



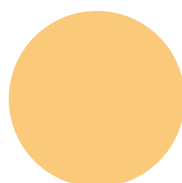
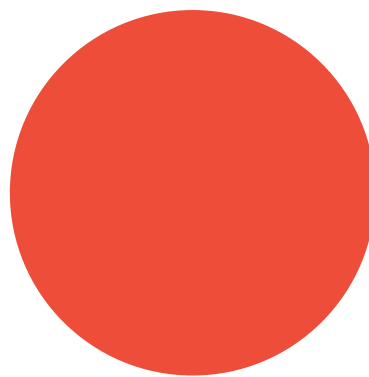
# MANUAL

**for nurses and healthcare professionals**  
in kindergartens and schools on multidisciplinary care  
and inclusive education of learners  
with spina bifida and hydrocephalus



**Developed in partnership between:**  
Spina Bifida and Hydrocephalus-Bulgaria Association  
Early Intervention Centre Trnava, Slovakia  
and  
B. BRAUN MEDICAL LTD, Bulgaria, as an associated partner

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This document is part of a set of educational materials to support inclusion of children with spina bifida and hydrocephalus in schools and kindergartens, developed under the Multi-IN project. The Guidelines, together with the complementary Manuals and Educational video courses, aim to support the multidisciplinary efforts of professionals and family towards inclusive education of children with spina bifida and hydrocephalus.

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The full set is available on

[www.multi-in.eu](http://www.multi-in.eu)

The authors would like to thank all parents and children from Bulgaria and Slovakia who shared their personal stories and contributed with their experience in education to our research and development of Multi-IN outputs.

**The Manual contains general recommendations based on examining the needs and rights of learners with spina bifida and hydrocephalus in the context of inclusive education and multidisciplinary approach. The authors recognize that there might be differences and variations in competences of nurses and healthcare professionals in kindergartens and schools in every country based on local legislation. First, you should follow your local legislation and then the Manual's recommendations.**

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## INTRODUCTION



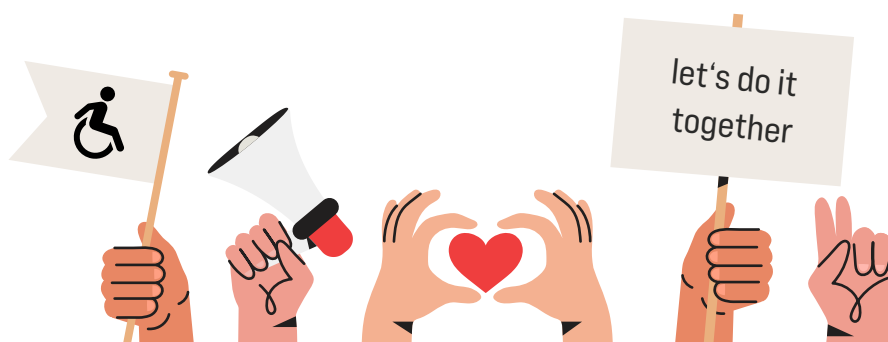
The Manual for nurses and healthcare professionals in kindergartens and schools is a part of a set of training materials created under the Multi-IN project to support the provision of multidisciplinary care and the social inclusion of students with spina bifida and hydrocephalus. Their goal is to assist the healthcare staff of the educational institutions in their efforts to provide quality health care and create a supportive and inclusive environment. Most often, these are the nurses, but this document is useful for all other healthcare professionals engaged in healthcare activities in schools and kindergartens.

This Manual discusses the role of the nurse in the multidisciplinary support team, given the exceptional potential that the nurse has in the successful social inclusion of children with spina bifida and hydrocephalus. In addition, the document covers the most common health challenges that students with these diagnoses face and describes the options for the prevention and control of secondary complications in school and kindergarten settings. The Manual provides specific tips and describes good practices that would help the healthcare staff.

The appendices to the Manual provide direct practical help in the child care process. They include the main steps of the Clean Intermittent Catheterization (CIC) procedure with attached illustrations provided by B. BRAUN MEDICAL LTD., the Health Passport of Children with Spina Bifida and Hydrocephalus, as well as the common medical condition requiring emergency medical care.

All materials are available on the website of Multi-IN:

[www.multi-in.eu](http://www.multi-in.eu)



## THE ROLE OF THE NURSE IN THE SCHOOL AND KINDERGARTEN



The World Health Organization (WHO) sees the great potential that the schools have in bringing significant benefits to the children's health and development, as they are the best and perhaps the only institution that reaches most adolescents on a daily basis. However, this potential remains largely unexplored. Although the in-school health services are valued as an excellent means for promoting health, the school healthcare staff needs a new set of skills to meet the modern needs of children.

Some European countries have many years of experience in providing healthcare in their schools and kindergartens. Most often, this is carried out through health offices operating in the schools and kindergartens. The services that these offices provide are most often performed by a nurse, and sometimes by a doctor or a doctor's assistant. Along with their administrative responsibilities in regard to monitoring and organizing various events related to health promotion and disease prevention, nurses have an extremely important role to support the process of monitoring and administering the prescribed treatment of children with chronic diseases.

## THE ROLE OF THE NURSE IN THE MULTIDISCIPLINARY TEAM SUPPORTING INCLUSIVE EDUCATION OF CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS



The school nurse plays an important role in catering for the basic physiological and health needs of students and children with spina bifida and hydrocephalus. The nurse is the health expert in the educational system and, as such, the nurse supports the work of teachers, special educators and psychologists by helping them to better understand how the health condition and health needs of the children can affect their performance and behaviour in the school/kindergarten.

The nurse can help the school management in making decisions related to student safety and architectural accessibility. Working in close cooperation with the school psychologists, the nurse can encourage the child in the development of skills related to his/her self-care and self-advocacy depending on the child's medical condition.

Our research has shown that the role of the school nurse features great potential, which is often underestimated and misunderstood. The availability of timely and high-quality healthcare care at school can be a decisive factor in improving the health and independence of students with spina bifida and hydrocephalus.

# SPINA BIFIDA AND HYDROCEPHALUS: PATHOPHYSIOLOGY



## Spina bifida

Spina bifida occurs as a result of defective closure during the first weeks of pregnancy, when the embryonic neural fold becomes the neural tube. The defect in the neural tube leads to failure in the formation of the spinal cord and the overlying tissues, which give rise to the spina bifida sac. The etiology in most cases of spina bifida is multifactorial, involving combination of genetic and environmental factors, in which maternal insufficient folate intake.

The World Health Organisation (WHO) recommends a supplemental dose of 400 µg (0.4 mg) of folic acid per day for prevention of neural tube defects. Folic acid supplementation must start periconceptional as folic acid requirements are increased in pregnancy because of the rapidly dividing cells in the fetus. After the first month of pregnancy folic acid intake will not prevent neural tube defects. However, it will contribute to other aspects of maternal and fetal health.

The prevalence of spina bifida in Europe is 8,16 per 10 000 births. In North America, it is almost twice lower, and the main factor behind this is considered to be the mandatory legislation enforcing folic acid fortification of the food supply since 1998.

In the process of embryonic development, the neural tube forms and develops into the baby's central nervous system. In spina bifida, the distal end of the tube does not close, resulting in failure of the spinal cord and spinal column to form properly.

The three most common types of spina bifida are Occulta, Meningocele and Myelomeningocele. The symptoms may vary depending on the type and level of involvement.

**Spina bifida occulta** is the mildest form and is being closed neural tube defect. One or more of the vertebrae are malformed but without damage of the spinal cord. The name "occulta" means "hidden" and often it is not visible externally. It may go undetected but there are some skin affecting signs such as a dimple, dark spot or hair tufts in the lumbosacral area. There is usually no neurologic involvement.



**Meningocele** is closed neural tube defect. It occurs when the meninges, contained in a sac, are pushed out through the opening in the vertebrae but without affecting the spinal cord. The sac is often covered by skin. There may be motor or sensory changes after the sac is surgically repaired.

**Myelomeningocele (MMC)** is the most severe form of spina bifida. Most often, when people talk about spina bifida, they are referring to myelomeningocele. It is an open neural tube defect. A portion of the spinal cord, along with the meninges, protrudes through the opening in the spine to form a sac. The spinal cord fails to develop correctly and spinal nerves are damaged. The skin usually is not completely closed over the sac. Infants with MMC have surgery shortly after birth to reduce the risk of further damage to the spinal cord and nerves. This surgery cannot repair the nerves that are already malformed.

The size of the defect and the level of the spinal cord involvement determine the severity of the neurologic manifestations. There is a loss of motor and sensory functions below the defect.

Some of the most common secondary medical conditions associated with spina bifida are hydrocephalus, Arnold-Chiari malformation type II, skin breakdown, pressure sores, mobility limitations, loss of sensation in legs, incontinence, latex allergy, obesity, pain and difficulties with endurance and balance.

Through prevention and management of secondary conditions, potential health-threatening complications can be avoided, so persons with spina bifida can enjoy a full and decent life.

### **Hydrocephalus**

Between 85-90% of infants with myelomeningocele, develop hydrocephalus in the womb or shortly after birth. Myelomeningocele is one of the most common causes of hydrocephalus, together with brain tumors, complications of prematurity and congenital aqueduct stenosis.

Hydrocephalus is the accumulation of cerebral spinal fluid (CSF) in the ventricles of the brain. Normally cerebral spinal fluid is circulating freely to protect the brain and spinal cord. In hydrocephalus, fluid accumulates in the ventricles when the body produces more CSF in than it can reabsorb. The add fluid enlarges the ventricles and increases intracranial pressure. In babies and younger children, an increase in head circumference may be noticed. In older children and adults, the skull is formed and cannot expand, so the intracranial pressure may directly affect the brain.

The global prevalence of hydrocephalus is 8,8 per 10 000 in the pediatric population. A significantly lower incidence has been identified in high-income countries.

## Diagnosis and treatment

Children with hydrocephalus are usually diagnosed soon after birth by a neurologist or neurosurgeon. They are using brain imaging techniques such as ultrasonography, computed tomography (CT), magnetic resonance imaging (MRI), and neurological evaluation.

The most common treatment for hydrocephalus is the surgical insertion of a drainage system, called a shunt. The shunt system diverts the excess accumulation of CSF from the brain to another part of the body that can absorb it into the regular circulatory system thus reduce the increased intracranial pressure. The peritoneum is the preferred area for shunting.

The shunt system consists of a ventricular catheter, which is usually inserted into one of the cerebral lateral ventricles and is attached to both a valve and a distal catheter, which is implanted within the peritoneal cavity (abdomen) where CSF is finally reabsorbed. Often, the catheter placed in the abdomen is coiled, limiting the need for surgical replacement of the shunt system with growth.

Other types of shunt systems such as ventriculoatrial shunt and a lumboperitoneal shunt are less frequently used. Endoscopic third ventriculostomy (ETV) and puncture are also used for treatment of hydrocephalus.

Many children require multiple shunt revisions during their lifetime. Common complications requiring surgical treatment are mechanical failure, infections, obstructions, the need to lengthen the catheter, as well as shunt underdrainage or shunt overdrainage. Medical follow up and close communication between healthcare professionals and family members is essential.

Some of the most common symptoms shown during shunt malfunction may include:

- Unusual irritability or personality changes;
- Deterioration in school performance;
- Morning headaches;
- Nausea or vomiting that is more significant in the morning;
- Neck and throat pain;
- Visual disturbances, blurred or double vision;
- Difficulty in walking;
- Unusual tiredness or difficulty staying awake;
- Loss of consciousness.

The student's age, cause of hydrocephalus, location of the obstruction and how fast the symptoms progress in each student should be considered when deciding what action need to be taken in particular time.

# SPINA BIFIDA AND HYDROCEPHALUS: HEALTH CARE AND MANAGEMENT



## NURSING CARE IN SCHOOLS AND KINDERGARTENS

As spina bifida affects many systems and functions of the body, children born with this disability need long-term comprehensive and multidisciplinary support. In the course of their treatment, follow-up and prevention, the participation of multiple experts is required, including neurosurgeons, neurologists, urologists, orthopedists, pediatricians as well as nurses, psychologists, physiotherapists, social workers and others. The active participation of the family is also a key factor.

A number of hospitals in Europe have multidisciplinary centers for patients with spina bifida, which provide comprehensive support to the family by coordinating the rehabilitation and healthcare services. There are no such centers in Bulgaria yet. For now, the important role of the coordinator is played by the family.

The main goals of the health care provided to the children with spina bifida are to manage the secondary conditions, to avoid potential health-threatening complications and to promote their independence and individual development. This is a lifelong and permanent process, the success of which largely determines the quality of social life of these children and their integration in school.

The possible secondary conditions described in this chapter are more common in children with myelomeningocele. In these children, the nervous system is most affected and there is a greater need for specific support and health care. Students with milder forms of spina bifida also need specific care, but probably not to the full extent described herein.

When identifying the needs and determining the degree of support at school that the children require, the most important thing for the specialists is first to consider the child's personality and then the diagnosis and the secondary conditions resulting from it.

We strongly encourage all nurses and other professionals who work with children with spina bifida and hydrocephalus to read the separate edition with personal stories which is part of the Multi-IN resources. We have included personal stories and real examples from the school life of children in Bulgaria and Slovakia. The children's names have been changed, but behind every story, there is a real child and some good and some not-so-good examples of social inclusion.



In the personal stories, you can read more about little Boris and the kindergarten nurse, who agreed to learn how to catheterize him. Boris has only urological problems and the support that the nurse provides to him is critical for the successful social inclusion of the boy. This allows his mother to continue with her career and get a sense of accomplishment in her family and professional life.

There is also the personal story of the eight-year-old Stella - an extremely vivid girl who uses a wheelchair from an early age. Due to the inability of the kindergarten to care for a child in a wheelchair (providing assistance in removing and placing orthoses, assistance in positioning and repositioning the wheelchair, catheterization, etc.), Stella was not able to attend kindergarten. The girl failed to build important communication skills from an early age and still tries to fit in with her peers.

You can also read about Alexandra, whose grandmother comes to school every day to catheterize her.

The school and the kindergarten are the places where children spend most of their active daily lives. Prevention and management of secondary complications should be part of the care for the children with spina bifida and hydrocephalus and must be available in the school so that the inclusion of the child can be successful.

## AMBULATION

The level of neurologic deficit determines the functional status that can be achieved. The higher up the spinal cord that the lesion occurs, the greater the paralysis. Although students with spina bifida may have partial or complete paralysis, they may still be able to move and to walk with a variety of assistive devices.

Children with cord damage above L2 usually use a wheelchair. Those with lower injuries are often able to ambulate with orthosis, crutches, canes, rollators or walkers.

Some children may need a variety of walking aids for indoor and outdoor use, for short and for long distances. Most children with myelomeningocele work regularly with a physical therapist and occupational therapist.

Some orthopedic conditions associated with spina bifida are hips dislocation, scoliosis, lordosis and kyphosis. Children might wear a corset brace during the school day as a part of the treatment. Wearing braces and orthosis longer during the day puts children at risk of skin breakdown. This usually happens at the edges of the orthosis, at the high pressure points or when the orthosis is put incorrectly.

Children who are non ambulatory are more prone to developing osteoporosis from an early age.



### Nursing care in schools and kindergartens:

To place and remove the child's orthoses. This is especially true for children who are in kindergarten and have to take an afternoon nap. When removing the orthoses, it is important to pay special attention to the presence of sores or redness that does not fade within 30 minutes after removing the orthosis;

To position the student in the wheelchair according to the recommendations of the doctor/therapist;

To be familiar with the operation of wheelchairs and other aids that the student may use and to promote their safe use;

To assist in repositioning the child from the wheelchair to a place for working or playing. The nurse should encourage and teach the children how to do it safely on their own;

To enroll the child in a program for the prevention of spinal deformities - what it includes;

To verticalize the child when possible. The parents can provide special orthosis for verticalization.

The nurse is the expert in the team who can best determine the safety and accessibility of the environment, the options for moving using aids as well as the need for support from an adult or a classmate. The nurse is also the person who should monitor the need for changes in the environment in order to improve the child's safety;

When preparing an emergency safety plan, the nurse may point out particular aids (such as stretchers) which would make the evacuation of students with disabilities easier;

To prepare and implement a first aid plan in case of injuries or fractures [\(Appendix 7\)](#)

To familiarize the other colleagues of the pedagogical staff with the plan.

## URINARY FUNCTION

Up to 90% of children with myelomeningocele have problems with urinary functioning, including urine retention and stress incontinence. Neuropathic bladder can develop urinary system distress with urinary tract infections that can progress to ureterohydronephrosis, vesicoureteral reflux and renal insufficiency. Severe urinary distress, especially early in infancy, often requires surgical interventions such as vesicostomy or augmentation enterocystoplasty.

Many children, however, can achieve social continence and lower the risk of urinary tract infections, through a program of clean intermittent catheterization and medications such as antispasmodics and possibly, anticholinergics.

Clean Intermittent Catheterization (CIC) is a method of draining urine via a disposable catheter inserted into the urethra at regular intervals during the day. Once the urine is drained, the catheter is removed. Even though this process is performed using not a sterile, but a clean technique, it is a 'gold standard for bladder management in patients with spina bifida'.

An urologist prescribes CIC and teaches parents how to perform it. This is usually done every 2-6 hours throughout the day. In small children and babies, parents or caregivers usually do CIC. Once the child is old enough and developmentally ready, they should learn self-catheterization.

Older children self-catheterize. The transition to self-catheterization usually coincides with pre-puberty and takes place between the ages of 9 and 14. Every child is different, so there are quite a few children who manage to do it on their own at the age of 6 or 7 and others who still need assistance or at least supervision in adulthood.

Despite the widespread use of Clean Intermittent Catheterization around the world for four decades now, in some countries, this technique is still not well known. To support the work of the healthcare staff, in an appendices to this Manual, we have provided some basic tips for the successful application of this method at school (Appendix 1 and 2) and have described the main steps in the catheterization of girls (Appendix 3) and boys (Appendix 4).

In some children, catheter is not inserted into the urethral opening, but through a continent catheterization stoma located on the abdomen, below or at the waist level. It is called Mitrofanoff stoma and allows the catheter to directly access the bladder (Appendix 5). Patients with Mitrofanoff stoma should be catheterized at strict intervals, for example, every 4 hours.

There are many different types, models, sizes and brands of catheters. In most of the European countries, health insurance systems partially or fully cover the cost of intermittent catheters for patients with spina bifida.

The entire CIC procedure is described in detail as Appendices to this document.

### **Nursing care in educational institutions:**

The nurse is the team member who is responsible for the catheterization of the child in the school. At the same time, the nurse has the important task to prepare the child for the transition to self-catheterization.

Getting support in these activities is so important that sometimes it is the only factor determining the successful social inclusion of a student with spina bifida.

Useful tips and basic steps are available in the appendix to this Manual.



## BOWEL CONTINENCE

Most of the people with spina bifida have some degree of bowel dysfunction, which occurs most often as chronic constipation and bowel incontinence.

An individualized bowel-management program can help most children with myelomeningocele to achieve some degree of bowel continence the children require timed toileting, changes in diet, and oral laxatives, suppositories, and enemas, singly or in combination.

### Nursing care in educational institutions:

Usually, the bowel washout procedure is carried out outside of school hours, as part of the evening regimen of the child, and the nurse is not involved in this. However, cases of underwear staining or more serious incontinence at school are possible. The child must know that help with cleaning and changing clothes is always available in the health office and that it will be provided discreetly and with understanding. It is good for students to have a second set of underwear available for such cases.

If the nurse notices that a bowel control program is not applied or the current program does not work, i.e. the child suffers from constipation or fecal incontinence too often, the nurse should refer the parents to healthcare professionals who can help them build a working program.

As part of the promotion of a healthy lifestyle, the role of the nurse is to acquaint children with the principles of healthy eating and inform them about the benefits of a high-fiber diet and fluid intake as well as about the need for daily exercise and sports activities.



## LATEX ALLERGY

Latex allergy is a specific reaction to products made of natural rubber latex. The degree of reaction varies from mild skin irritation and redness of the eyes to more severe manifestations such as anaphylactic shock.

Students with spina bifida and hydrocephalus are considered a group at a higher risk of developing an allergic reaction to latex. Children with cerebral palsy and those who have undergone multiple surgeries fall into the same risk group due to the frequent contact with latex they have during hospital procedures. The risk of developing latex allergy increases with repeated exposure to latex products. Even without a history of allergy, people with spina bifida and hydrocephalus should avoid contact with latex products from birth. Instead, they should use products made of silicone, plastic, nitrile or vinyl.

### Common latex products at home, school or in the hospital are:

- Household and medical gloves
- Condom catheters against incontinence
- Wheelchair tires
- Adhesive plasters
- Some urinary catheters
- Some tubes and enema nozzle tips
- Protective pads
- Colostomy/urostomy products
- Balloons and rubber balls
- Rubber bands
- Rubber flooring of playgrounds
- Beach toys

Proteins contained in certain foods can cause a similar reaction of the immune system like the one caused by proteins contained in the latex. Such foods are bananas, kiwis, avocados, papayas and chestnuts.

### Nursing care in educational institutions:

If a child has a confirmed latex allergy, the nurse should be informed about it. In this case, the nurse should remove any latex products from the health office and other premises that the student visits regularly.

The nurse must inform the teaching staff about the risks and the measures for avoiding them, including replacement with alternative products. Together with the management staff, the nurse should review the options for delivery of latex-free materials for the children with allergies and for the classes in which they study.

Even if the student has not been diagnosed, the nurse should monitor for possible reactions and take the appropriate measures.

The role of the nurse is to prepare a first-aid plan in case of latex allergy and to train the teaching staff on how to act in case of an allergic reaction.

Another important role of the nurse is to provide support to the child in achieving independence. The nurse should explain to the child in understandable language the risks of latex exposure and should teach the child how to avoid them and what types of reactions require help from an adult.



## SKIN CARE

Nerve damage in spina bifida could lead to loss of sensitivity associated with the level at which the lesion occurs. Some children are not able to feel heat, cold, pain, pressure, abrasions or excessive moisture. Without the feeling of discomfort or pain, children can easily get injuries or skin damage. On the other hand, impaired blood supply and slow lymph circulation in the lower part of the body could make wound healing extremely difficult. Untreated decubitus ulcers can affect the bone. Therefore, prevention is the main focus of skin care for people with spina bifida.

Due to the neurological deficit, children with spina bifida do not feel discomfort and numbness when sitting down in the same position for a long time. They need to be reminded to change their position in order to release the tension in the respective part of the body.

Incontinence makes the skin even more susceptible to injury, as urine and feces contain substances that injure the skin and cause infections. The introduction of a control program and maintaining optimal hygiene are mandatory.

A well-balanced diet with a variety of fruits and vegetables is extremely important for maintaining healthy skin. Adequate fluid intake is needed together with enough vitamin C and zinc, which help the healing process.

The daily inspections of the skin are part of routine care for children with spina bifida. Attention should be given to the back, buttocks and legs, especially when using orthoses. In young children, this inspection should be carried out by an adult. Teaching children to self-care should start as early as possible.

### Nursing care in educational institutions:

To examine the child's skin regularly for signs of redness, especially in children who stay in the school or kindergarten for the entire day;

To remove and place the orthoses of children who stay for an afternoon nap;

When examining the skin and placing the orthoses, to explain to the child the purpose of the examination and the series of steps, with the intent to make the transition to independence easier. It is important for the nurse to emphasize to the child the concerning signs and symptoms that the child should be aware of in order to know when to seek help from an adult;

To make sure that the diapers and nappies of incontinent children are changed frequently so that their skin stays clean and dry for longer;

To make slight changes in the child's position every 2 hours during the day in children with limited mobility. The nurse should encourage movement and light exercise during breaks;

Skin inflammation can quickly progress to an abscess, usually accompanied by fever, malaise, nausea or vomiting. If any of these symptoms are present, the nurse should conduct a thorough examination of the skin, paying attention to the pressure points and those underneath splints, corsets or shoes;

The Norton Pressure Sore Scale Scoring System can be used for risks assessment.

To prepare an emergency plan in case of skin injuries, including due to burning or freezing of the skin  
[\[Appendix 7\]](#)

## **HEALTHY LIFESTYLE: WEIGHT CONTROL, EXERCISE AND EATING HABITS**

During their growth, children affected by spina bifida, and especially those who have hydrocephalus, are at high risk of obesity. Studies in the United States have shown that after the age of six, at least 50% of children with spina bifida are overweight, and among adolescents and adults, over 50% have obesity.

Being overweight is associated with an increased risk of high blood pressure, diabetes, osteoarthritis, impaired cholesterol metabolism and heart diseases. In people with spina bifida, the consequences can be even more serious, due to further exacerbation of concomitant medical conditions that affect the joints, the muscles or the skin.

Along with its negative effects on the overall health, being overweight has a negative effect on a person's independence, self-care, self-esteem and mental status.

Prevention is extremely important because the extra kilograms limit mobility and ambulation which, in turn, decreases the body's energy expenditure and hinders the ability to lose weight.

The high obesity rate in adults with disabilities makes it especially important for children and young people of this group to maintain good physical shape and healthy weight so that obesity does not negatively affect their quality of life.



When determining the daily calorie intake, it should be borne in mind that people with spina bifida have less lean body mass than their peers. Even when other factors such as physical activity are the same, they have a lower basal metabolic rate. This means that students with spina bifida beyond early childhood have lower caloric needs than their peers.

#### Nursing care in educational institutions:

To promote a positive attitude towards the body as well as a healthy lifestyle and exercise;

To promote a healthy diet and eating habits, which include a high intake of fiber and fluids, and inform the child of their benefits using understandable language;

To monitor the weight of the child and, in case of a rapid weight gain, to alert the parents and the healthcare professionals who perform the periodic monitoring;

To advise the physical education teachers on the child's health and ability to practice various sports;

To monitor the condition of the child's spine and to alert the parents and the healthcare professionals who perform periodic monitoring in case of deterioration.

## COGNITIVE AND LEARNING DIFFICULTIES

Spina Bifida has traditionally been thought of as an orthopedic condition. Although, a number of brain abnormalities typically occur in patients with spina bifida, which makes it also a cognitive condition.

The most frequent brain malformations is a reduction in the size or a complete absence of the corpus callosum, which is found in 69% of persons with myelomeningocele. Corpus callosum is a white matter structure that connects the two halves of the brain, making it important for integrated thought and coordinated motor action.

Reduced cortical thickness in the posterior brain regions in persons with spina bifida refers to difficulties in the process of visual spatial information in this population. On the other hand, increased neocortical thickness in the frontal regions is associated with some of the executive dysfunction seen in students with spina bifida.

Although most students have an IQ in the average range, hydrocephalus and multiple shunt revisions are associated with lower intelligence scores. Studies have found that motor, spatial, and executive function tasks were more sensitive to hydrocephalus status than vocabulary and reading tasks

Better understanding of the possible cognitive difficulties in children with spina bifida is very important when choosing learning strategies to support the strengths of children in school and help them build valuable life skills.

### **Nursing care in educational institutions:**

Cognitive difficulties affect not only the learning process but also the activities of daily living, including the development of the skills required for achieving independence and self-care. The nurse has an important role to support the transition to independence by teaching the child on a daily basis how to self-care - how to self-catheterize, how to put on the orthoses properly, how to position on the wheelchair, to regularly check his/her skin for redness, etc. Cognitive challenges can complicate this process and require the nurse to implement different learning strategies. Here are some standard tips that make it easier to work with children with spina bifida and hydrocephalus:

- Divide long procedures/tasks into small and easy steps;

- Use visualization tools - cards, models, pictures and diagrams;

- Give clear and concise instructions using understandable language;

- Make lists and use audio recordings;

- Link the sequence in which the everyday tasks are performed with specific events, not with a particular hour (i.e. the catheterization time should be after the second lesson rather than at 9:30);

- Concentrate on the implementation of a single task/single topic of conversation;

- Make eye contact before you start giving instructions;

- Eliminate noise and other distractions;

- Repeat orally together with the child;

- There are already various smart apps that are very useful for creating daily programs and schedules and for reminding the tasks included in them.

The nurse has the important task of familiarizing other team members with the possible cognitive difficulties associated with spina bifida and hydrocephalus.

## SHUNT MONITORING

In children with hydrocephalus, there is always a risk of complications associated with shunt malfunctioning. A malfunction can occur due to mechanical failure, infections, blockages, drainage problems or the need for a longer catheter. It is essential that adults caring for the child are well aware of the symptoms of valve malfunctioning and know that they have to consult the child's doctor if they notice any symptoms. It is also very important that children are trained to recognize such symptoms and know that they have to tell about them.

Timely treatment reduces the risk of possible complications and brain damage!

### Nursing care in educational institutions:

- To monitor the student and watch for possible signs of valve malfunctioning;
- To teach the student how to recognize the alarming symptoms related to the operation of the valve and to tell about them;
- Prepare an emergency plan in case of a valve malfunction;
- To implement the plan and provide first aid until the arrival of a specialized team;
- To familiarize the pedagogical staff with the plan and train them on how to act if certain symptoms appear.

## USE OF MEDICATIONS

Most children and adults with spina bifida and hydrocephalus require daily use of medications and supplements that target secondary conditions associated with their diagnosis. The medications that this group of patients most commonly use are:

- Antispasmodic and anticholinergic agents to control incontinence;
- Antibiotics; some children need to take low doses of antibiotics to prevent urinary, kidney or skin infections;
- laxatives;
- Anticonvulsant agents for seizure control.

### Nursing care in educational institutions:

The nurse should be well familiar with the medications that the student is taking and ensure that they are taken during school hours. This should be carried out at the time that corresponds to the doctor's prescriptions, the child's schedule and the schooling process.

## FIRST EXAMINATION, RECORD KEEPING AND PREPARATION OF THE HEALTH PASSPORT



Achieving a full understanding of the health needs of children with spina bifida and hydrocephalus is difficult because these are complex conditions that affect many functions of the body. Therefore, it is recommended that, in addition to the health record which contains copies of the basic medical documentation, the nurse should prepare and keep a Health Passport of the child. The Health Passport contains the systematized basic medical information and allows the nurse to quickly and easily review the most important aspects of the child's condition. In addition, the Health Passport describes the basic needs of the student that the nurse should cater for at school.

A sample form that the healthcare staff in the school can use is attached to this Manual ([Appendix 6](#)). Completing and keeping a Health Passport is not mandatory, but it would make the process of providing health care and the work of the specialists much easier.

The first meeting with the child and the parents is better to take place outside of school hours, even before the beginning of the school year. In a relaxed atmosphere, the child's parents can hand over copies of the main healthcare records and the health prophylactic card, fill in the Health Passport together with the nurse, share their concerns and identify the nursing care that the child will need at school.

The days before the beginning of the school year are a good time for the nurse to assess the safety needs and accessibility of the infrastructure. Without other students around, the nurse can observe whether the classroom is arranged properly, whether the child needs assistance in opening and closing the door, whether he/she is able to use the school toilet, etc. During this period, the parents can show how they perform the catheterization.



## PROVIDING FIRST AID IN SCHOOL AND KINDERGARTEN



All children can find themselves in a situation where they require emergency medical help. If this happens at school or in the kindergarten, the nurse as a healthcare professional must provide first aid to everyone who needs it. If necessary, the nurse must call 112.

The risk of occurrence of an emergency situation is higher in children with spina bifida and hydrocephalus due to their specific health conditions. Of course, this does not happen every day, but it is recommended that the nurse knows the common risks and how to act according to the needs and the condition of the child. To help the practical work of the nurse in the school and kindergarten, we have summarized the most common emergencies in children with spina bifida and hydrocephalus in [Appendix 7](#) to these Guidelines. In this Appendix, every nurse can find information on the main steps that the nurse should take before the arrival of the emergency team in the case of:

- Valve problems in children with hydrocephalus;
- Seizures;
- Skin burns;
- Frostbite of the lower limbs;
- Heatstroke;
- Fractures, because of osteoporosis and low bone mineral density in people with spina bifida;
- Bleeding;
- Skin infections;
- Blow to the head after a fall;
- Foreign body in the airways;
- Allergic reaction to latex;
- Swallowing disorders in children with hydrocephalus and Chiari malformation type 2.

Spina bifida is a rare disease which means that child's health is monitored by a specialized multidisciplinary team of physicians. These physicians are the ones most familiar with the child's condition and it is highly recommended that they take care of the patient in the case of emergencies. It is therefore important that the contact information of these specialists is provided in the child's health passport ([see Appendix 6](#)) so that the nurse can refer the emergency team to them. This will help the child get the best care from a medical team familiar with his/her needs.

In any emergency situation, regardless of whether or not an emergency team is called, the nurse must immediately inform the child's parents/guardians.

In the case of an emergency, the nurse should:

Call 112.

Provide medical care in the case of an emergency medical condition in a child or a student until the arrival of the emergency team.

Inform the child's parents/guardians.

The responsibility of the nurse is to familiarize the teachers and other members of the school staff with conditions that require emergency medical care in children with spina bifida and hydrocephalus.



## WORKING TOGETHER WITH OTHER MEMBERS OF THE MULTIDISCIPLINARY TEAM



The role of the nurse in the multidisciplinary team is not limited only to directly catering for the health needs of the children through specific nursing procedures. The help of the nurse is also needed in the work of the other members of the team so that their efforts aimed at successful social inclusion are as complete and effective as possible. As the health expert in the team, the nurse has the important responsibility to inform other team members about certain aspects of the child's health in the context of the child's need for specific support. Below are some examples that do not completely cover all of the areas where cooperation is needed.

Cognitive and learning difficulties can affect not only the child's performance at school but also the child's social inclusion and peer contact. The nurse should make it clear to the pedagogical and non-pedagogical staff that children with spina bifida and hydrocephalus, as a result of their diagnoses, are a risk group in this regard. When the team is prepared, they can take timely measures to adapt the curriculum and consolidate the class.

Regarding catheterization, the nurse should inform the teachers and the administration staff that visits to the toilet may take longer than usual. Children should not feel pressured by short breaks and should know that they are allowed to be late or leave the classroom when they need to. The nurse should inform the teachers that incontinence accidents may occur so that they are prepared to act quickly and discreetly enough in such situations.

The nurse should help the physical education teachers in their work by informing them about the individual motor abilities and limitations of the children. The nurse should give them guidance on what type of movements and activities to avoid; what are the appropriate exercises and sports and draw their attention to the possible health risks.

For younger children attending full-day kindergarten, the nurse should help with removing the orthoses for the afternoon sleep and putting them on afterwards and with the positioning and repositioning of the child in the wheelchair or other aids. This should be carried out in accordance with the schedule of the group/class and requires good timing with the teachers.

The nurse can help the school management in assessing the accessibility and safety of the school environment in regard to children with reduced ambulation, including by assisting in the preparation and implementation of the fire and emergency evacuation plan.

The nurse should inform the other team members what the most common health risks in children with spina bifida and hydrocephalus are and how to avoid them by pointing out the symptoms that they have to look for. The nurse should train the team on how to act in a case of emergency related to the children's health, including from whom to seek help and whom to call.

If the child has a personal assistant at school, some of the nurse's functions may overlap with those of the assistant. The most common of these are catheterization, removing and placing orthoses, repositioning, etc. In this case, it is recommended to clearly divide the responsibilities, with the possibility for substitution in case of absence.

Like every other member of the team, the nurse should constantly encourage the child in his/her efforts of achieving independence. Given the medical condition of the students with spina bifida and hydrocephalus, the nurse's efforts should be focused on developing self-care and self-safety skills. Close cooperation with the school psychologists will be beneficial.

Children usually go through a difficult period when returning to kindergarten/ school after a long leave due to health reasons or hospitalization. Many of them will need a longer period of adaptation and it is important for the nurse to inform the teachers and other team members about it. Working with a school psychologist would make this adaptation much easier.

The nurse should work in cooperation with the child's family. The parents are a valuable source of information about the child's health. They could help the nurse identify the child's health needs more easily and successfully; They can assist in the preparation of the health passport; provide copies of basic health records for the school's record; they are responsible for the supply of specific consumables such as catheters and can give advice related to the catheterization procedure. The parents and the nurse should work together in building and promoting healthy living habits, diet and exercise.



## CONCLUSION



In these Guidelines and in the General Guidelines, strong emphasis is put on the potential that the nurse has in helping children with spina bifida and hydrocephalus achieve successful social inclusion. In conclusion, we again would like to draw attention to the importance of the support that the nurse provides at school and in the kindergarten so that all children can participate safely and fully in the educational process, pursue their academic goals and build friendships.

We believe that through the tips and good practices herein, we could help the nurses discover the full power of the impact they have on the lives of children and their families and use that power to do good.



”

*The best nurses have the essential qualifications before they go to school.*

Florence Nightingale

“



## CLEAN INTERMITTENT CATHETERIZATION AND PROMOTION OF UROLOGICAL HEALTH

By helping perform clean intermittent catheterization, the nurse plays a leading role in the social inclusion of children with spina bifida in the school and kindergarten. Younger children are catheterized by an adult, and older children perform this procedure themselves.

At home, catheterization is usually carried out by a parent or another relative. At school, this could be carried out by the nurse or another health professional, as part of the activities that support the process of monitoring and treatment of children with chronic diseases. After an introductory training, the personal assistant can also catheterize the child. The supervising physician should prescribe how often the procedure should be carried out.

Before we explain the specific steps of the procedure, we want to review some general aspects:

Along with the prescriptions of the child's physician, it is important for the parents to provide copies of other medical documentation related to the child's urological condition: test results, hospital discharge reports of urological surgeries, a list of prescribed medications, etc. At least one meeting in a calm atmosphere, during which both parties can discuss their expectations and, if possible, prepare a health passport is needed;

If the school nurse has no experience in the procedure, it is best to have a parent present during the first few times the procedure is performed;

Catheterization can be performed in the toilet if the room is large enough, clean, lit and provides the necessary privacy. If these conditions are not available, it would be appropriate to use the health office or another room with plumbing;

The catheters and other necessary supplies must be provided by the child's family. It is best to do this in advance and to have supplies for a longer period of time, for example for the next 5 to 6 days in order to avoid the risk of the child being left without catheters. It is necessary to prepare a schedule for the supply of consumables that is convenient for both parties;

The catheterization schedule should be in accordance with the physician's prescriptions and the child's schedule. In order to promote social inclusion and free communication with peers, it would be appropriate that the time of catheterization not coincide with the long break;

Teachers should be warned that the procedure is time-consuming and that the child could be late for class.

This is not a sterile technique, but it is still important to keep to high hygiene standards;

The appearance and smell of the urine are indicators of the presence of urinary tract infections. If the urine is cloudy with a sharp odor, it is very likely that the child has an infection. In fact, a large proportion of patients on clean intermittent catheterization have asymptomatic bacteriuria, which, per se, is not an indication for treatment (Bakke, 1991). When there are no symptoms such as malaise, fatigue, headache or fever, it is usually enough to increase fluid in

The time spent with the child during the catheterization procedures is a good opportunity for the nurse to promote healthy habits related to the child's urological condition, paying attention to good hygiene, fluid intake, etc.;

During the catheterization, the child may have questions about his/her health or specific actions which are part of the procedure. The nurse should not be afraid to give explanations by presenting the information clearly, with a positive attitude and using understandable language;

By explaining and repeating aloud the individual steps of the procedure, the nurse helps the child's transition to self-catheterization. Even if the child is not ready yet, by repeating the steps he/she learns the sequence and when the child matures emotionally, the transition will be easier;

For some children it is difficult to do it on their own even at an older age due to cognitive difficulties. They often forget the sequence of steps or forget that it is time for a catheter. In these cases, the role of the nurse is rather to supervise the child.

The nurse should approach the catheterization with the necessary discretion that is in line with the perceptions of the child and the child's family. There are children who speak freely about this to their peers, but for others this topic is taboo. The nurse must respect the child's values and adhere to them. take and take cranberry juice for a few days;



## CLEAN INTERMITTENT CATHETERIZATION AND SOME PRACTICAL TIPS

The procedure is neither painful nor uncomfortable. When the basic steps and hygiene standards are followed, it is completely safe. Below three options are presented - for girls, boys and children with Mitrofanoff stoma. Discuss the steps in advance with the parents and the child, because there may be slight differences in the way they perform the procedure - they may clean the urethra with a special agent or the type of catheter may require additional lubrication. Find out which position is most comfortable for the child and follow the guidelines provided by the family.

Maximum hygiene is mandatory - clean your hands, do not touch the tip of the catheter and do not touch other surfaces before using it. If the catheter gets dirty, use a new one!

If the catheter requires additional lubrication, apply the lubricant just before the catheter is inserted.

If you use gloves, they should be latex-free.

It is advisable to use a catheter of the largest possible size [CH].

Below are some possible problems that may occur during the procedure and the way to solve them.

### Necessary supplies

(indicative list)

Sterile catheter;

Lubricant. Boys usually need a lubricant if the catheter is not pre-lubricated;

Running water;

Intimate/baby wet wipes;

Waterproof pad;

Bactericidal hand sanitizer;

Agent for cleaning the urethra;

Urine collection container/bag

Diapers/pads

### Preparation for self-catheterization

To encourage the child's independence and in order to facilitate the transition to self-catheterization, allow the child to help in some of the steps of the procedure. For example, have the child hand over the supplies, take off his/her clothes, clean up, etc. Say the steps aloud together at each stage.

**Possible problems that may occur during the procedure**

In case of a problem with the catheter insertion, you can try using catheters with a different size, coating, tip type or hardness.

In case of pain or discomfort caused by the vacuum when removing the catheter, try using a catheter with a smaller width or place your finger on the opposite end of the catheter to close it before removing it.

A few drops of blood on the catheter are usually due to a minor injury caused by a damaged surface of the catheter (factory defect). If they disappear after 2-3 procedures, they are not considered a problem.

If the blood is more than that, it is probably due to an internal wound and in this case, a consultation with a physician is required.


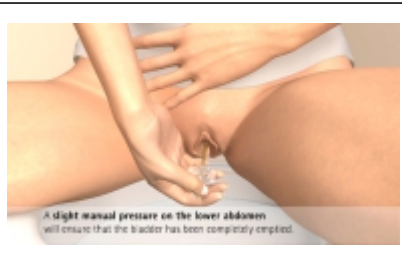
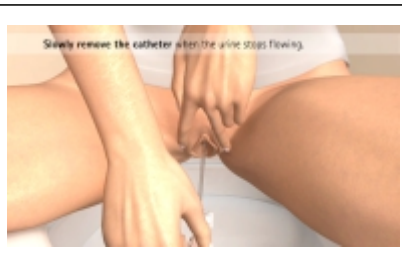


In case of a spasm, wait for it to resolve and then continue the procedure.

It is not a problem if you happen to insert the catheter into the vagina. Discard the catheter and repeat the procedure using a new catheter.



# CLEAN INTERMITTENT CATHETERIZATION IN GIRLS. STEP BY STEP

<p>Make sure that all equipment and materials are available. Lay them out close.</p> <p>The child removes or pushes down their underwear. Some assistance may be needed. The child takes position.</p> <p>Wash your hands.</p>	
<p>Clean the urethral opening from top to bottom.</p>	
<p>Remove the catheter from the packaging. Do not touch the part, which will be inserted. Hold it firmly.</p>	
<p>With the other hand spread the labia and pull them up slightly so that the urethra is clearly visible.</p>	
<p>Push the top of the catheter gently against the urethral opening and slowly insert it.</p> <p>Make sure that the opposite end of the catheter is pointed at the urine collector or toilet bowl.</p>	
<p>Once the catheter has reached the bladder, push it a little bit further and let the urine flow out.</p>	

<p>Wait in this position for the urine to flow.</p>	
<p>When the urine stops flowing, gently apply pressure above the pubis. A small portion is likely to flow out.</p>	
<p>Use the following technique to remove the catheter: Withdraw 2-3 cm by turning the catheter slowly and stop when there is no more urine coming out. Put the catheter in a little bit deeper and withdraw until the bladder is empty. When the urine stops flowing, slowly remove the catheter.</p>	
<p>Dispose of the used catheter and supplies in the trash.</p>	
<p>Dispose of the urine in case you have used a urine collector.  Put on clean diapers if necessary.  Wash your hands.</p>	






The images are provided by B.BRAUN MEDICAL Bulgaria, a partner in the Multi-IN project. [www.bbraun.bg](http://www.bbraun.bg)



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# CLEAN INTERMITTENT CATHETERIZATION IN BOYS. STEP BY STEP

<p>Make sure that all equipment and materials are available. Lay them out close.</p> <p>The child removes or pushes down their underwear. Some assistance may be needed. The child takes position.</p> <p>Wash your hands.</p>	
<p>Wash the penis. Pull back the foreskin and wash the end of the penis around the urethral opening.</p> <p>Remove the catheter from the packaging. Do not touch the part, which will be inserted. Hold it firmly</p>	
<p>With the other hand hold the penis straight out (at an angle of 45 degrees with the boy's body)</p> <p>Push the top of the catheter gently against the urethral opening and slowly insert it.</p>	
<p>Push it in further until it reaches the sphincter muscle. Now point the penis toward the boy's toes and apply light pressure. Once the catheter has reached the bladder push it a couple more cm and let the urine flow out.</p> <p>Make sure that the opposite end of the catheter is pointed at the urine collector or toilet bowl.</p>	
<p>Wait in this position for the urine to flow.</p> <p>When the urine stops flowing, gently apply pressure above the pubis. A small portion is likely to flow out.</p>	

<p>Use the following technique to remove the catheter:</p> <p>Withdraw 2-3 cm by turning the catheter slowly and stop when there is no more urine coming out.</p> <p>Put the catheter in a little bit deeper and withdraw until the bladder is empty.</p> <p>When the urine stops flowing, slowly remove the catheter.</p>	
<p>Dispose of the used catheter and supplies in the trash.</p> <p>Dispose of the urine in case you have used a urine collector.</p> <p>Put on clean diapers if necessary.</p> <p>Wash your hands.</p>	

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## CLEAN INTERMITTENT CATHETERIZATION IN CHILDREN WITH MITROFANOFF STOMA

1. Make sure that all equipment and materials are available. Lay them out close.
2. Wash your hands.
3. Clean carefully the area around the stoma.
4. Remove the catheter from the packaging. Do not touch the part, which will be inserted. Hold it firmly.
5. Push the top of the catheter gently against the stoma and slowly insert it.
6. Make sure that the opposite end of the catheter is pointed at the urine collector or toilet bowl.
7. Once the catheter has reached the bladder, push it a little bit further and let the urine flow out.
8. Wait in this position for the urine to flow.
9. When the urine stops flowing, slowly remove the catheter.
10. Dispose of the used catheter and supplies in the trash.
11. Dispose of the urine in case you have used a urine collector.
12. Wash your hands.

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# SCHOOL HEALTH PASSPORT OF CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS

Name:	
Date of birth:	
School/kindergarten:	

<b>Spina bifida:</b>	<input type="checkbox"/> Myelomeningocele	<b>Hydrocephalus:</b>		<input type="checkbox"/> YES	<input type="checkbox"/> NO
	<input type="checkbox"/> Meningocele	Controlled by:	<input type="checkbox"/> VP shunt on the right	<input type="checkbox"/> VA shunt on the right	
	<input type="checkbox"/> Spina bifida occulta	Model and brand:			
	<input type="checkbox"/> Other type:				
Level of lesion:					
		<input type="checkbox"/> ETV	<input type="checkbox"/> Other:		
		<input type="checkbox"/> Arnold Chiari II malformation	<input type="checkbox"/> YES	<input type="checkbox"/> NO	
Other:					

Neurosurgical Procedures or Operations			
	Operations	Date	Notes
<input type="checkbox"/>	Shunt insertion		
<input type="checkbox"/>	Shunt revision I		
<input type="checkbox"/>	Shunt revision II		
<input type="checkbox"/>	Shunt revision III		
<input type="checkbox"/>	Tethered Cord release I		
<input type="checkbox"/>	Tethered Cord release II		
<input type="checkbox"/>	Chiari Decompression		
<input type="checkbox"/>	Other:		

Orthopedic Operations			
	Operations	Dates	Notes
<input type="checkbox"/>			
<input type="checkbox"/>			
<input type="checkbox"/>			
<input type="checkbox"/>			
<input type="checkbox"/>			

<b>Mobility aids:</b>	<input type="checkbox"/>	No
	<input type="checkbox"/>	Orthosis - AFO
	<input type="checkbox"/>	Orthosis - KAFO
	<input type="checkbox"/>	Orthosis - RGO
	<input type="checkbox"/>	Cane
	<input type="checkbox"/>	Crutches
	<input type="checkbox"/>	Walker
	<input type="checkbox"/>	Wheelchair/ relatively independently
	<input type="checkbox"/>	Wheelchair /assistance
	<input type="checkbox"/>	Power chair
<input type="checkbox"/>	Scooter	
Other:		

<b>Other type of orthosis</b>	<input type="checkbox"/>	Corset brace
	<input type="checkbox"/>	Hand orthosis - left
	<input type="checkbox"/>	Hand orthosis - right
Other:		

<b>Transfer need in school</b>	<input type="checkbox"/> YES	<input type="checkbox"/> NO
Please specify:		

Orthopedic conditions	Notes
<input type="checkbox"/> Spine	
<input type="checkbox"/> Hips	
<input type="checkbox"/> Feet	
<input type="checkbox"/> Contractures	
Other:	

Bladder incontinence
<input type="checkbox"/> Self-continnence
<input type="checkbox"/> CIC
<input type="checkbox"/> Indwelling catheter
<input type="checkbox"/> Diapers
<input type="checkbox"/> Medications:
Other:

Urological operations and surgeries
<input type="checkbox"/> Bladder augmentation
<input type="checkbox"/> Mitrofanoff
<input type="checkbox"/> Sling procedure
<input type="checkbox"/> Vesicostomy
<input type="checkbox"/> Deflux injection
<input type="checkbox"/> Botox injection
<input type="checkbox"/> Macroplastique injection
Other:

Clean Intermittent Catheterization	
Frequency for 24 hours	
Frequency during school day	
Time for CIC during school day/preferred by the student	1. .... 2.
Catheter type	
Catheter size/CH	
Self-catheterization?	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> Need supervision

Bowel incontinence	Bowel routine
<input type="checkbox"/> Self-continece	Please specify procedure, frequency...
<input type="checkbox"/> Constipation	
<input type="checkbox"/> Incontinence/frequent leakage	
<input type="checkbox"/> Diapers	
<input type="checkbox"/> Medications:	
<input type="checkbox"/> Fecal impaction:	
Other:	

Medications	
<input type="checkbox"/>	
<input type="checkbox"/>	
<input type="checkbox"/>	
<input type="checkbox"/>	
<input type="checkbox"/>	

Medications during the school day		
Name	Dosage	Time
<input type="checkbox"/>		
<input type="checkbox"/>		
<input type="checkbox"/>		

Allergies:	
<input type="checkbox"/> Latex	Please specify:
Other allergies:	

Other medical conditions not mentioned here /skin conditions, seizures, diabetes, depression/

Other surgeries and operations not mentioned here

Nursing care at school/kindergarten:

- CIC
- Supervision during self-CIC
- Help in toilet
- Medications
- Assistance in positioning/repositioning
- Assistance in placing orthosis
- Assistance in mobility aid
- Diapers change

Other:

Contacts		
	Name	Telephone number
Parent 1/guardian 1		
Parent 2/guardian 2		
GP		
...		
...		
...		
...		

The passport is prepared by:	1. ... 2. ...
Date:	

*This passport contains the most important medical data of students with spina bifida and hydrocephalus. More details are available in the medical documents attached to the child's file in the health office. The passport is filled in jointly by the medical person at the school, the parents and the child. If a section does not apply to the patient, it should be omitted.*

*The Health Passport is part of the Manual for nurses and healthcare professionals in kindergartens and schools on multidisciplinary care and inclusive education of students with spina bifida and hydrocephalus, developed under the Multi-IN project. More resources in inclusive education of students with spina bifida and hydrocephalus are available on the project website [www.multi-in.eu](http://www.multi-in.eu)*

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## **COMMON CONDITIONS IN CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS REQUIRING EMERGENCY MEDICAL CARE**

This booklet is designed to help the medical staff in schools and kindergartens act quickly, safely and effectively when children with spina bifida and hydrocephalus need emergency medical care. The information provided herein is not intended to substitute first aid training and courses.

### **SHUNT PROBLEMS**

Hydrocephalus refers to dilatation of the cerebral ventricles. Cerebrospinal fluid is produced and reabsorbed constantly and all cerebrospinal fluid is refreshed between 3, 4 or 6 times a day. When the space occupied by the cerebrospinal fluid is deformed or when cerebrospinal fluid is produced in excess inside the skull or the spine, its impaired resorption and reabsorption in the blood leads to compression of the brain. The valve placed helps drain the fluid into the abdominal cavity or into the circulatory system. Thus, the compressed brain is relieved of the pressure. The valve allows maintaining an exact pressure difference between the cerebral ventricles and the abdominal cavity.

The shunt is a delicate device that can become clogged or infected. As the child grows, the shunt may need to be replaced. A clogged valve or a malfunctioning mechanism causes the symptoms of hydrocephalus. This requires urgent surgery to replace the malfunctioning shunt.

Shunt infection is a relatively common complication after surgery. The risk of infection is up to 1 in 5 children and decreases in adults. Infection is more likely to occur during the first few months after the surgery.

The symptoms of an infection or shunt problems may vary. Some symptoms develop more slowly and are chronic, and they may include:

- Irritability or other abrupt changes in the child's personality;
- Deterioration of school performance;
- Headache, more pronounced in the morning;
- Generalized weakness

In these cases, the nurse should alert the parents and the child's family doctor.

## APPENDIX 7

Other symptoms require immediate consultation with a neurosurgeon and/or neurologist. These include:

- Severe, intolerable headache
- Nausea and vomiting, more pronounced in the morning;
- Neck and throat pain;
- Impaired vision;
- Double vision;
- Sensitivity to light;
- Redness along the shunt line;
- Abdominal pain if there is drainage to the abdomen;
- Difficulty moving due to spasticity;
- Drowsiness or inability of the child to stay awake;
- Loss of consciousness.

In the case of an emergency, the nurse must call 112 and provide information to the emergency team about the neurosurgeon/neurologist/doctor who monitors the child, as specified in the health passport. The nurse must also inform the child's parents.

### **SEIZURES**

After any type of brain surgery, there is always a risk of seizures. Seizures can lead to reduced oxygen supply of the brain.

#### **First aid in the case of a seizure**

Before the arrival of the emergency team: Place the child lying in a horizontal position on his/her back, with the lower limbs raised at 45-degree angle. The head and shoulders should be levelled with the pelvis. The legs may be placed on a stool. Adequate oxygen supply must be provided, the child's collar and belt must be unfastened, and any scarfs should be removed. The windows of the room should be open. The child's head should be turned slightly to the side in order to avoid aspiration of vomit. If ammonia, vinegar or essential oil is available, put it on a swab and bring it to the child's nose. Its inhalation stimulates the respiratory and vascular centres.

Another approach is to put a wet and cold kerchief on the forehead or to wet the face with cold water, pat the cheeks or warm the body.

### **SKIN BURNS**

Skin injuries caused by burns can range from mild to severe necrotic conditions in the event of third- or fourth-degree burns.

Some children with spina bifida may not feel pain in the lower part of the body at all!

### First aid in the case of burns

Before the arrival of the emergency team: Place a sterile gauze pad on the burned area and secure it by wrapping it with a bandage several times. A clean ironed kerchief or a bedsheet can be used until the patient is transported to a medical centre. An analgesic may be used for pain relief. The skin can be cooled for 5 to 10 minutes under running water before placing the sterile gauze pad as this significantly reduces pain. If the blisters have ruptured, apply cold running water again and then place a sterile gauze pad or bandage again.

In the case of limited burns that cause only redness of the skin, cooling the skin with running water and applying ointment such as Deflamol or spraying Panthenol spray are the treatments performed most often. The blisters can appear up to 24 hours after the burn, and the need to consult a surgeon is determined according to their size.

## **CHEMICAL BURNS**

Acids can cause necrosis. When the body is burned with sulfuric acid, the resulting necrosis is brownish-black in colour, grayish - in burns with hydrochloric acid, yellow - in burns with nitric acid, and golden-yellow - in burns with picric acid, respectively. Bases are known to cause moist necrosis, which is grayish-yellowish in colour, and limited but deep burns to the skin.

### First aid in the case of chemical burns

Wash profusely with water using a shower or a jet. Acids are neutralized using 2-5% sodium bicarbonate solution, while bases are neutralized with 1% acetic acid solution. The wounds should be dressed with a gauze pad and a bandage, and the child should be referred to the child's family doctor.

In the case of phosphorus burns, the surface of the skin should be cleaned and a dressing damped with a potassium permanganate solution (1:50,000) should be placed.

## **FROSTBITE OF THE LOWER LIMBS**

Frostbite could result due to low temperatures and due to circulatory disorders. The child may not be able to feel cold.

### First aid for frostbite of the lower limbs

Wet clothes should be changed, if possible, and the child should be wrapped and warmed.

The widespread practice of "warming up" by rubbing with snow is harmful! It is essential to massage the frozen area with a dry and warm palm after which a "heat-insulating dressing" of cotton, a gauze pad or a bandage should be applied to the affected area. The feet should be immersed in a water bath at a temperature of 36 degrees for 20 to 30 minutes. Gradually add warm water and then place a heat-insulating dressing. The child should be referred to a medical centre.

## **HEATSTROKE**

Some children with spina bifida and hydrocephalus have difficulty with thermoregulation. This can happen even if the temperature is not very high. The signs of heatstroke may include fatigue, restlessness, flushing, fever, dizziness, headache, dry and hot skin or rapid heartbeat. In severe cases, seizures and loss of consciousness may occur.

### First aid in the case of a heatstroke

Quickly bring the child to a cool and ventilated place. Place the child in a horizontal position. Remove all tight clothing. The child should be given cold liquids. Spray the child with cold water.

## **FRACTURES**

Some children with spina bifida have thinning of the bone structure and therefore are at increased risk of fractures, especially of the lower extremities. The absence of pain due to fractures of the lower extremities is common in this group of children

### First aid for fractures

Call 112 if a fracture occurs. Before the arrival of the medical team, the following steps can be taken:

The upper limb should be immobilized by attaching it to the chest, elbow bent at right angle. In the part with the fracture, the lower limb should be immobilized using a splint. Readily available tools such as wood boards or other hard materials suitable for making splints can be used. Do not try to reduce the fractured bones when providing first aid in the case of a fracture. If the fracture is open and there are bones poking through the wound, no attempt to reduce the bones should be made; instead, the wound should be covered with a sterile gauze pad. Splints should be placed over the clothes or should be padded in advance so that they do not damage the skin. When placing the splint, two adjacent joints (below and above the fracture) must be covered by the splint. In the case of a spinal injury, a fracture of the spine should be considered. This is a very serious trauma and the child should not be moved without the presence of a doctor. If the injury is life-threatening, minimal movement is allowed.

## **BLEEDING**

Hemostatic dressings should be applied only in the case of bleeding from the limbs and a gauze pad, a cloth or a triangular bandage should always be applied to the wound.

Arterial bleeding - when the integrity of an arterial vessel is compromised, the colour of the blood is bright red. These bleedings are most dangerous because they result in rapid blood loss.

### First aid in the case of arterial bleeding

In the case of arterial bleeding, call 112 immediately.

Compression of the bleeding vessel. Apply a tight bandage above the bleeding wound using a belt, a kerchief or a bandage. Dress the wound. Take a note of what time the bandage was placed, because it should not remain in place for more than two hours or more than one hour in winter, as there is a risk of tissue death if left without blood circulation. If the bandage needs to stay in place longer than the above-mentioned, it should be loosened for a few minutes to supply the peripheral tissue. The release of the bandage should be done gradually. The child should be lying.

Venous bleeding - when the integrity of a vein is compromised, the blood flows smoothly. When a large venous vessel is damaged, this is a life-threatening condition. The blood is dark red. The steps for providing first aid are the same as those in arterial bleeding.

### Capillary bleeding

The integrity of capillaries is compromised. Impaired capillary integrity. The blood oozes as a result of superficial injuries.

Clean the wound with hydrogen peroxide if possible and cover it with a sterile gauze pad. At the discretion of the nurse, the child should be referred to an emergency pediatric care office for wound treatment and consultation.

## **SKIN INFECTIONS**

Skin infections can quickly develop into an abscess with concomitant fever, nausea or vomiting. The child may not feel that there is a wound or that this wound has become infected;

When these symptoms are present, the nurse should perform a thorough examination of the child's skin, paying special attention to the pressure points; places underneath splints or corsets as well as the groin, ankles, heels, buttocks and the caudal region.

An infected wound requires urgent consultation with a surgeon.

## **BLOW TO THE HEAD AFTER A FALL**

If we have a reason to think that the injury to the child's head could be life-threatening, we must immediately call 112. If the child is breathing easily and is not in immediate danger, we should not move the child. If the child is unconscious, we should position the child lying on one side in a stable position and seek help. The child can be turned to lie on the other side every 30 minutes.

If the child has suffered an injury and is not breathing, oxygen should be provided no later than 4 minutes in order to avoid brain damage. Start by clearing the airways by lifting the child's chin and tilting the head backwards. In children between 1 and 8 years of age, give two short breaths or one if the patient is a baby. If the child has an injury, do not tilt the chin, but move the lower jaw forward and do artificial respiration. If the patient is an adult, give one breath every 5 seconds, and in children under 8 years of age do one breath every 3 seconds. The normal respiration rate is 20 per minute.

## **FOREIGN BODY IN THE AIRWAYS**

Wrap your arms around the child's waist coming from the back. Place one hand above the navel and under his ribs while keeping your thumb bent and directed inwards under the child's breastbone. Place your other hand over your first hand and push the abdomen hard inwards and upwards until the child begins to breathe. If the child is unconscious, the procedure can be repeated twice. If breathing is still absent, artificial respiration with cardiac massage should be performed by making 15 chest compressions and giving 2 breaths if the patient is an adult, and 5 compressions and 1 breath in children from 1 to 8 years of age. Before giving breath, the mouth should be checked for foreign bodies.

## **ALLERGIC REACTIONS**

The most common allergic reactions in children with spina bifida are those to latex products. Most often the reactions are mild and present as allergic contact dermatitis - skin redness, blisters, itching, flaking of the skin, eye burning and tearing.

In some children, symptoms may progress to:

- Fast heartbeat (tachycardia)

- Tremor

- Chest pain

- Difficulty breathing

- Low blood pressure

Allergic reactions should be treated with antihistamines, adrenaline or steroids.

### **First aid in the case of severe allergic reactions:**

Call 112, remove clothes that fit tight around the neck and open the windows of the room wide to get a better oxygen supply.

## **SWALLOWING DISORDERS IN CHILDREN WITH HYDROCEPHALUS AND CHIARI MALFORMATION TYPE 2.**

Chiari malformation type 2 is a malformation in children with developmental disorders, in which parts of the cerebellum are displaced in the spinal canal and it is associated with smaller occipital fossa. When the medulla oblongata is compressed, symptoms of swallowing disorders appear, the voice changes, and the heart function and respiration are also affected.

In older children, this condition is characterized by neck/occipital pain, paralysis of the vocal cords, muscle atrophy, scoliosis and head flexion.

Swallowing disorders may cause aspiration of food into the trachea. Aspiration usually provokes a strong cough reflex. If sensitivity is impaired, "silent aspiration" may occur. Subsequently, an aspiration pneumonia may develop.

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# MANUAL

**for nurses and healthcare professionals**  
in kindergartens and schools on multidisciplinary care  
and inclusive education of learners  
with spina bifida and hydrocephalus

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