✓ Good supported positioning

Do not feed the child lying down. This can cause coughing, choking or vomiting and create the risk of food or a drink flowing back up and into the lungs. This can create a lung infection.

Good positioning in eating and drinking





Support in eating and drinking

- ✓ Hand-over-hand technique: This means guiding the hand of the person that is eating or drinking. Gradually decrease the amount of support you are giving. If possible, practice in front of a mirror so that the person sees the movement he/she makes. This can support the person learning how to do the movement and repeat next time by themselves.
- ✓ Use mouth control (jaw and lip support) if necessary
- ✓ Provide support and use **adapted spoons, cups**, ...

Support in eating and drinking



About hygiene

- ✓ Wash your hands before and after preparing food and eating
- ✓ Clean the teeth after eating/drinking

About hygiene



About communication

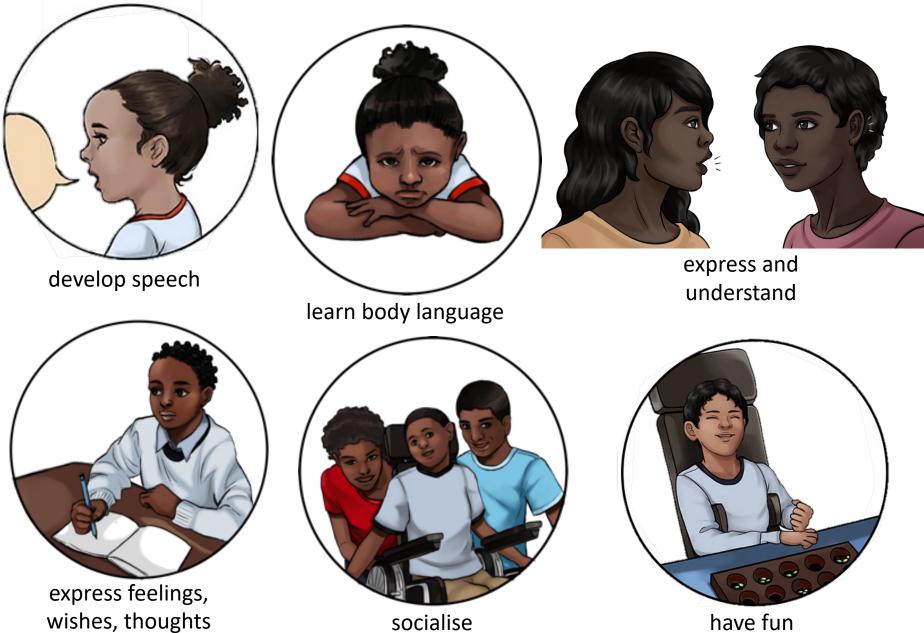
Communication is important to express wishes and needs, pain, interact with familiar and unfamiliar people around you and being understood.

There are different ways how people communicate: by words or body language such as expressions in the face and pointing.

With verbal and non-verbal communication, children and people with severe disabilities can:

- Develop speech
- Learn body language
- Express and understand
- Express feelings, wishes, thoughts
- Socialise
- Have fun

About communication



have fun

How to encourage communication

Communication can be encouraged in many ways:

- ✓ get attention
- ✓ get eye contact
- ✓ give extra time, praise, encourage
- ✓ use facial expression and gestures
- ✓ repeat the message
- ✓ present ideas gradually, one thing at a time
- ✓ offer choices
- ✓ stimulate pointing or looking at
- ✓ take turns
- ✓ talk about what is happening

BUT do not force to speak

How to encourage communication



Communications aids

Make communication possible, through words or other by trying different ways:

- ✓ reading aloud, simple words, singing
- ✓ picture booklet
- ✓ sign language & manual alphabet
- ✓ daily objects

Keep in mind it takes time to learn different ways and sometimes you have to instruct the people around the person as well on how to do.

Communications aids

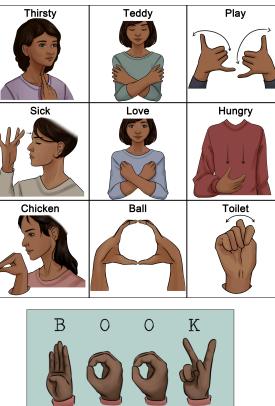




















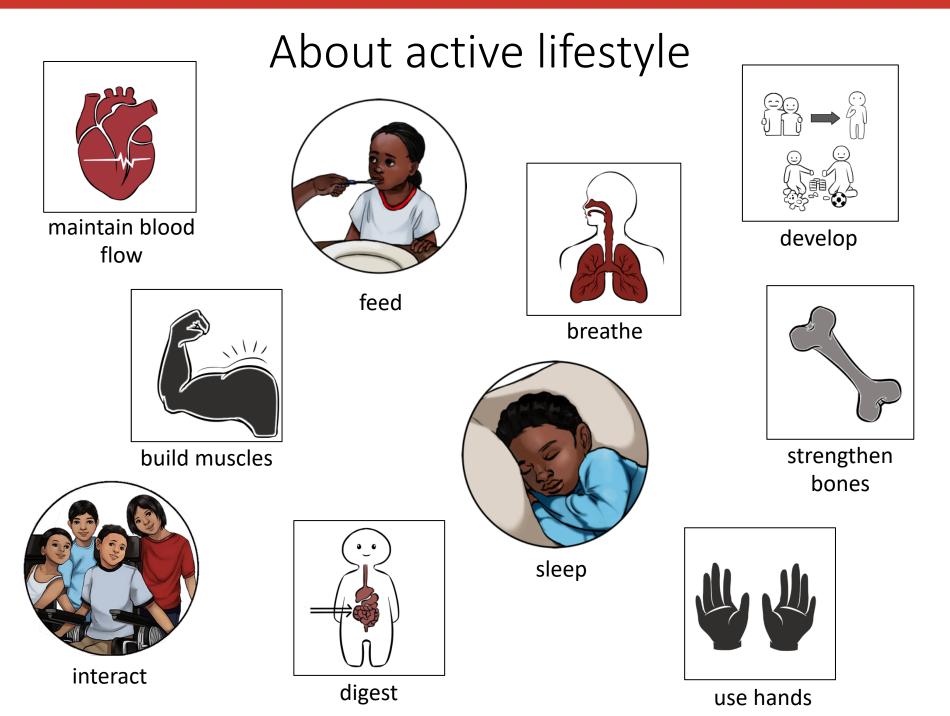


About active lifestyle

This is essential for children or people with severe disabilities. It allows them and helps to:

- Maintain blood flow
- Build muscles
- Breathe
- Strengthen bones
- Use their hands
- Be fed
- Digest
- Sleep
- Develop
- Interact

It is important to look for the things they can do and learn and not only focus on what a person cannot do. Their strengths and abilities can support challenges in daily life. Don't assume they have no skills. Only parts of the brain are damaged, not the whole brain. The younger you start with supporting development, the better.



About active lifestyle

The person needs to actively be involved in daily life activities such as moving, helping with eating, play or other. Coach the family in practicing skills that are integrated in activities that are close to daily life.

To encourage an active lifestyle, make sure the child or person:

- ✓ is performing activities of daily life
- ✓ is looking at books or pictures by himself or herself
- ✓ is playing with toys, using them, having fun
- ✓ is looking around and socialising
- ✓ is in a position to learn school activities
- ✓ is able to work at school/ home



Daily life activities



















