



For help to a novice volunteer

The Saint-Petersburg
charitable
organization,
"Perspektivy"

Saint Petersburg
2018

Dear volunteers!

We are glad to welcome you.

Every volunteer year brings new hopes, opportunities and joy.

This year we have tried to renovate and slightly improve this collection of materials that might be helpful for you during the work.

It was interesting and joyful to create this collection, because we were thinking that you would find something useful for yourself.

Good luck and have a good volunteer year!



Authors:

Absandze Ilona, a physiotherapist, a bobath-therapist

Baturina Anastasia, a coordinator of Sunday volunteers, Pavlovsk 2016-2018

Berkovich Maria, a teacher-defectologist

Golubeva Elizaveta, an expert on fundraising

Guseva Valentina, a psychologist

Iklyushina Maria, the head of volunteer services, 2010–2012

Safiullina Galina, a feeding specialist

Sedysheva Valentina, a teacher

Fedorova Yulia, a physiotherapist

Editor functions were performed by Anastasiya Baturina

The design and layout – Evgenia Moshchuk

Design editor – Alexander Bakurov

The translation was made by:

Borgardt Linda

Kurchanova Irina

Kushina Veronica

Prokhorova Anastasia

Sukhanova Taisiya

Editor – Irina Kurchanova

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Who we are?

"Perspektivy" appeared in 1996 in order to help severely disabled children. Now "Perspektivy" is a partnership of



charities, which is working for improvements in life of adults and children with functional disorder. Volunteers play a prominent role in all programs. The activity of "Perspektivy" would not be possible without volunteers. One of the organization's aims is to disseminate its experience among colleagues and parents of children with special needs.

The Saint Petersburg charitable organization, "Perspektivy", supports children with severe disability in the fourth building of the orphanage N 4 (program "Children outside the family "Pavlovsk") and supports families bringing up a severely disabled children ("Family support program"). For these needs, there are the Center for children and the Center for stay during the day and employment for teenagers. In addition, there are the system of crisis care and "Guest house".

Autonomous non-profit organization "New Perspektivy" provides support and assistance to care recipients, who



are older than 18 years old. This program is called "Adults outside the family "Peterhof" in an adult boarding school (Psychoneurologic boarding-school N 3, Peterhof) and the project "Accompanied accommodation". In the boarding school, "Perspektivy" created the program "Employment", which includes some practical classes in the workshops of ceramic and needlework, in the computer lab and in the kitchen. Moreover, there are some trips, "Art program", which includes studios of fine arts and theatre. In addition, specialists in adapted physical activity, social pedagogues and assistants work with care recipients. Within the framework of the project "Accompanied accommodation" seven adults with severe disability try to live independently in the village "Razdolye" with the support of organization.

Our specialists

More than 100 persons work in Perspektivy, most of them are teachers, social workers, specialists in adapted physical activity and other professionals, who are working directly with our care recipients.

To constantly improve their expertise, the members of our organization use the practical experience of Russian and foreign experts in their work.

Our volunteers

Every year about 40 volunteers from Russia, Germany, Spain, Austria and other European countries work in our projects throughout the year.

This program is called "Voluntary social year", which "Perspektivy" was the first to launch in Russia.

Volunteers are engaged in the program from Monday to Friday, working 35 hours a week. Every volunteer helps with certain care recipients, with whom he or she communicates most of all.

The volunteer works together with teachers, specialists in adapted physical activity, psychologists, coordinators and other volunteers. Volunteers are the assistants for care recipients, they are always around and ready to help, satisfy the needs and respond to interests of children.

In order to make this voluntary year peculiar and meaningful, to maintain the desire to help other people, we provide volunteers with some events, for example, meetings of volunteers of all projects, trips to other cities, seminars, consultations with specialists, supervisions.

Moreover, every volunteer has an opportunity to participate in interesting events in our organization, to realize their own new ideas, to apply their talents and skills, working with care recipients. For example, the majority of projects carried out by "Perspektivy" were initiated by volunteers. The initiative is welcome!

About 50 volunteers participate in projects on weekends in their free time. In addition, we get pro bono help from photographers, designers, translators, operators and other specialists. All our events are also held with the assistance of volunteers.

Who funds our work

Thanks to numerous Russian and foreign citizens, state and non-state organizations and funds we are able to help care recipients and organize our work.



Our reporting

In addition to obligatory reporting to state funds and special offices, we conduct an annual financial audit.

Each donor can receive accurate and specified information of how the donation was used.

Our mission

We believe that severely disabled people, who are not able to be fully independent, have the same dignity and they are important to the society as any other person.

We improve their situation, because they are in unacceptable living conditions, in which the satisfaction of basic human needs is not possible: in security, in freedom of movement, of making own decisions, in space, in communication, in belonging, in work, in the change of life expressions.

We are not able to change conditions of all disabled people at once, therefore, we work primarily for children and adolescents, who are living in orphanage N4 building 4, and when they become adults, we continue to help them in Psychoneurologic



boarding school N3 and to assist families with severely physically and mentally disabled children.

We strive for equal opportunities for people regardless of the severity of their impairment. We comprehend that it is difficult and costly to provide disabled people with such conditions, but we aspire for it.

We help to achieve the observance of the disabled children's and adults' Constitution right to the education and integration into the society.

We try to understand life and needs of these people in order to constantly improve together with them the ways of assistance. We create alternative methods of support for children and adults with severe disabilities and we propose our experience to state and non-state organizations.

We support the organizations which, like us, strive to improve the life of the people with severe and, primarily, multiple disorders.

The main resource of our organization is our employees and volunteers. We are all members of public charity. We create such environment, in which our workers feel

demanding and they are able to realize their talent and skills. We support creative ideas of our employees and their professional growth.

We seek money to fund the assistance programs created by our employees by ourselves. Our work is not possible without financing, and therefore, we try to improve the ways of raising funds.

We provide various people with the opportunity to participate in the assistance to disabled people. "Perspektiv" is a good way for it, because organization effectively uses the funds provided by benefactors to realize programs.

We endeavor to work as honestly, transparently and openly as possible. Our reputation and professionalism are important for us.

We exchange our experience and cooperate with other organizations, which are working in social field, in public health, in educational and cultural sphere.

With whom we work (our target group)

Children and adults with multiple disabilities

Our target group is children and young people with severe multiple disabilities.

Complicated, or multiple, disability is a primary defect of two or more systems of the human body (for example, movement or vision disorder is combined with mental retardation). The combination of defects, in turn, causes complex disorder of the next level (they are called secondary), associated with the development, receipt and processing of information, communication, etc.

Often our care recipients, children or young people, cannot move by themselves and their musculoskeletal disorders can be so strong that they cannot do without assistance. They have difficulties with the use of hands (take, bring closer to themselves, give away). They often can not communicate with others through speech, and we must use different means of communication.

They have difficulties with imitation (imitation is very important in the development of the child, children learn from it) and the reproduction of what they have heard and seen, and, accordingly, with the learning of the new. They have their own pace of life, usually a very slow one.

This is the most vulnerable group of people. There is still an opinion that they are "uneducable", "vegetables", "plants", "they do not understand anything and do not feel anything." Of course, this is not true. Just their capabilities and abilities are different, and it's important to know about some aspects.

Children and adults with mental retardation

Mental retardation (underdevelopment of intellectual functions associated with underdevelopment of the motivational-volitional sphere) can be caused by a huge number of very different causes (Karl Grunewald in the book "Care and Support" writes that there are more than five hundred). These are infectious diseases during pregnancy or early childhood, the mother's intake of alcohol or drugs, exposure to harmful environmental factors and so on. Often, mental retardation is a



component of various genetic disorders (for example, Down's syndrome). And sometimes the reason stays unclear.

Mental retardation is not a disease that can be cured. This is something inherent in a person, like a personality traits. Although doctors and psychologists describe various typical features of people with mental retardation, each of them is distinct and unique, has its own temperament, character traits, propensities, attachments. As well as any of us.

There are different degrees of mental retardation: mild, moderate, severe and profound. People with mild degree of mental retardation may not stand out. They can learn, work, build families, raise children (perhaps with the help and support), be criminally liable, i.e. are considered responsible for their actions. They may have difficulty with abstract thinking, generally with abstract information, often with an orientation in time and cause-effect relationships.

We usually work with those who have severe or profound forms of mental retardation, substantial disorders of speech, awareness, thinking. But it is important to remember that life in facilities greatly affects a person, his development, abilities. This phenomenon is called secondary mental retardation when negative environmental factors such as lack of new impressions, attention, warmth, love are added to the organic brain disorder.

Also, the situation is affected by the fact that most



of our care recipients have multiple defects, and in early childhood, the restriction in movement, for example, significantly influenced the development of the person as a whole.

Therefore, it is difficult to understand what are the initial

defects, what life experience has added to them ...

In general, it is hardly worth asking the question "How deep are his disorders?" Rather, it is worth asking yourself

- what does he like? What can he do?

What can I offer him?



... To some extent, of course, we share the opinion that all people are equally valuable. We somewhere even agree that everyone has the same needs (although some are still a bit less? ...) And yet we call some people "bales." If you once said this word, you took it into your intellectual baggage, then by that you have already proved what kind of look at the person you are following. All people are equally valuable, but some of them are "bales." In this word and related statements like "he still does not benefit from this ..."; "but is it worth to spend time, energy and money on it ...?"; "maybe someone else will get more advantage from all of that? " we reflect not only to the principle attitude towards the weakest members of society (which are also valuable, but a little less). In these words there are

- a fundamental lack of understanding of the fact that every person regardless of his current level, needs a stimulating environment actively influencing his life situation,

-as well as a fundamental ignorance of how the lack of stimulus and ability to influence his life situation affects a person's development, his physical and mental well-being.

Margaret Shang,
a psychologist (from the book Care and Support)

Intellect, intellectual achievements are extremely important for our society. What are you able to do? What do you know? What are you good at? – these questions surround us since childhood and throughout the life. We try to meet the standards. Need I say that in achievements oriented society, people with mental retardation are extremely vulnerable? In fact, they just do not fit into it. We do not know how much time must pass before they become accepted so that the values of society change - from the values of achievements (you are valuable according to what you can do) to the values of existence (you are valuable because you exist).

We believe that our work is a contribution to this important process.



People with Down's Syndrome

Down's Syndrome is the most common genetic disorder. According to statistics, one in 600-800 newborns is born with this syndrome. Down's syndrome was first described in 1866 by a British doctor John Langdon Down and named after him. In 1959, the French scientist Jerome Lejeune discovered that Down's syndrome is a genetic condition that exists from the moment of conception and is determined by the presence of an additional chromosome in the human cells.

External signs of Down's Syndrome:

- Flat face
- Short nose and flat nose bridge
- Narrow, "Oriental" eye shape
- A big tongue that "does not fit into the mouth."
- Open mouth (due to the large tongue and weak muscle tone)
- Children with Down's syndrome often suffer from visual impairment and congenital heart disease.
- Another characteristic of the syndrome is hypotension (low muscle tone). Therefore, children with Down's syndrome tardily learn to sit on their own, crawl, walk, hold a spoon in their hands.



Earlier, children with Down's syndrome were considered uneducable and were not taken even in special schools. Now, thanks to the efforts of public organizations, the situation began to change for the better. However, that goes very slowly. But still...

Global experience of work with children with Down's syndrome proves that although they develop slower than their peers, most of them still can learn to walk, eat, dress, talk, play and make friends with other children, go to school and play sports, in other words, to do what other kids can do.

Of course, a necessary condition for that is a loving family. But in a boarding school, a child with Down's syndrome can learn a lot if the personnel will care about that.

People with Down's Syndrome are surrounded by prejudices and delusions. Some people believe that all those who have Down's syndrome are aggressive

and uncontrollable, others – that all of them are kind and easygoing. Some people think that all of them are brilliant artists. The truth is that every person with Down syndrome has his own unique personality, has his own character. The degree of developmental delay and associated disorders of Down's syndrome is different. Among our care recipients there are very independent, active people, and there are very weak guys.

In Pavlovsk we have some very weak children with Down's syndrome who cannot stand by themselves and hold a spoon. Children who have just come from a children care center into the 4th building are very often sluggish and passive. They almost do not show interest in the world around them and people, they do not try to do anything on their own (of course, there are exceptions). Many of them in a few years learn to walk, dress, eat, actively play. Sometimes it requires many years, but experience shows that a person with Down's Syndrome can be taught a lot. If, of course, we care, communicate and believe in him.

Cerebral palsy

Cerebral palsy is a disorder of movement and control over the position of the body in space. Cerebral palsy develops as a result of damage to the immature brain and always begins in childhood. It doesn't progress but modifies the disorder of control over movements and posture.

Cerebral palsy has several forms. The main forms are:

- Spastic diplegia when all four limbs are tense, and legs are affected more than arms;
- Dual hemiplegia when all four limbs are tense, legs and arms equally affected, but sometimes the tone is more rigid (viscosity type);
- Hyperkinetic, characterized by forced, poorly controlled moves of limbs, torso and vocal musculature;
- Atonic-astatic. Movement disorders emerge as paresis (strength reduction) with the lower muscles tone;

• Hemiparetic. Movement disorders appear only in one side of the body (right arm, right leg).

In our work, we usually deal with spastic form.

Disorders that can occur in cerebral palsy:

- motor disorders (spasticity, hypotension — low muscle tone);
- speech disorders (delayed speech development, pronunciation disorder);
- visual and auditory disorders;
- psychoemotional and cognitive impairment;
- symptomatic epilepsy or seizures; difficulty in eating.

The problem of our patients with cerebral palsy is that in conditions of boarding school, isolation and immobility, in the absence of special adaptations and occupations, their motor state degrades. Contractures might arise (joints can't move), deformities of musculoskeletal system become worse, and because of this there are problems with breathing, respiratory diseases, digestion, etc.

In addition, initial problems with movement, awareness of their body lead to a delay in development.

Some recommendations for working with children with cerebral palsy can be found in the section "Advice on working with care recipients" (Positioning, Replacing, Movement»).

Visual disorders

children and adults with multiple disorders often have a visual disorder. Some of our care recipients can't see anything at all, some of them distinguish light and shadow, some can see the contours of objects and reacts to bright colors. If there are blind or visually impaired persons among your care recipients, it is important to remember a few simple things:

- don't grab them unexpectedly (at the beginning of the conversation, if you want to ask). First you need to approach him, call your name. If your conversation is over and you leave the the blind man, you need to tell him about it. If you go somewhere with the blind man and have to move away, leave him for a while, you need to direct him to a convenient safe place (" Here is the wall. ")
- You should not avoid expressions related to vision (Like " Look! ", " See? "). This is normal, it's a part of a common vocabulary. You can easily say "Look" to the blind man instead of "Feel";
- no need to whisper in the presence of the blind man. He still hears it and understands that there is someone else in the room;
- it is important to explain things to the person all the time — to say where we are going, what is around, what we are passing by.
- Don't move his belongings which he put somewhere by himself. It should be where he used to put it, so that he could find them by himself.
- Do not say "here" and "there." "Here is the window" is difficult for the blind man. It will be more understandable if you say "To the left of you is a window," "To the right ahead is a chair".

Games and activities with a blind person

Rely on other feelings:

- touch: offer different objects to touch. Try to play together with the pasta, cereal, sand;
- hearing: many blind adults and children are very fond of music and sounding toys;
- sense of smell: for example, you can open and smell cans of cinnamon, cloves, coffee;
- vibrating feeling: some people who are blind love vibration. For example, you can put the hand of a blind child or an adult on the lid of a piano or a guitar, then he can listen to music not only with his ears, but also with his hands.



Larissa is the smallest and weakest girl in my group. She can hardly move, and besides, she is blind. Larissa very often cries during feeding, changing clothes, taking a bath. Before, I did not understand - why? Total darkness. You hear different sounds, but do not understand what they mean. You do not feel your body, you do not know where your hands are, and where your legs are, because you can not move them. You can not control the situation at all: suddenly, without any warning, and they take you up into the air, carry you somewhere, put you on something uncomfortable and unfamiliar, turn you around ... <...> Larissa needs to put on her pants.

First, you come over to her

— Larissa! Larissa, hello.

Pause. Give her time to prepare. Slowly put your hands on her shoulders. Slightly press.

— Hello, Larissa.

Pause. She must understand who you are. It takes time. You touch her feet, stroking them — "here are your legs. Now we will dress" — recalling that Larissa has legs, this is very important: if you can not move, you "lose your body". " Move your hand from the hip to the toes, and here you stop: "Here your legs end," because Larissa does not understand the boundaries of her body.

Very slowly turn her on another side, and just as slowly and smoothly raise her so that Larissa can understand how the position of her body changes. You put her on your knees. — Larissa is sitting. Touch: here I am. And it's you. This is Larissa. Touch your legs. Larissa's hands are tense, palms are compressed, and it takes her some time to relax a bit and stroke her legs with your help.

Then you let her touch her pants - for a person who can not take anything and keep it in hands — this is a new and very important feeling. And finally, together with Larissa - hand in hand — we are pulling her pants. It is an experience that she can not get on her own, because she does not yet know how to use her hands. "You put on your pants." What a fine girl you are! You did it!

*Maria Berkovich,
"Non-scary World"*

If you know or suspect that your care recipient can see something (distinguishes between light and shadow, sees the contours of objects):

- Offer objects of contrasting colors. For example, in black and white stripes;
- Use bright toys. Many children with visual disorders can see iridescent objects, for example, jars covered with colored foil, fir-tree tinsel, etc.;
- The place where you play or practice should be well-lit.;
- Sometimes it is good to practice in a dark room: play with flashlights, candles, Christmas garlands;
- It is better not to use flashing glowing toys - they can provoke an epileptic seizure.
- If it is a blind child or an adult with very serious disabilities, then in dealing with him you need to be extra-careful.

Hospitalism



Hospitalism, or hospital syndrome (from the Latin hospitalis - hospitable, hospital - medical institution) - the set of mental and physical (bodily) disorders caused by a prolonged stay of a person in a hospital in isolation from close people and home. The concept was introduced by the Austrian psychoanalyst R. Spits in 1945, who investigated its causes, signs and consequences among infants and children who stayed in hospitals for a long time.

R. Spits referred to such symptoms as a slowdown in mental and physical development, a lag in mastering one's own body and language, a lower level of adaptation to the environment, a weaker resistance to infections, etc. Even children from institutions that were later adopted and grew up in families, often demonstrated the signs of the hospital syndrome for a very long time (for example, rocking, shaking your head when falling asleep, weakened immunity, etc.).

In our work we often deal with various signs of hospitalism. Speaking in simple terms, all of this are ways that help our children and young adults to gain experience, impressions, fill in their time in conditions when practically no other methods are possible.

What could it be?

- Stereotyped movements (rocking, movement of the fingers in front of the eyes)
- Stereotyped actions with objects (twist the ball, hold the lace, lick the rubber toy, tap with the construction kit cubes)
- Interaction with your own body (autoaggression, vomiting, scratching or itching)

*Maria Berkovich,
"Non-scary World"*



Out of emptiness and silence, he pulled out this diaper and found that if you chew it, the world of sensations becomes a little less monotonous. This is his own precious discovery, comparable — if you look for an analogue in our world — with the discovery of a wheel, fire and the theory of relativity and even more important, because without the wheel, fire and Einstein people somehow lived, but he cannot live without a diaper, without senses.

And we just want to take it away, even if we offer all the treasures of the world in return. Are they real treasures? For him it doesn't mean anything.

Marianne:

"You need to put a blanket slightly higher to enlarge the view. The diaper can be hung on the back of the bed so that Danya turns his head and looks for it. You can sew him two colorful diaper-clothes — to distinguish colors, or two cloths from different material - for new tactile sensations - and so on — the main thing, to make "a bridge" from the diaper into our world.

Maybe it will take six months before he pays attention to something else, maybe a year, maybe even more. It is very important that we are genuinely interested in his game. Only then he will get in touch with us. Then he will begin to believe in life again. Then he can open the world of other people and things. "

*Maria Berkovich,
"Non-scary World"*

All these things are very difficult to handle. Often they simply interfere with the work and often cause visible harm to the care recipient (as in the case of autoaggression, for example).

As a rule, to change them, to force a person to refuse them is very difficult, almost impossible. What to do? You must remember that all these actions are very important for a person, almost vital. He chose this way of supporting himself, he is very used to it, it is part of his life. If you try to influence it, then you need to do it carefully and accurately, trying not to cause extra stress for him. Try not to hurry. Suggest something else — maybe he will not accept your suggestion — but at least the option of choice will appear, before it was not so. And if he puts aside his rope at least for a couple of minutes and switches his attention to something else, it will be the fact of a great achievement — yours and his.

At one of the seminars for volunteers, we offered to choose

one of the stereotypes of their care recipients and ... try to do it yourself for a while (for example, to commit the same stereotyped movement). Try to understand what happens in this case.

One girl after such an exercise said: "I had a feeling that I just can not stop, that I have to perform and make this movement, that there is nothing else in the world except this ..."

Autism

It has been well said that Autism is one of the most enigmatic development disorders.

Starting to work with an autistic person, we ask ourselves a lot of questions: why does not he want to communicate with us? Or wants to, but does not know how? Does he understand what we say to him? What do his strange movements mean? How to break into his closed world and whether it is necessary to break through? And above all, what is autism?

A person with autism:

- Has difficulties in communicating and establishing contact.
- Does not like to look into one's eyes (although there are exceptions).
- Is afraid of anything new: changes in the environment, his day schedule, the usual route, etc.
- Is often obsessed with monotonous action (wiggles, shakes hands, repeats the same sounds)
- Is attached to the same objects (for example, he never puts aside his ball, string, a detail of the building set)

Autistic people, as a rule, have speech disorders. Such as:

- Its complete absence
- Echolalia (immediate or delayed repetition of heard words or phrases: "Volunteer: Kiril, say" bye! "Kiril: Say" bye! "When a person speaks about himself in the second person: "You want some bread! You want to go for a walk!"

In the orphanage, we rarely can see autism in its pure form. The contact disorders of many of our care recipients are caused by other reasons. They appear due to severe developmental disorders, a lack of communication, and psychological trauma.

Many of our guys have some autistic features, which means that it is important for us to know some rules of communication with autistic people.

When communicating to an autistic person, it is important to remember:

1. It's not true that the autistic person does not want to communicate. He just doesn't know how to communicate by our rules.
2. Very often autistic people understand and know much more than we think. Do not hurry. Watch.
3. An autistic person, as a rule, aspires to the constancy of the surrounding world and is afraid of anything new. This means that autistic people hardly take any changes. It is important to them that everything happens in the same way: place at the table, bed, room, etc. does not change. They accept changes with difficulty, it may make them nervous. If changes are inevitable, it is important to warn a person about it, to be with him and support him.
4. Many autistic people do not like noisy companies and gatherings (although there are exceptions, especially in the conditions of a boarding school). Try, whenever possible, to find time for dialogue one on one.
5. It is easier to teach an autistic person something new if it happens regularly and in the same way.
6. Autistic people can quickly get fed up with communication, even if it gives them pleasure and joy. A sign of satiety can be:
 - the intensification of compulsive (stereotyped) actions,
 - loud laughter,
 - aggression,
 - the desire to stop communicating, to leave the room.

An autistic person should be given a break from communication
7. Autistic people perceive visual information better. In communication with them, it is useful to use pictures, drawings and schedules.
8. Some autistic people may avoid physical contact.
9. If an autistic person has a "talisman" — an object that he does not part with (a rope, a lid from a bottle, a cube, etc.), do not try to take it away. Subjects-talismans soothe the autistic person, and give stability to the surrounding world. Sometimes it is very interesting to observe the manipulations of an autistic person, for example, with a string, and reflect on what it means to him and why he twists it with these specific movements.

Epilepsy



Many people with multiple developmental disorders suffer from epilepsy.

Epilepsy is a disorder of the brain function, occurring as sudden, recurring attacks.

Attacks occur when the electrical activity of a group of brain cells (neurons) or the entire brain suddenly increases.

Medical personnel (sisters, doctors, nurses) usually know whom of the patients suffer from epilepsy. It is important that you also know about it.

Some children suffering from epilepsy have regular epileptic seizures, some – very rare ones. The duration of attacks may also differ.

The most vivid signs of an epileptic attack are convulsions and loss of consciousness.

It is important to know:

Sometimes we come across this point of view: "This child (adult) has epilepsy, so it is better not to touch him, or take to the classes, or take for a walk. Then he will have fewer attacks".

As a rule, this is not so.

On the contrary, studies have shown that physical activity is not only not harmful, but even helpful to a person with epilepsy.

Only certain things that can provoke an attack are harmful. Walking, playing games, movement is not harmful to a person with epilepsy.

Of course, it is important that all of this doesn't become too exhausting or over-stimulating for the care recipient. Excessive work is not useful to anyone.



What to do if a person has an epileptic seizure:

What can provoke an attack?

- Lasting sleep deprivation. If, for some reason, a person suffering from epilepsy does not sleep at night, this can lead to an attack.
- Exhaustion. Especially if a care recipient is weak. Make sure that classes or communication is not too intense.
- Irregular taking of antiepileptic drugs.
- Stress. Try to ensure that in your communication with the care recipient there are fewer sharp movements, sudden sounds, etc.
- A certain music, based on a heavy rhythm.
- Pungent smells (spirits, some spices)
- Flashing light. (Disco, flashing glowing toys)

An epileptic seizure doesn't always have an obvious reason. Some people have a certain periodicity of the seizures. It's caused by a person's brain, it's electrical activity.

- *First, do not panic.*
- *Call the nurse or ask someone to call her (do not leave a person during an attack alone). What to do if you have to wait for a nurse for a while: put the person on his side so that he does not choke by his tongue or bite it.*
- *Put something soft and flat under his head (best of all - a pillow, or you can roll a sweater or a jacket)*
- *Remove any objects that a person may hit with his head.*
- *Do not put any objects in the mouth (spatula, spoon, etc.), and do not attempt to unclench the person's jaw.*
- *Do not fill the mouth with any liquid until your care recipient fully regains consciousness.*
- *It is not recommended to hold a person while he has an epileptic seizure.*
- *Record the time when the seizure started to measure its' duration. Then report this information to the nurse.*
- *If the seizure lasts for more than 5 minutes, medical attention is needed.*

Tips on working with care recipients

Common tips

Our care recipients have a need for contact and support. What is it? It is quite simple: make eye contact, take them in your arms (if it's a child) or take their hand (if it's an adult), call them by their names, talk to them. It is essential to support their desire to live and grow. Touches and tactile contact are very important for them. This is the kind of experience, which is available even to people with the most serious disorders.

However, there are some very weak care recipients with hypersensitivity. It is essential to touch them very carefully in order not to cause pain or discomfort.

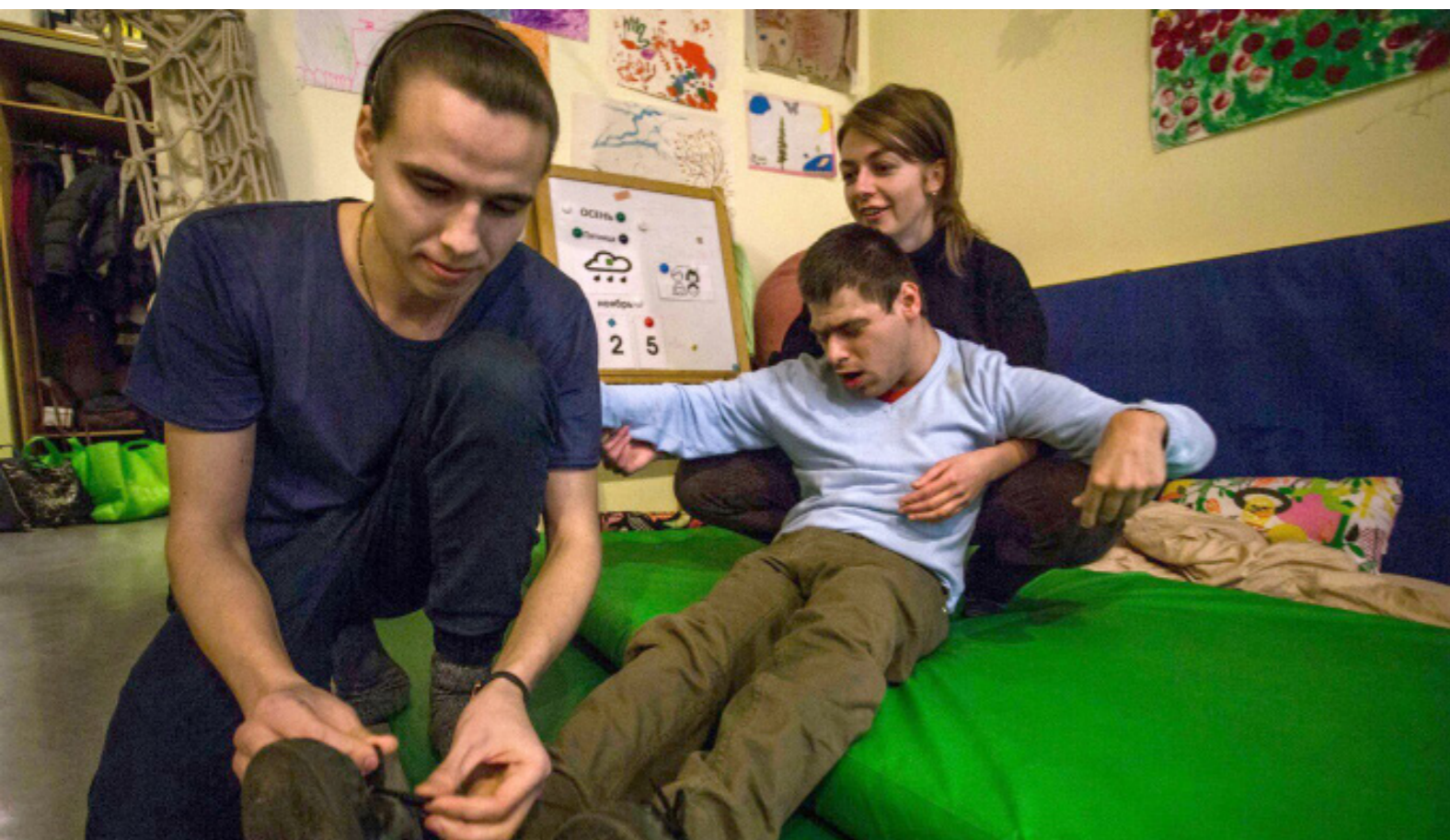
Treatment of care recipients is not only a hygiene maintaining but also a communication, a contact, a motivation for action, a gentle perception and attention. There is some need behind each action of our care recipient. They all make sense, though we cannot immediately understand it (strange movements, odd sounds, scream, refuse to eat or play, etc.) The development of self-perception is the main task of any assistance. Due to our work, our care recipients become more aware of themselves, find out that they

can influence the environment, and that they are important and valuable.

If you come once a week...

Every day from Monday to Friday, the children study, work and master important skills and knowledge with the help of specialists. Imagine how nice it is to have a rest on weekends — to do what you like, to walk outside and just play the fool, especially if there is a friend nearby. A weekend volunteer can become such a friend.

Volunteers visit children on Saturdays and Sundays, help to organize their free time, give them warmth, communication and new experiences such as walks in the fresh air (it is incredibly important for children because they can't walk by themselves), games, drawing, crafts made of paper and simple materials, singing and playing musical instruments, reading books, tea-drinking, board games, theatrical performances and bus trips. At the weekends, volunteers often escort



"...Both times I worked with boys. I wanted to become their friend and their gentle support for the day. As a result, they taught and disclosed me. We had to make our way through the wall of their illness and my inexperience. Time helped us. Moreover, something humane in our souls responded and strove to each other. I believe in that. In 30 minutes, I already did not look at the child as at a severely disabled person, but I saw the grey eyes, pointed nose, I was caressing the tender hands, a thin neck with a transparent baby fluff, followed the gaze and sang along with his mumbling. The child tightly grabbed my fingers, pressed, pulled, tried the fabric of the jacket, zipper, removed my bracelet and was studying me. For the sake of this contact, I arrived there. Today I was able to swing the boy on two swings. He finally got distracted, stopped biting his hands in the napkin, he was holding on the railings, stroking the wheel, shaking his head, his face relaxed and he smiled a few times. After that I told him about Pushkin, I said that he had known how to notice and find beauty. There was also a lot of beauty today"

*Marina Krivonosova,
Sunday volunteer*

care recipients to the city for excursions, exhibitions and other events.

Where to start?

Try to find a contact with care recipients, tell them about yourself — what your name is, where you are from, probably you have mutual interests. Probably you are an artist at heart; try to draw together or to listen to a favorite music.

Our care recipients have an amazing inner world, and if you try to look into it with them, it can be a wonderful time of friendship and mutual understanding for both of you.



The main rules for the weekend volunteers:

- Do not leave a care recipient alone;
- Do not feed and give drinks to care recipients: some of them may have an allergy and have a special diet;
- The employees of the institution where care recipients live wash them and change their clothes. Weekend volunteers don't do this;
- It is allowed to go for a walk, spend time with care recipients only if children are healthy, and feel good. That is why it is obligatory to coordinate our work with medical staff;
- It is prohibited to share photos and personal information of the children in public sources and on the Internet unless their parents or guardians allow it.

Treatment

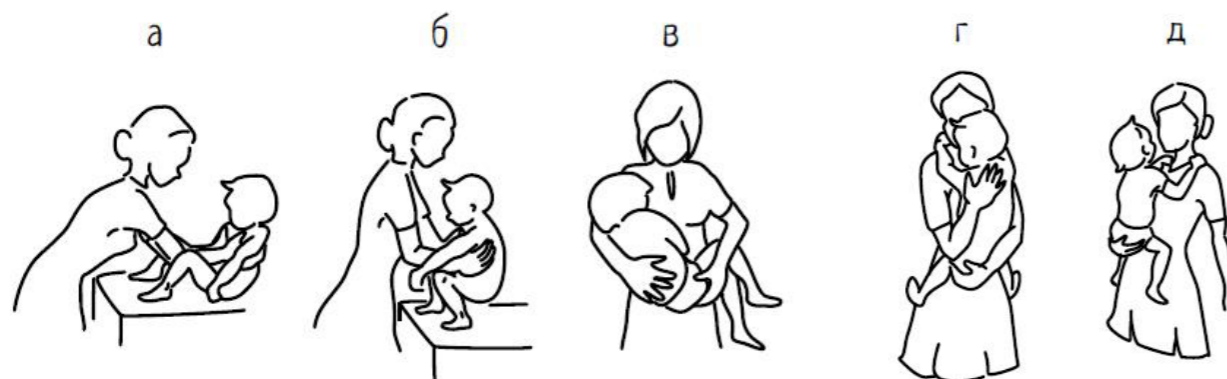
Displacing

Moving and displacing

People with cerebral palsy are very restricted in their moves, they are often must be carried. It's important to pay attention to how a kid or an adult should be lifted. Before lifting care recipient lying on the back, is't necessary to:

- Bend the head and the body forward and also bend the hips;
- Put your arms under his armpits and embrace his body with your hands;
- A bending and lifting a kid can also be done from the position 'lying on the side'.

See pictures a, б, в



Moving

- To turn towards yourself with bending the legs, lean on the hip, to hold the head and the body if necessary;
- To carry a care recipient in front of yourself pressing his back to you, the legs are bent.

See pictures г, д

When displacing a care recipient, it's necessary:

- To prepare a workplace in advance (diapers, clothes, wheelchair etc)
- To be predictable for a kid
- To spell out everything you do
- Not to help out more than what a kid cannot do himself
- To comply with a care recipient's pace

- To teach a care recipient to act independently

Teaching while displacing:

When teaching movement skills, we have 3 tasks:

1. A posture retention (lying, sitting, standing)
2. Changing from one posture to another
3. Moving from one point to another

A pace

- The right pace allows a care recipient to analyze a movement;
- Everybody has his own pace, people with disorders have a slower pace, so we must follow a care recipient's pace;
- The rapid movements don't allow a care recipient

to realize how he changed the position, so he won't be able to do it by himself;

- The rapid movement increases the risk of traumatization.



Laying/positioning

Laying/positioning is putting a care recipient in the sitting position (in a wheelchair or armchair) or lying position (on side, on front, on back). The position must be set up taking into account the biomechanics of the care recipient's body. It's especially important for those who spend most of time in a passive or fixed (forced) position. Therefore, before you begin putting a kid in the required position, make sure you have enough pillows and rollers of the various thickness, size and softness. You also can use a rolled-up blanket, towel, pillows, scarf, diaper, even clothes for arranging a laying.

For what positioning is required:

- For the optimal body and limbs posture for keeping the normal breathing;
- For contracture prevention;
- For vitals disorders prevention;
- For pressure sores prevention;
- A comfortable posture contributes to a better involvement of the care recipient into the learning process;
- For forming a right idea of a body design, center of gravity and intermediate axle position;
- For a muscle tone and pain relief;
- For the prevention of the development of pathological fixings in limbs and body.

A physical therapist or an adaptive physical education specialist will help you and tell you what kind of laying is needed by your care recipient, how often and for how long.

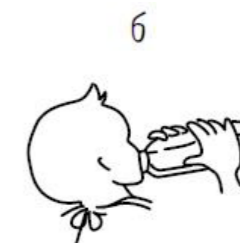
Position while feeding

Ability to eat is one of the first competencies that a person gains. A kid still cannot turn over and sit, but the nature provided him with an ability to get an adequate food and with the required reflexes.

As a kid grows older, he develops his skills, appearance of the teeth triggers the chewing ability.



One-year old child can hold a bottle and drink, hold a spoon and eat with it. By 2 years old, a kid can eat and drink as an adult.



Many of our care recipients cannot eat by themselves just because there was nobody empathetic and patient beside who could help them. Many people with developmental disorders can participate in the

feeding process in some degree: by sending a spoon into the mouth hand-in-hand with the supervisor or by taking a food from the spoon by the upper lip. Any activity helps a person to control what's happening to him which is very important for his self-evaluation.

The amount of food is not the only indicator of a normal nutrition. Not only a flavor and a quality of the food is important, but also an atmosphere, rituals and traditions related to the process of eating.

The process of eating has a special meaning to the kids and adults living in the various social institutions. For the weakest kids, eating can be the only one time benchmark: there is no guarantee that you will be taken to the classes or to the walk, but you definitely will be fed.

For some people the eating time is the only opportunity to interact with another person.

1. Posture

While eating, a care recipient's position should be as upright and stable as possible, aligned with the midline.

A physical therapist can help you to find an optimal posture, taking into account a care recipient's motor disorders. In any case, it's necessary to control and fix the body position if a person cannot control his posture himself.

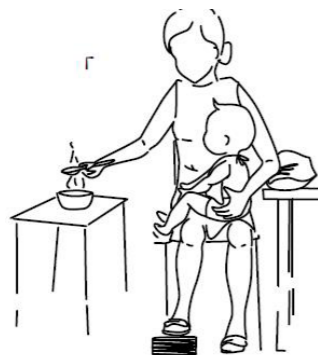
Any additional moves by legs, arms, head, a body leveling require a considerable efforts and distract a kid from eating. It's quite difficult to eat when swinging on a swing. It's nearly the same feeling as constantly sliding from the chair.

A care recipient's position while eating:

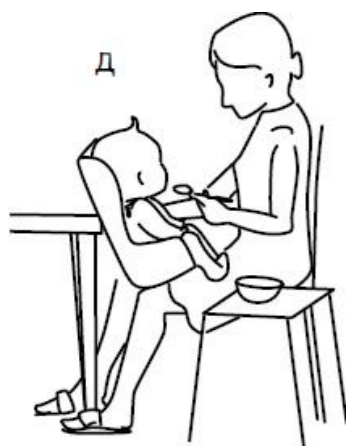
- A pelvis is kept to the back of the chair, wheel chair or armchair as much as possible;
- Feet are on the floor or on the step;



- A care recipient's body should not be too much bent forward, lean backwards or aside. It's normal if a person slightly leans forward when eating — it's a comfortable position for swallowing and using a spoon;
- Elbows are on the table or any other support, they are not just hanging down to the sides;
- A head is slightly leant forward, and in no case leant backwards because it complicates the swallowing. Try to lean your head backwards and swallow your saliva. The most of people have difficulty to swallow in such position. If a care recipient's head is leant backwards, it increases a risk of choking on.



The supervisor's position should also be comfortable and stable. His tension and fatigue is instantly transferred to the care recipient who immediately becomes anxious and nervous. The best supervisor's position is sitting (not standing) on the side of a care recipient, especially if he (care recipient) is learning to hold a spoon.



2. Food

A food definitely must be tasty. And convenient. For those who have difficulties with swallowing and people with a low sensitivity level, a food temperature should be a bit warmer or a bit cooler than a room temperature, so that a person can feel that something came to his mouth and focus on the further actions.

It's important to make sure that the food is homogeneous. The most convenient for swallowing food consistency is a kid's puree because it can be felt in the mouth and it doesn't expand like water. Lumps in the porridge, pieces of fruits in yogurt or a very fluid soup are especially

difficult for swallowing because it's necessary to firstly separate a liquid from the hard pieces, swallow the liquid, than put a piece on the side teeth, puree the pieces, swallow puree. It's a complicated process that requires a good coordination of cheeks, lips, tongue and teeth. So, if a person has difficulties with swallowing, a food must be homogeneous. Soup can be divided into two parts and suggested separately: to drink a broth and eat the pureed vegetables. Or to prepare a dense soup-puree.

3. Spoon

A spoon must completely fit inside a mouth. If a person often bites a spoon, it's better to choose a plastic one in order not to damage his teeth. For people with the reduced sensitivity the metal spoon is more suitable as a metal passes the food temperature quicker and it's better felt in the mouth.

If it's difficult for a care recipient to hold a spoon with a thin handle, it's necessary to somehow thicken a handle: with a sticky tape, a piece of hose, hair curler, plastic, special cap for a handle...



4. Feeding pace

A spoon should be brought into the mouth only when the previous part of food is swallowed. For example, it takes 3 small sips to swallow one spoon of a yogurt. The first — to swallow a saliva and the first part of a yogurt, the second — to swallow the main part of a yogurt, then to gather the rest of a yogurt in the mouth and swallow it.

If a person doesn't have enough time for swallowing, he could choke on the food accumulated in the mouth. If you are not sure that a care recipient has swallowed all the food, you could give him an empty spoon, so he would swallow the rest of what he has in the mouth.

The feeding process may become a mutually pleasant interaction, or a real torture for one or both parties. If a supervisor respects the preferences of the care recipient, gives him an opportunity to be as autonomous as possible, gives him enough time to enjoy the taste of food, swallow it without rush, it demonstrates that a supervisor takes care of the care recipient, respects his personality.

Movement

There is a permanent movement happening inside and outside a person. Movement is life, so if a person can't move by himself or he is not taught yet, our goal is to help him. Our care recipient must understand the boundaries and scheme of his body, his position in space. In order to get result, it's necessary to adhere to the main rules of movement when working with kids and adults. Those are the rules of positioning, pace, autonomy and learning the movement in the daily activities.

A person has difficulties with the sensory integration (combining the experience got from his body and the information received from the various perception channels). So, for the development of the body perception separately from the external world, the irritation of vestibular system is required (it's a center responsible for the balance control, it's located in the inner ear).

Our care recipients need help in development of their bodily and motor perceptions. The combination of such actions is called a basal stimulation. It means we try to influence the most basic, core senses, that are available to even the weakest person. For example, you could swing a kid in your arms or in a hammock, turn his body (on the blanket or mat on the floor, for instance) or move his arms and legs. To let him feel the pace of some movement and then speed it up or slow down.



Transportation:

HOW TO DO IT RIGHT?

ALWAYS put the brakes on when you transport a person to the chair/wheelchair/verticalizer or take him out from the chair/wheelchair/verticalizer.

TELL a care recipient WHAT you are going to do.

DON'T put on a tight cloths, skirt, high heels or backless shoes.

HOLD a care recipient as close to yourself as possible.

KEEP SUSTAINABLE POSITION, put your feet widely.

DON'T FORGET to unfasten the fixing belts.

BEND THE HIPS AND KNEES!

KEEP THE BACK STRAIGHT!

DON'T BEND OVER!

DON'T BEND A SPINE!

Non-verbal communication or how to speak to non-speaking

Many of our children have a problem with speaking. Some of them cannot speak well, some of them can't speak at all. Moreover, some of them cannot hear or have a problem with an understanding of the speech. Some kids can understand the speech, but cannot speak due to the severe motor disorders.

Is it possible to talk to non-speaking person? Yes, it is, if you use a non-verbal communication when talking to him.

Communication is an information exchange. In broader terms, communication is an interaction. Non-verbal communication is an interaction without using any words but using some objects, pictures, symbols, photos, gestures. Even more than that. The weaker a kid is, the more sophisticated things we use when communicating to him.

When a kid is sitting on your knees and you are trying to catch his breathing rhythm and breath in his rhythm — it's a communication. When we repeat the kid's or adult's stereotypical motions (for example, a swinging)

— it's also a communication, or, more precisely, an attempt of communication. If our kid is distracted at least for a second and looks at you — it means your attempt was successful.

You also can speak by your eyes. And by touch. To laugh together. To solve something interesting together. All of this is a communication. A conversation. An exchange of something very personal and important. Something that connects people to each other. In a splendid book 'Care and treatment' the authors say that a non-speaking person should absolutely be asked about his feelings, interests and desires.

We can show a cup to the kid and ask him: "Do you want to drink"? He cannot say 'yes' or 'no' but he can express his will by gesture, by glance, by opening his mouth or by turning away. Then we should vocalize "you want to drink" or 'you don't want to drink'.

When we offer some choice to the kid or adult (between two toys, two t-shirts, sweets, activities) — it's also a communication. Making his choice, he says 'I like this red t-shirt more', 'I want to play with a ball now more than to draw'.



All of these are the simple and deep ways of communication. But there are some additional ways which can also be of use.

Photos

You can say a lot with photos and also you can find out a lot about person. We make photo-albums for some kids where we collect the photos of their favorite objects and important people. For example, in Zhenya's photo-album he has some pictures of the bus (his favorite toy), some volunteers and teachers whom he knows well, his roommates, some familiar things — the recorder, the wheelchair, even a diaper. Zhenya cannot speak well, but he becomes lively when looking at an object or a person in his album and tries to comment on them — 'mu-sic' (the recorder), 'a-alya' (Valya).

Tanya also has her photo-album. It tells Tanya's story with the pictures. There are the pictures of the things she likes, the places she has been to, her favorite nurse. Tanya can hardly speak and she cannot tell her story herself. She likes to listen to the comments to her pictures. 'This is Tanya. Tanya likes to listen to the music. She has a recorder and tapes'. 'The last summer Tanya was in the camp'. 'She visited a church with the other children'.

Photo-albums or albums with the pictures can help in communicating with people who can understand but cannot speak due to the severe spasticity caused by cerebral palsy, for instance. For example, Vika often asks for 'saying hello' to some of the teacher by the hand gesture. In order to understand whom she means, you must stay beside her and list all the teachers' names. Vika understands a lot and wants to talk about many things, but due to the spasticity she can't speak.

Vika's room curator once came up with an idea to make a photo-album with the pictures of the teachers, volunteers, the places which Vika visits, the seasons, the various events. Now, when Vika wants to say hello to someone, she just need to find that person in the photo-album and point it out.

Plans and schedules

Some kids and adults are very sensitive to the predictability of the events. They need to know what and where will happen to them. Some kids cry and

brawl just because they don't understand why you took them to the play-room yesterday but don't do it today and what is the logic of all that.

We say:

'I can't take you, today is other kids' turn'

'I will take you tomorrow'

'Ceramics is not today, it's on Wednesday'



Today, tomorrow, on Wednesday — for the most of the kids it's too abstract. How can we make their life more predictable? A kid demands all the time to be taken to the playroom and starts crying if he is not taken. In the morning of the day when you plan to take him, give him the same toy.

For instance, some bright rattle. It becomes a symbol of the playroom. In some time (and it can take quite long) the kid will understand 'she's brought this toy, it means we will go to the playroom'.

The kid wants to go to the class, and you vainly tries to explain him that the ceramics class (or the theatre class, or gym) happens tomorrow. Make a schedule: put his teacher's photo on the day when he runs a class. 'Today is Monday. You have no classes. Tomorrow is Tuesday. You will have a class with Lena'.

We've described only some ways of the non-verbal communication. Actually, there are much more of them. All of them give us an opportunity to communicate to those who have speech disorders and to be understood by them.

The important thing to remember is that the verbal speech is not the only one way to communicate.

What to play or Games on everything

Playing is as vital for a kid as breathing. A kid learns to play by interacting with other kids or with adults. He starts a dialogue with the world — by watching, imitating, trying things out. He listens to the sounds, tries to reach the objects, puts them in the mouth, shakes, pushes. It's a game and a serious work at the same time: it's how the kid gets to know the world, other people and himself.



The restricted movements, intellectual disorders, eyes-sight or hearing problems, limited tactile feeling — all of this prevent a kid from investigating the world freely. A kid spending the most of his life laying in the bed or playpen cannot normally communicate with other people and investigate the objects. The playpen walls are covered by the white cloth. There is nobody around. There is a white ceiling above...

*Ruben David Gonzalez Gallego
'White on the black'*



'What does he love? He loves everything! I'm taking him to my arms. So we are sitting: you are in my arms, shaking your head, sometimes we look at the window. The rain is knocking to the roof but we can't hear it – double-glazed unit. The car, the song about pony – nothing is working. The pool with the balls seemed to even scare you. I'm gently cradling you, you are rumpling the pink clown's wig in your hands. Somewhere in the distance Marina is singing a song about a spruce, I quietly join her — just for you: 'so it came to our celebration so fine...' It seems to me that nothing is working. 'Tell me how to play with you.'

*Varya,
Sunday volunteer*

There is a wrong opinion that the people with the severe disorders don't react to anything, don't care how their room looks like, don't need any toys, not interested in the learning anything new...

But the truth is that the more severe their disability is the more a person needs a bright, stimulating environment, new impressions and sensations. But, of course, the possibilities and interests of the specific individual should be taken into account.

We call the kids with the most severe disorders 'weak'. They are very slow, they need much time to perceive something new. They need a slow, careful way of learning.



Don't overload such a kid with the new stuff. It would be better for him to study one thing carefully and deeply.

*Tsita Keller, speech therapist,
feeding therapist,
physical therapist
(Switzerland)*

We play one kind of games with the 'weak' kids, and other games with the 'active' ones. There are many games. You cannot tell what will be more appropriate for this kid, before you try. But there are some games which are important for everyone (at least, for the majority of the kids). Those are the games that appeal to the individual's deepest interests and needs.

1. Me and you

In order to start investigating the world, a kid must separate himself from the environment and to understand that there is him and there is the rest of the world.

It's vital for a kid to understand that he has his own body. 'These are your legs. These are your arms. This is your head'. Help a kid to touch his legs, his belly, his head, let him stroke one hand by another. Many kids with cerebral palsy don't have such an experience due to motion restrictions. Kids with Down syndrome are

often concentrated on their arms – suck them, move their fingers in front of their eyes... Draw their attention to the other parts of the body.

To realize 'yourself'. To relate yourself with your name, your body and your reflection in the mirror. 'It's a mirror. Look — it's you over there. You are Sasha. Touch yourself. It's you.'

There are a lot of the funny games which help a kid to investigate himself, his body. 'Birds are flying, flying and land on your head...', 'A magpie was cooking a porridge...'

2. Four elements

Fire, water, soil and air — those are 4 ancient elements which are the base of the world. There is something very deep and original in the interest to the fire, water, soil and sand.

Probably, that is why kids like playing with the water so much. To pour, to wet their hands, play ships, splash, make a foam... To look at the fire. At the candle, sparkler, lantern. You can get together around the warm lamp or burning candle, sing the songs, tell the stories or just keep silence together. Play with a sand or other loose stuff: peas, beans, spaghetti. To make noise, throw it, sink your hands and legs in it... Watch flying objects. Bubbles and kites, multicolored 'parachutes' made of fabric, balloons and a thin plastics bag flying with a wind.

3. Painting, music, speech

There is nothing accidental in the childhood. Everything a kid likes is a reflection of something very deep and important.

Painting.

Millions of years ago a man slid one stone by another stone. He noticed a trace — it's how the painting started. By painting, a kid can realize that he can make a trace, so he can change something in the world. It's a very important experience. He can draw with a brush, with a finger or with a whole hand, with a leg on the sand, with a foam on a mirror. It's just important that there is a visible trace.



Music.

Almost everybody reacts to the music. Probably, still nobody knows what is the music's influence to the people. But we know that it's calming and healing. The moment when we are holding a kid in our hands and singing to him is a moment of trust and togetherness. You can play the children's songs or serious classic music to the kids, play the music instruments for them, arrange some improvised orchestras — there are so many opportunities.



Speech.

Many of our kids cannot speak. But we know that it's still very important to talk to them, tell them what's happening around, read poetry and sing.

We often play the funny games with our kids when the words are accompanied with the moves. 'By bumps, by bumps, by narrow path, boom to the pit!' Such games are very important to the kids — they teach them to better understand the speech.

Those are just a few examples. The world of games is endless. Invent your own games, try, experiment and feel a joy of discovery, because

An adult soulfully living with a kid has a gift of returning time.

*Tatiana Babushkina '
Clock struck twelve'*

Free time organization or what to do with an adult care recipient?

When all care and treatment is done, it's time to arrange something interesting with your group or a specific individual. It would be great if it's also interesting to you — our care recipients are very sensitive to your mood and the atmosphere which you create.

What can you do on a free time?

- To walk;
- To read out loud (not necessarily something for kids — even if a listener can't understand every word you read, your voice, its timbre, rhythm create your common space and this process will please both of you);
- To watch photo-albums, books with big multicolor illustrations, to speak on what you can see in them;
- To sort through and touch the balls of various textures, or fabrics, or other stuff, to shift them from one container to another, to try to sort them and put in separate piles;
- To put on hats, gloves, necklace, bracelet, bands.. All this beauty could be photographed and you can watch this album together later on. Look at how this activity will transform your care recipient!
- To dance to the calm beautiful music or just listen to it together;
- To play the music instruments: to repeat each other's rhythm on the drums, tambourines, to touch the guitar or psaltery strings, to play the guitar or flute; if you can, singing is also a very good activity;
- To draw, to paint, to make collages of the magazine's illustrations or photos (collages of the seasons, collages of the room-mates pictures, collages of the favorite activities like summer camping or tea party);
- To visit the neighbor room.

Act on the kids' interests and capabilities, on what they are good at. At the same time, sometimes it would be good to offer something absolutely new.



A bit about the walks

During the walk, you can do almost all the same things as in the usual spare time plus some special activities. It's great if you can make the walking time a special experience for the kid — meaningful and eventful, which he will remember for a long time and feel good about it.

What can you do?

- To be in contact with the care recipient, talk to him, read him a poetry or sing songs (if you do it not in Russian, it's not that important, a kid feels that you address it to him). It's especially important if it's a weak care recipient. You can talk about what's happening around, what's changing, about the season.
- To give new impressions. To let him touch a tree trunk, the leaves. Help him to stand barefoot on the grass or sand in the summer, to smell flowers. Watch together a snail or a big beetle, a tiny piece of ice or a snowball.
- To play: blow bubbles, inflate balloons, fly a kite, play snowballs, make a snowman. Draw on the asphalt with a chalk.

A walk is often a big problem. Our care recipients spend a little time outside, so we want to take to a walk as many kids as possible, so we become exhausted... we simply don't have enough energy for the games, for other useful activities... But even if you just have it as an idea in your head, even if you do it only from time to time — that would be very important.



Holiday

On the darkest time of the year, we arrange a Light Holiday in the school. Why so? Because in the midst of the winter, when it's still a long time before a New Year, but we are already fed up with a snow and cold, one wants some warm magic, something simple and old. And eternal. A beauty which will never wear out.



What do we need for a Light Holiday?

We need some candles – it would be great to make them by yourselves. So, you already can light a candle and look at it... A winter is a white time of the year. A snow is also a light, but of the different kind. A snow is also a part of our party. A snow and an ice. One can touch a snow. One can see it so close for the first time. One can see an ice and hold it - wow, an icicle can be really huge! It looks like an icy sword... You can also make a winter house of a snow and ice. But it's warm and light inside. Or you can launch small ships with the lights on the mast... Or maybe these are the islands with the beacons?

*Valentina Guseva,
psychologist, 2010*

We need celebrations. It's difficult to imagine our life without them. We even don't want to imagine that. Holidays improve our life, save us from the routine, help to fight a longing and fatigue. We need holidays so much that it's even hard to say who needs them most — our care recipients or ourselves... Probably, equally.



We celebrate all the holidays we can: New Year, Christmas, Easter, Autumn Holiday, Summer Holiday, Light Holiday. You can feel a holiday not only with the senses (a vinegar smell of Easter, New Year sparklers), but with something deeper. With our soul. That's why holidays are healing.

Maria Berkovich, 'Non-scary world'

Tatiana Babushkina wrote about the holiday language which appeals to all senses. A holiday has a smell (a tangerine smell of the New Year). It's a special food, not the usual one which kids have every day. We gather around the tasty food, the warm hearth. A holiday has its' sounds: songs, laugh. It's also a light: candles, sparklers, New Year garlands.

You can use a holiday language to talk to each other about something that is really important: about joy, togetherness, soul... A holiday brings joy and gives us a courage to further deal with the day-to-day routine. At the same time, it marks the time flow — the time is not just the same flow of events, it becomes rhythmical.



There is something deeply human in a holiday. All the most beautiful things are used here: songs, various music instruments, dance, room decoration, special clothes, flowers, scents, food... As all the creation sings a song of joy and unity.

Jean Vanier 'Each person is a sacred story'



Holidays are not just a New Year and a Birthday. Each day can become a holiday. An important characteristic of a holiday is that it can emerge from nothing. The need for joy is a sufficient reason for a holiday. In the end of the winter, we had a Holiday of Baked Apples. The kids gather together and we were cutting out apple cores, fill apples with the honey, walnuts and cinnamon. It was a real holiday of smell and flavor. Holiday time saturation equals weeks, and the inner transformation which can happen in the child's soul equals years.

Tatiana Babushkina 'Clock struck twelve'

Let's add: not only in the child's one.



A holiday helps them to discover the joy of common life. A holiday helps us to say them: 'We are glad that you exist. The way you are.'

Jean Vanier 'Each person is a sacred story'

You can close your eyes and imagine the holidays that could be arranged...

- A holiday of balloons...
- A holiday of drawing on asphalt...
- An ice-cream holiday...
- A holiday of traveling musicians (travel from room to room and sing songs)
- A paper ships holiday...
- A holiday of Word (poetry evening, fairy-tale reading or story-telling)



Difficult cases

Aggressive behavior

The concept of aggression and auto-aggression:

When working with adult care recipients, you may encounter the cases of aggressive or auto-aggressive behavior. Such symptoms can be caused by life in closed institutions, the inability to be alone, the lack of love and warmth, as well as the mental disorders of the person himself.

Auto-aggression (auto- + lat. aggressio attack, assault) is a deliberate (conscious or unconscious) activity aimed at causing harm to yourself in the physical and mental spheres. It refers to the psychological defense mechanism.

Auto-aggression may occur as a self-blame, self-abasement, causing bodily injuries of various severity level. (Agazade N.V. Auto-aggressive phenomena in the clinic of mental illnesses. — M.: Science, 1989. — 189 p.)

Aggression — any form of human behavior, being of a destructive nature and aimed to bringing harm to people or cause them psychological discomfort.

Broadly speaking aggressive feelings to any extent are present in most people's mind. They are caused by many reasons:

- impairment of the most important needs of the individual;
- inability to realize one's interests;
- continuous humiliation and oppression;
- unresolved moral problems leading to envy and vengefulness.



... a person cannot cope with either external or internal psychological difficulties, can not let his feelings out in a socially acceptable form — anger is accumulated inside and there is a danger of explosion. Then the victim may not be the one with whom the problem is connected, which created tension and anger, but an unlucky scapegoat.

Myers D. "Social Psychology"



Some recommendations in case of aggression:

- staying calm and confident, demonstrating non-aggressive behavior;
- Switching a child's or adult's attention to something else, offering him some assignment («Let's do...», «Look...»), offering something tasty, describing his actions); For example: Tikhon G. did not want to come back to his room and began to beat himself, tear books, hit the wall, throwing everything that fall into his hands. We could not calm him down until a mother of one of the kids offered him a piece of bread, he ate it with pleasure, after that, his aggression diminished, attention was switched.
- focusing on actions (behavior), and not on personality (to speak in a calm tone about his action and (or) state of being: "you now beat/insult somebody"; « You feel bad now, resentful, scared...» !!!! But not «You are bad or angry»).

It is important to know:

- anger, aggression, auto-aggression are often the attempts to change the environment and are not aimed to hurt anybody, not aiming against someone in particular, but someone who happened to be nearby at the moment (for example, Julia K. has severe pain, she can not cope with it, so she cries at others, splashes out anger. Or Julia R. can not resist, for various reasons, humiliation and violence from the stronger roommates, therefore she expresses offense and anger by shouting,

insulting on those who are weaker, etc.);

- The expression of aggression may reflect a desire to attract somebody's attention and get what you want, manipulate (a child or an adult rushes to the floor, screams, cries, loudly insults others). Auto-aggression should be re-directed if possible (Dima K. strikes himself hard in the face, you can take away his hands, so that he could stroke his face or cover his face with his arms, then Dima strikes himself on the leg, which is less painful).
- The expression of aggression or auto-aggression of children and adults are different and individual:
- the desire to hit yourself or another person, screaming, anger, insults, etc.
- Information about the people we work with, their aggression or auto-aggression, how to behave, without harming ourselves or them, can be obtained in a special folder or in IPR (individual development plan in state orphanage), which is filled out by a volunteer who work with a specific child or adults. You can also ask questions to a specific specialist who knows the patient well.

What should we do with our anger?



... Sometimes Lucien was bored. No one could understand what exactly awakened this terrible feelings in him, but then he began to howl without a stop.

He shouted at the top of his voice that pierced me like a sword. <...> I could not stand it. It seemed that I was ready to kill Lucien, throw him out of the window.

I wanted to escape, but I could not do it ... I was confused, I felt ashamed and guilty.

*Jean Vanier
'Each person is a sacred story'*

Sometimes it's more difficult to cope with your own aggression than with the aggression of your care recipient. Own aggression is destroying us from within.

Where does our anger come from?

It can be a reaction to your care recipient's anger: aggression provokes aggression. Anger is our response to the feeling of powerlessness which we often have in our work. We get angry when we are very tired, when

confused and do not know what to do.



When I was a volunteer, there was a little blind girl Larisa in my group who ate very badly. During breakfast and lunch, I put her on my knees and tried to feed her.

Larissa choked, coughed and spit out food. This continued endlessly. One day, when Larissa once again spit out the porridge, I felt utterly helpless. The next moment, I had an attack of anger. I wanted to shock Larisa and scream: eat, eat, eat!

*Maria Berkovich,
teacher*

The first thing to do when the anger comes is to stop. Whatever you do. Stop. If possible, leave the room.

If not — take a deep breath, count to ten, or remember your favorite poem, or pray. Switch.

Try to understand what is happening to you. "I'm very angry. I am irritated"

It is very difficult to accept the fact that we can be angry at our care recipients. Sometimes we are just terrified of ourselves. After all, we believe that a good volunteer is a person gifted with unlimited patience and inexhaustible resources of kindness and acceptance. Thus we are tormented by guilt. "I'm a bad volunteer (or generally a bad person), since I can be so angry at the weak and defenseless person."

Anger is a normal and natural emotion Very few people are endowed with boundless patience. Anger is a normal reaction to the heavy things that we constantly face at work. The point is not to never get angry, but to learn how to handle your anger.

So, you breathed deeply and calmed down a little. Try to understand why you are so angry.

Maybe you're just very tired? Do not forget — the working day is finite. Even when time keeps dragging on, it passes very quickly.

Maybe you had too high expectations from the care recipient? Do I want the child to always control himself and think about my feelings?

Maybe you get angry because you do not know what to do? Maybe it makes sense to consult with other volunteers or with someone from the teachers? Maybe ...

The are many reasons for anger. At our work we often have very heavy feelings. It's important not to hide them, but to share with people you trust. Anger, aggression — it's very hard. But do not forget that "this can not destroy neither me nor you" (" Treatment and Care").

When care recipients pass away ...

We are not almighty. We try to give a lot to our care recipients — care, attention, new impressions, communication ... But nevertheless, sometimes people die. It is very difficult to deal with this. It's hard when the person you had a special connection with passes away. And it's hard when it was a person you had lots of difficulties and conflicts with or simply there was a feeling that you did not understand him well enough. It seems that death cuts off the opportunity to correct something, to really recognize someone.



"For me it was a pretty shock, because I liked Katia . I had a very close relationship with her, at least from my side. I still can not believe that she would never return to my group, and never smile to me from her bed. Working the last week was very hard to me, precisely because I miss her very much, Simply because it is very difficult for me to accept that everything will now continue without her. It must continue ..."

*Volunteer Elena von Massen,
Pavlovsk, March 2008.*

When we learn about death and go through this loss, we first experience disbelief, shock, later — pain, depression, apathy, our guilt over the departed, our weakness, anger.



"In February Ilya passed away. His death has caused mixed feelings. On the one hand, "Thank God, he is not suffering anymore!" And on the other hand it turned out that it's very hard when a person, for whom you tried to do everything possible so that he could live and enjoy his life, passes away. And it turns out that you think: "It's good that Ilya left for another life, which is surely more beautiful than this." And at the same time you regret that he did not live a little longer, because you had a lot of good things which you wanted to share with him. Sometimes it seems to me that there is some selfishness in the regret that a person passed away: you do not suffer from the fact that he left somewhere, but because he left you alone".

*Volunteer Anna Alenchenkova,
Peterhof, February 2010.*



"Never in my life I have felt so much weakness and fury as this year. Because kids were dying, and no one seems to care about this, and how it is possible that the value of human existence disappears almost without any trace. I will never agree with this".

*Volunteer Elena von Massen,
Pavlovsk, from the final report.*

What you can do when it seems nothing can be done?

Talk with the loved ones about what happened, about what you experienced and keep experiencing. Get your feelings out.



"This month turned out to be quite difficult, not in terms of work, but rather morally. One boy from our department, Andrey, passed away. It was very difficult for me ... At that moment, I thought that I would break. But my coordinator came to the rescue. We talked about what was happening, and I felt a little relieved. I realized that I was not alone, that I was surrounded by wonderful people who would help at a difficult moment!"

*Volunteer Ksenia Erofeeva,
Peterhof, May 2010.*

You can write a letter to that person or leave a message in the book of memory (in Pavlovsk).



I was very, very sad, despite the fact that we met with her just recently. The thought that there was no one who really would have lamented for her, that when she was dying, there was nobody beside her, and it is still unbearable for me. I just do not understand this, and maybe I will never understand. Even at the end of this year. There are things a person can not and does not want to take! Zaskiya gave me a book in which volunteers who knew a deceased child can write something. I took this book home for the weekend and wrote down all my feelings to Anya...

*Volunteer Elena von Massen,
Pavlovsk, September 2007*

Talk with those who knew this person. When we hear stories from different people, we understand that he was loved and appreciated at different times, we can restore a more holistic picture of his life, you can feel that you become closer to him.



I respect and love you. I believe that you feel good where you are now. That there are different round objects that can be twisted. Thank you for the moments that I will never forget. I remember as you announced a week-long hunger strike, when I taught you how to eat with a spoon. Today, Kate, your teacher, told me that eventually (it was already after me), you began to eat with a spoon all by yourself. This is very, very important. It is more important than to defend the thesis. I remember how I wrote you down to a dictophone (you could sound like a whole rainforest), and then I put the dictophone in your bed. Hearing your voice, you paused, and then suddenly began to respond (finally you found a worthy person to talk to).

In summer 2018, you were ill and stayed in the Kolpino hospital. After the painful procedures (you had an abscess in your throat), you were afraid of people and screamed wildly at the sight of a spoon. I tried to feed you with an apple puree. You did not eat. You did not even want to play with your favorite ball. I was sitting near the bed, at a considerable distance, and I was thinking. I was thinking about you and about myself, about trust, fear, about life in the world of people. Then you let me pull myself together for a couple of minutes. Lida, I'm sorry that I did not meet you now, when I have less fear and uncertainty, which prevented me so much from seeing and understanding. But I'm glad that I knew you and I did not have a question even for a second: "Why did you live?" what was the point? "Most of your world remained hidden from us, but you gave us a lot. You were an amazing person

*Maria Berkovich,
Teacher, April 2010*



Oddly enough, the day of Ilya's funeral was a very bright day. We saw him off with his mother and talked about him. It was a great relief - to know not just a part of human life, but to see it as a whole story, with the beginning, growth and ending.

*Valentina Guseva,
psychologist, Peterhof, February 2010*

It's important that you help the other care recipients to understand what happened and to say goodbye to the departed. For example get together in your room, put a lantern with a candle and a photo of the departed person in the center. Talk about what he was like, what he loved, remember some bright moments ...

Common grief brings people together, and even if some of the guys cannot speak, they will necessarily feel the importance of what is happening, your mood, the atmosphere. Of course, this meeting will be sad but light at the same time.



I think that he is right next to us, but we do not see him. He is doing what he loved and that he rarely succeeded in recently. Walking along the walls ... eating plaster ...

*Anastasia Goncharova,
Coordinator of Volunteers, February 2010*

We think that when one of our care recipients passes away, it is important to do everything that is usually done in these cases: to grieve, cry, feel sad, talk about what happened, cherish the memory carefully. It's amazing that difficult things can be associated with gratitude. Gratitude to those who left us, for leaving an imprint for us, for what they have changed in us, for life and destiny – for the fact that our meeting took place.



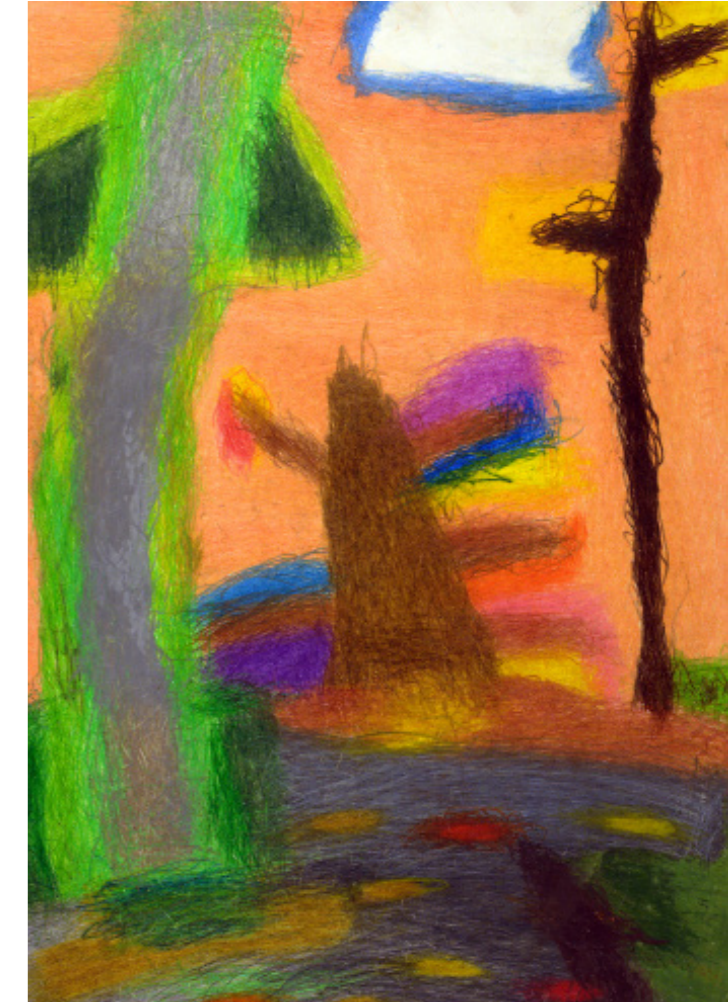
... I think it's so good that he had someone who paid last respect to him ... who said goodbye ... that there are people who grieve about him ... That all his life hasn't sunk into emptiness...

*Maria Berkovich,
Teacher, Peterhof, 2010*



Yesterday one person passed away, and today it was already strange to come to the group; but I tried to comfort the others. After a while, the pain will not be so strong. In the church they will hold a memorial service in honor of her, one of the women mastering something with her photographs, and we will pray for her holding the candles. And this is not a new experience for me. The one thing is new to me — language barrier, which, however, in these situations does not make me dumb, because you can say a lot without words, and this is even more important than what is said in words.

*Volunteer Stefanie Sauer,
Peterhof, September 2009*



Growing up. Sexuality. Protecting dignity

All people, even with very severe disorders are growing and developing. Our care recipients go through the same stages of life as other people. Children become teenagers, then - adult women and men, then elderly people ... The movement from one stage to another depends on the individual and the extent of the development delay. Some people's (mostly people with very severe development delays) life flows very slowly, but nonetheless, they are growing, changing, gaining experience and create their own unique story.

We often see a person with the delay in development as a kid – someone with no gender, without inclinations, desires, without any sort of problems related to the bodily and sexual spheres. But in his 16/20/35 he is no longer a child, but a teenager / young man / adult. Even if he behaves inconsistently with his age, we still need to learn how to see him as an adult and communicate with him accordingly.

What is growing up?

This is acceptance of responsibility. A person should have something he is responsible for that won't be done by anyone but him. What can our care recipients be responsible for? For many things – depending on their capabilities. For the tidiness in their locker. For making tea or salad for roommates. For turning the wheels of the stroller, getting to the gaming room. For not forgetting to put the wheelchair on the brake.

Growing up means the freedom of choice and expansion of the freedom. You decide yourself whether you want to go to the gym, what color of a sweater you will wear today, to which workshop you will go- ceramic or carpentry.

Growing up is the beginning of awareness of yourself as an adult man or an adult woman. This is the awakening of sexuality. The sexuality of people with developmental disorders is a very complex, painful and largely taboo topic. Here we will only briefly touch on some issues related to this field.

We can be confused by the signs of sexuality of our care recipients. It may be advisable to prepare yourself a little bit in this area – to read about the



sexual development (for example, there is a lot of useful information in the book "Love – the most wonderful life"), to think what embarrasses you and why, submit your question to the supervision.

It's confusing for us, when a care recipient sees us as the object of his attraction. You can talk about this. It is difficult when the situation is not clarified. You can explain in simple words: "I can not be your partner."

It is difficult for us to see the infringement of the human dignity of our care recipients in the conditions of the institution. This is really so. In the orphanage at least 6 people live in one room. Often they are got changed or washed in front of others. The use of a toilet is public. There is no individual space, there is no space for any privacy. We often feel powerless, because we can not change the situation globally.

Talk about this difficult feeling with those you trust. Think about how you can resist it. You can pay attention to small things that are easy to do to preserve the dignity of a person - for example, if possible, do not get changed a young man in front of girls and vice versa, cover up a half-naked man with a diaper (when he is using a bed-pan).

Sexual identity and its formation

A child without developmental disabilities, living in a family, early enough gets to know whether he is a boy or a girl. This greatly affects his image of himself. Dress or pants, pigtails or short haircuts, dolls or cars, phrases such as "you're a girl!", "Do the boys cry?" – all this helps a child to identify himself with either male or female. However, in recent years, more and more girls wear pants and a short haircut. But anyway.

A child with disabilities, who lives in an orphanage, has a very little chance of knowing whether he is a boy or a girl and what it means to be a boy or a girl.

Everyone is similarly cut , everyone is equally dressed in pantyhose and t-shirts, and toys are common. Therefore it is very important to explain to the child what his gender is. Of course, by affordable means: dress girls in beautiful dresses (at least for holidays), give them to try on necklace, scarves, hats in front of the mirror: look how beautiful you are!



When we brush the teeth, I sometimes put some of the kids on the windowsill, hold them and look at them with admiration. After all few people looked at them with admiration ...

*Anastasia Goncharova,
Volunteer, 2007.*

The boys are offered "boyish" games – cars, ball, etc., if, of course, they are interested in it.

Young people who already live in boarding schools, of course, also have difficulties in perceiving themselves as being of a certain sex. But we can still do something that helps them understand this, just in a more mature form.



Games in the train or "After this pillar ..."

We are talking about work on the way to work, on the way back from work, on the lunch break, when we meet together in a cozy evening – we always and everywhere talk about work.

At the beginning of the volunteer year, it can not be different. We are so overwhelmed with impressions, experiences, surprises, questions, that if we do not talk about it, our consciousness will be irreparable. (OK, I admit that I'm exaggerating a little).

But the moment comes when we can no longer talk about work. We need to get distracted from it. Relax. We want to talk about something else. Is there enough for discussion?

And then it turns out that we forgot how to talk not about work. No matter where the conversation began, it always slides on a complex relationship with the staff or my favorite care recipient. I need to find out why he does not bite anyone but me.

And then the most courageous of us suggests:

— **Let's not talk about work after that pillar. What do we do to relax from work conversations?**

We play games.

Even if you are very advanced and know how not to talk about work without any auxiliary techniques, still read on. What if you like them and decide to play them at some point. With no special reason.

1. Question game.

It's very simple: each participant asks the other participant any question. The questions depend on the degree of mutual trust, the mood of the participants, and so on. They are very different in depth and mood. From "Do you love bagels?" To "Do you think the superego is resistant to the collective unconscious?"

2. The game of compliments.

Also a simple game. One participant tells the other what he likes about him. Compliments, like questions, can be very different. "I really like ... your bag / your ability to listen / how you read poetry / how you pour a condensed milk in the pasta"

This game is very supportive to us in difficult times. All of us sometimes think that we can do nothing, well, nothing at all ... And then compliments come to the rescue.

3. Treasures game.

There are days when it seems that there was nothing good. And then we try to remember the little treasures of the past day. It cannot be that there were none of them at all.

"- how Vasya and I were watching the downpour out of the window. – How Dima took a spoon in his hand for the first time. – A beautiful tree on the way to the orphanage ..."

4. Just read poetry to each other.

Sometimes we specially take a book or a printout of our favorite poetry. The best thing about these games is that they can be invented indefinitely: "Associations", divination by the book, a joint composition of fairy tales, "contact", etc., etc. We are very grateful to the games that they cheer up and help to get distracted from thinking about ... Stop! Not a word about work!



Glossary

A

Agnosia – disorder of various perception types.

Asymmetry – the condition when one part of the body differs from another in some way.

Asphyxia – severe breath and blood circulation disorder up to its complete stop due to the lack or absence of the oxygen.

Apraxia – a strong disorder of the planning capability and, therefore, the capability of fulfilling the unfamiliar actions.

Autistic behavior type – immersion in the inner self with the reduction or losing the contact with the reality, deprivation of interest to reality, absence of the contact with people. Scarcity of emotional experience.

Awareness of the body – knowing the design of one's body (which parts it consists of and how those parts are related to each other).

C

Contracture – persistent constraining of the mobility of the joint.

D

Deprivation – loss of something; the condition in which a person feels an unsatisfied need.

Deformation – the condition when the whole body or its' parts are fixed in the incorrect position.

H

Hydrocephalus – a condition in which there is an excessive accumulation of the spinal fluid in a brain which causes the increased pressure inside the skull and a considerable increase of the head size of babies.

Hypertone – increased muscle tone.

Hypersensitivity (increased sensitivity) – a disorder of sensory modulation when the normal sensory inputs become too intense and a person reacts by defending or avoiding them; it's often accompanied by the negative emotions.

Hypotonia – decreased muscle tone (low tone).

I

Involuntary moves – the moves a person can't control.

M

Microcephaly – abnormally small size of a head, especially cerebral part of the skull, explicit lack of mental development while the height and the size of the other parts of the body are normal.

Multiple disorders – a condition when a child has several developmental disorders.

P

Passive moves – motions when an adult moves some part of a child's body (for example, bends its hand) while a child himself doesn't participate in this move.

Pathological – abnormal.

Posture – body position, mutual disposition of the body parts. Every move starts with some posture and finishes in some posture.

S

Sensory deprivation – the condition of reduction of the incoming sensory stimul.

Stimulation – special techniques when automatic moves are caused by the certain manipulation (for example, by the certain touch or keeping a child in the certain posture) as contrast to the motions which are performed by a child autonomously or by request.

T

Tactile sensitivity – perception and processing the senses received from the skin receptors which respond to the touch.

V

Vision of the body – the perception of the parts of one's body; plays a significant role in the development of the motion and sensation.



Our contacts

The Saint Petersburg charitable organization "Perspektivy"

Address 191180, Saint Petersburg, Ul. Gorokhovaya, 64-17


tel./fax: (812) 320-06-43

website: www.perspektivy.ru

e-mail: office@perspektivy.ru

 www.vk.com/volunteers_perspektivy

 www.facebook.com/perspektivy.ru

 www.instagram.com/perspektivy





+7 (812) 320-06-43

www.perspektivy.ru
office@perspektivy.ru