

Growing up

A booklet for parents of young people
with intellectual disabilities.



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We are all unique

“Who does this child take after? They’re completely like their mother! Well, they totally take after their father,” is something that perhaps all parents say often. They carefully examine the appearance of the child and look for characteristics that they have in common with their mother or father. One thing is certain: it’s their child and it has gotten something genetically from each parent. Sometimes, besides their appearance, a parent’s character can be strongly mirrored in the child, along with their qualities, strengths, and weaknesses. But how is it with sexuality?

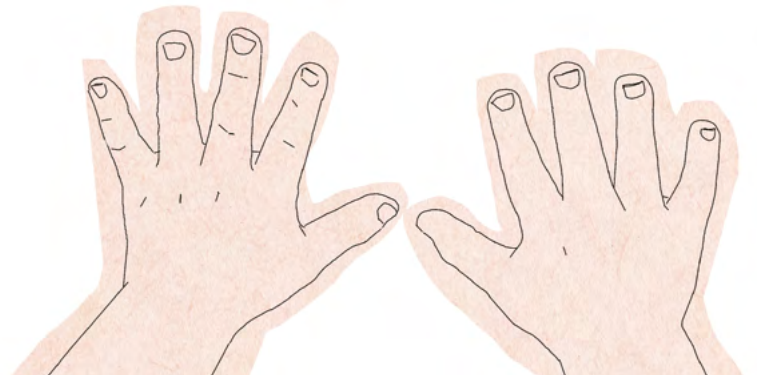
As a parent, if you think of your child as a boy/girl or woman/man, that is, of course, great. Take care not to liken their sexuality to your own sexual experience and behaviour. Our sexuality and that of our son or daughter is completely individual and it’s not possible to find any norms in this respect let alone think that my child will or even must experience it the same way that I do. The apple can fall near the tree, but it can fall very far away, too. Don’t prevent your children from being different.

The social and legal norms that apply in a specific society are the one thing that applies for everyone in the same way. We must all observe these; parents and their children. It is the task of parents to draw their children’s attention to these norms and to familiarize them with these standards. Satisfying our sexual and relationship needs should not limit,

endanger, or hurt someone. Otherwise, anything is possible, but it should always be closely associated with intimacy.

Our sexual behaviour does not represent a “norm.” The sexuality of a person with disability is just as unique and individual as our own, and we all need space in life for its safe realisation and fulfilment. The only thing that’s wrong is that many parents constantly monitor and assess their children without giving them a scrap of privacy. What sort of assessment could parents themselves expect if their children were to monitor and evaluate their means of satisfaction?

In conclusion, therefore, one should remember this: “Let’s not compare ourselves with each other. No norms exist for experiencing sexuality. Everything is completely unique and individual. It would be foolish to look for a template that could never work and which would not actually suit any of us.”





Why it's important to support the sexuality of our sons and daughters

Relationships are important to most people, regardless of whether they're friendly, sexual, partnership, or family relations. It is therefore necessary to focus on this area and not to ignore it, either in our own life or in the life of our child. The fact that our child has a disability does not play any role in this respect. This is something that concerns them just like everyone else. And since we certainly want the best for our child as a good parent, we must take note of their sexuality from the outset and support its healthy development. It's clear that, if a child cannot or even may not fulfil these needs, then they cannot expect much satisfaction or happiness in life. We can have an influence on all of this as parents.

People with disabilities are not children their whole lives

People with disabilities are not lifelong children. Although their intellectual disabilities can limit them in some respects, they become adult men and women with their own emotions and feelings, needs and desires. Everyone has the right to love and to be loved – not just within the family. Everyone has the right to intimate experiences and information that can help them find their bearings in this area.

It is important to realize that everything begins in our family. Children first learn to perceive important social norms (how to behave, what is and isn't appropriate, etc.) and then adapt their own behaviour accordingly. It is an important role for each parent to acquaint their child with these norms and to draw their child's attention to them if they themselves don't perceive or understand them. And it is necessary to find for a child an understandable way of explaining norms and the boundaries that they must not cross. And, most importantly, children mimic the behaviour of their parents, so passing on information must be in harmony with how parents behave with each other in the home and towards their child.

If, however, young people with intellectual disabilities are perceived as "eternal kids," and their behaviour in the family and in the wider world is constantly viewed as "childish," they will begin to behave in a way that is not commensurate with their age and physical development. A person and those around them can suffer greatly from this contradiction, and it will be very difficult for the child to make the required change in their behaviour. Some persons with autism, for instance, may no longer be able to change at all. The fact that they don't respect boundaries and that a person with a disability is perceived as a child can even lead to so-called incestuous behaviour. For example, a young person strokes her par-

ents' hands and none of the adults realize that this petting suddenly has a sexual subtext, because they are still seen as a child that does not experience any sexuality.

Maruška¹ was born with a moderately severe intellectual disability and several other problems related to motor skills and mobility. Her parents took very thorough care of her. They carried and cradled her a lot, and nearly always sat her on their lap. The extended family behaved toward Maruška in the same way, as did employees of the social services facilities she visited. This behaviour began to seem strange when Maruška had a sudden growth spurt at around 11 years of age and began showing signs of puberty. But Maruška's parents still treated her as a small child. Maruška herself witnessed the contact that other – genuinely small – children had with their parents and other people, and she constantly demanded the same contact for herself. And so, in the park, the young lady would climb up on people on benches, sit in their laps, and demand that they stroke her. The problems deepened as the years went by and the contact she desired also began to have a sexual subtext. When the parents finally visited a specialist clinic, Maruška was already over 14 years old. She was highly developed as a woman and menstruating. This had not had any bearing on how Maruška's parents still saw her as a little girl. They had deferred to the opinion of a doctor who estimated that Maruška was "at the level of a four-year-old child." The parents therefore assumed that their daughter was and always would be a small child. In the end, they finally understood that Maruška was now Marie, and that her behaviour had to have clear boundaries due to the change in context. Marie, however, did not understand this sudden change. She did not understand why contact that had been permitted and routine yesterday was suddenly forbidden. For

¹ She was still being referred to by the childish pet form of her name, Maruška, instead of Marie even though she was a grown woman

many more months she refused to abandon the identity of a small girl, who could take various liberties and do whatever came into her head. Only focused support and the onset of puberty, i.e. being confronted with her own body, helped her to find her true identity as a maturing woman and to adapt her social behaviour accordingly. This transformation phase was very difficult and complicated for the parents, but especially for Marie. For a long time, it wasn't clear that she would manage it. Fortunately, she succeeded in the end.

Adolescence

Even though it won't necessarily be strikingly apparent, adolescence in a child with a disability is a fact that every parent must accept and prepare for. For the child, it can be hard to understand and accept their changing body, but on the other hand, these changes can help them take on a new role in life and leave their childish world behind. Those around the child begin to perceive them differently than before. And the child also begins to perceive themselves and their surrounding world in a different way. The changes begin to happen with the action of hormones, which are activated in a person's body at a certain age. Their action can influence changes in the body, and they can also be the cause of changes in a child's behaviour and moods. The child is looking for their place in life, their role, and style. Together with this, they may also think about their dreams, plans, and goals in various areas of life, including sexuality and relationships. They may take after their parents and want to follow their example in some respects; in others they will want to define themselves and perhaps seek out a completely opposite position or diametrically different templates. As with sexual needs, which may vary greatly from one individual to another, there may also be differen-

ces in relationship needs and the need for social contact. A large portion of children, however, begin to build and deepen relationships with people outside their own family, mostly with their peers – their potential sexual partners. Even though healthy relations with other people are one of the most important elements of an adult life, we can find people with and without disabilities for whom relationships with people are not as important as their relationships with things and activities. This can, for example, also apply to some – but not all! – people with autism, who may satisfy their needs in unusual ways in which they are not focused on other people. They focus, for instance, on trains, lights, soft toys. It would be unnecessary and violent to force them into relationships.

Since childhood, Jakub, a young man with autism, had had his favourite objects, toys he could hardly do without. The surface of objects was very important to him. He liked smooth and soft things – such as a specific cuddly toy with soft fur. It was very important for him to have the material in contact with his face. This inclination became more pronounced in puberty and Jakub began seeking out similar materials. His behaviour started to be problematic for those around him. Jakub, for example, would begin snuggling a woman who was wearing a fleece, and so on. Jakub's mother was frightened. She could see that Jakub was aroused and his school had also called on her to deal with the situation. She reacted at first by beginning to eliminate Jakub's contact with these materials and objects, but the situation only got worse. Jakub began to be even more nervous and restless. Some slight self-harm also occurred. On the advice of a school psychologist, the mother tried to give Jakub medication for this, which would suppress his sexual needs. Fortunately,

this didn't happen, however. The mother also couldn't understand why Jakub was not sexually interested in girls or boys. After visiting a clinic, the mother understood that Jakub's behaviour was natural and that it was necessary to create a safe place and time for this. And so Jakub was then given access to the clothes and objects that he liked and which aroused him in the way that was required for satisfying his needs. These items were kept exclusively in his room and over time Jakub stopped needing to seek them out in public.

Most people, however, really need relationships in their life. Relationships may take many forms, of course. But all relationships should be accompanied by mutual respect and the freedom to decide whether we want to remain in them or not. Some people can be happy and satisfied without sexual contact; others can't imagine life without it. These needs can change and take shape over time, and it is therefore also fine to change relationships. Some people with disabilities (but also without) can be a bit more vulnerable in relationships. It's a fact that an intellectual disability may result in someone having poor self-awareness or a reduced ability to evaluate situations and emotions. This can give rise to a greater risk of misunderstandings. Some people with disabilities may be very easily manipulated. They can be naïve and trusting, or they simply might not be able to recognize the intentions of another person. That can lead to negative experiences in relationships and emotional harm. A negative experience, however, does not have to mean that the person repeats the same mistake. Nonetheless, it's essential for their learning and development that such situations arise in life. The aim is not to restrain people in relationships and protect them from harm, but to provide them with support and information and to take them through the relationship even if it doesn't end well.

Don't forget the age limits for criminal responsibility (15 and 18 years) and don't hesitate to draw your child's attention to them. You, as possible guardians, are not criminally responsible for the actions of your adult children. A child must sense responsibility in order to understand the seriousness of a situation and change their behaviour. Many parents make the mistake of constantly taking responsibility for their child, who sails carefree through life, thinking that they can do anything and whose experience is that their mummy takes care of everything. The situation, however, will inevitably come to a head over time, which is unfortunate for both the child and its parents. Every person, including children with disabilities, must face certain risks in life. It's normal that all parents encounter problems when raising their children. Being aware of their sexuality and supporting its healthy development must be an integral part of their upbringing. If a child's sexuality is suppressed, if they're punished for normal expressions of their sexuality, it can cause big problems. The child may then begin to feel guilty. Such an approach by parents can lead to neurotic behaviour in the child as well as depression, aggression, etc.

Petr lived in a family who took exemplary care of him. His material needs were catered for; he had nice clothes and his parents also arranged many leisure activities. Everything changed when Petr was around 15 years of age and began to have erections in the presence of girls and women. Petr did not know what to do. He could feel the pressure of his erect penis in his trousers, so he stuck his hands down his pants, staring intently at women as he did so. Petr's mother scolded him at home and forbade him from touching his trousers. Petr resolved this by lying on his belly when he had his next erection and rubbing himself up against the

carpet. His parents had another stern talk with him and told him that, if it happened again, he would stop seeing his friends and would always be at home. Petr became more irritable and nervous. He began flapping with his hands and making strange faces. He was embroiled in an internal conflict between trying to please his parents and remaining “a good boy” and not being able to suppress the natural expressions of his own sexuality. Petr’s mother subsequently took him to a doctor, who prescribed depressant medication to subdue him. After a while, because this medication didn’t work, the doctor administered a drug to block the creation of testosterone. Petr began self-harming; he scraped his elbows till they bled, he bit himself. He was given more and more medication. Petr gained weight, his communication skills deteriorated, and he overate. After many problems with his behaviour at home and in social services, Petr’s family found him a place in a home with a special regime. It took another 15 years before workers in cooperation with a new doctor dared to stop the medication and return Petr gradually back to normal life. But they never completely succeeded in doing so. At the same time, all it would have taken was for the parents to explain to him what an erection was and how to deal with it correctly. Instead of being given a place for safe masturbation in private, he was given medication and there was an accumulation of problems that ended up destroying Petr’s life.

Sexuality is closely linked to intimacy and it should always be an intimate topic, but this does not mean that it should be taboo. It’s completely fine to experience it and to satisfy the needs that arise as a result, but always in private only, in safety with safe people.

Children share a lot of information with each other, especially during puberty, when the subject is alre-

ady a timely one, but we can’t depend on this as parents of a child with a disability. Consequently, it’s important for us as parents to address our children’s and our own sexual education, and to check what the child perceives and how they understand it.

New technologies and the internet

All of us are encountering new technologies that didn’t exist a few years ago. These technologies are not only having a significant influence on communication between people, but also on their sexual contacts. This is happening in a good and beneficial sense, but unfortunately, it’s also happening in the opposite sense, too. The internet is not just a source of information and contacts, but also a source of risks. Of course, the internet and the media associated with it are very good to use for education, making acquaintances, etc. but we cannot rely on these resources, particularly when it comes to children with disabilities.

Relationships established through social networks or various dating sites² can engender a feeling of connection and lead to the satisfaction of some human needs. But reality is different and essentially it’s a delusion. It’s an environment where it’s very easy to abuse a trusting person; it’s an environment that is neither safe nor controlled. The feeling that we have found a “soulmate” or friend somewhere in a digital chatroom can lead us to begin saying things and sharing information that we would never share with a new person whom we were in contact with in real life. Trusting and easily influenced people, as well as “eager” people are a lot more vulnerable in this virtual world. It’s not possible to ignore the technology, and it wouldn’t be fair to forbid children to use it. But let’s try to keep control of its use and let’s check that the child is using it safely.

² See easy-to-read booklet on Sexual Violence: http://www.zveza-sozitie.si/modules/uploader/uploads/system_menu/dokumentj/Sexual_violence.pdf

Set rules, explain the risks, and talk to children about what they'll experience in the virtual world in the same way as you would if you were talking to them about what was happening in school, for example.

Intimate zones and the risk of sexual abuse

There are intimate zones on every person's body³. These are places that we usually cover with clothes; we protect them and we don't let other people touch them. The main, so-called general intimate zones include the genital area, the buttocks, and also breasts in women. But for both genders, they also include the area of the head – the face, ears, and neck. But, of course, we can also have intimate zones in other parts of the body, if that's what we ourselves feel them to be. The body is ours alone and only we can decide which part somebody can see and where we can be touched. It is therefore obvious that clear consent is necessary to enter one's intimate zones.

For children who are restricted in tending to themselves, and who can't wash themselves, for example, the situation is more difficult. It's possible that as a result of this someone will be entering their intimate zones on a lifelong basis. Find a way to explain to these young persons that this is not a matter of course and that only chosen people, parents or assistants, are allowed enter their intimate zones. Try to support them in distinguishing between people providing assistance and others. It is very important for a child to be able to evaluate what is or isn't pleasant for them and from whom they are receiving it. It is therefore crucial to give consent, but most importantly to be able to emphatically say NO and to possibly defend themselves from an attack on their body.

³ See easy-to-read booklet on Sexual Violence: http://www.zveza-sozitje.si/modules/uploader/uploads/system_menu/dokumenti/Sexual_violence.pdf

This brings us to the difficult subject of sexual abuse,⁴ which we unfortunately cannot avoid. Many people with disabilities have experienced sexual abuse in the course of their lives. The reasons are clear: many people have no privacy and the aggressor can easily get to them; they don't know how to defend themselves, they don't know how to talk, or cannot talk, about the situation; they are easily intimidated and manipulated and they lack the information to evaluate and identify the situation. Remember that knowledge of one's own intimate zones and their protection is the primary prevention against sexual abuse and let your child know this by your own example. A person who is informed and prepared is always better able to defend themselves against sexual abuse than someone who knows nothing, doesn't understand the situation, and is unable to evaluate it.

Development of sexuality during puberty

A person is a sexual being from birth to death, and their sexuality is constantly present. In the course of our lives, we develop, grow, and change. Naturally, this is no secret or mystery. And so, even though they may have a permanent disability, our child will also develop and change. As we shall repeat several times, it is necessary to reckon on puberty and to prepare for it, even though many things are already occurring from birth, before puberty.

Every child experiences puberty in their own way, and the same applies to children with disabilities. Neither the beginning nor end of puberty can be precisely predicted in advance, and there can be considerable differences among various children. Puberty can begin to manifest itself with some people as

⁴ See easy-to-read booklet on Sexual Violence: http://www.zveza-sozitje.si/modules/uploader/uploads/system_menu/dokumenti/Sexual_violence.pdf

early as eight years of age, or even sooner; with others we might have to wait until they're 16. The changes begin to happen based on the action of hormones.

Menstruation is a sign of sexual maturity for girls; with boys it's mostly their first full nocturnal emission. Remember that these youngsters are fertile as of this moment, and that they are capable of conceiving even though intellectually, and perhaps even physically, they still look and behave as though they're not mature. It would therefore be good to have information about contraception ready in reserve. Without doubt, everyone can easily recall these changes and we'll have to admit that it was not easy to cope with some of them, even as people without disabilities.

Accepting a changing body, a new role, and later the identity of an adult man or woman, including sexual orientation, can be quite difficult for some young men and women with disabilities, particularly if puberty happens fast and quick. That's why it's good to talk with them about it in advance, to tell them what will happen, how their body will change, what to expect, and how you will respond to these changes together. It is good to invite youngsters to partake in activities that will concern them so that they will get used to them. Sometimes they might even begin looking forward to them. For example, a mother who brings her daughter to the bathroom so that she can watch how she puts on make-up and does her hair, or the father whose ritual is to shave together with his son, who then looks forward to when his own beard starts growing so that he can shave like his dad.

Changes during puberty are very much associated with hygiene.⁵ The composition of a person's sweat changes and so their scent does too. Failing to observe the rules associated with greater hygiene is a fundamental problem for many people with or without disabilities, which negatively influences their approach

⁵ See easy-to-read booklet Being a Woman: http://www.zveza-sozitje.si/modules/uploader/uploads/system_menu/dokumenti/Being_a_Woman.pdf

ach to their surroundings and needlessly spoils their new image. Puberty also concerns one's wardrobe. It's necessary to leave childish motifs and clothes behind. Young ladies can expect to see a completely new item of underwear in their wardrobe – the bra.

Parents, if possible the mothers, should discuss the process of menstruation with their daughters ahead of time and in a relaxed way. They should explain what will happen in their bodies and what feelings or conditions could arise. Being introduced directly to sanitary aids for menstruation is another plus for a young woman who may soon have to use them herself. Parents, mothers, should also devote the same care to the first visit to a gynaecologist,⁶ which could easily turn into a traumatic experience for an uninformed and frightened girl. Parents, if possible the dad, should also discuss sexual maturation with young men⁷ and prepare them for the fact that erections will begin occurring, as will nocturnal emissions. They might also teach them about matters concerning masturbation, particularly hygiene and privacy. Don't forget that children with disabilities generally have worse access to information and process it with greater difficulty. Moreover, they are among similarly "unaware" peers, so it is totally appropriate for a parent to be a guide through puberty and evolving sexuality. Sometimes, an older sibling or perhaps a grandparent can also work very well. Try to lighten the topic a little bit, but always approach it in a dignified way. If you use humour, it can never be humour that devalues the subject.

If you don't feel comfortable as parents playing such an accompanying role, don't be afraid to seek help from schools, clinics, social services, or general practitioners. Sometimes, this anonymity is very

⁶ See easy-to-read booklet A visit to the gynaecologist: http://www.zveza-sozitje.si/modules/uploader/uploads/system_menu/dokumenti/A_visit_to_the_gynaecologist.pdf

⁷ See easy-to-read booklet Being a Man: http://www.zveza-sozitje.si/modules/uploader/uploads/system_menu/dokumenti/Being_a_Man.pdf

important for the person and they are able to talk very openly with a specialist even though they are very shy in front of their parents and don't want to broach the subject with them. Therefore, find the most feasible ways of getting there. Nothing can happen violently, not toward your son or daughter or you yourself. If we force information on a person who is not yet prepared for it, we could damage them, disrupt their relationship with their sexuality, or even cause trauma.

Coming to terms with changes, accepting a new role and identity assumes a relatively high intellectual potential, and that's why the process can last longer with people with disabilities, who may have to deal with problems that a young person without disabilities doesn't encounter, or at least not to the same extent. For instance, many young people with physical or combined disabilities may have a problem in puberty with accepting their new body, which in no way resembles those of their sporty teenage idols. Depression, anxiety, aggression, defiance and resistance to themselves and everyone around them can occur. If such difficulties are severe and persistent, it's a good idea to seek out psychotherapeutic support for the young person. But it is otherwise normal for a person in puberty to find themselves in these states and it's necessary for them to go through them. Processing new and sometimes accumulated emotions can be the cause of inappropriate and socially problematic behaviour, but it is often typical for puberty. Don't suppose that the child is doing something on purpose. Believe that this stage is even more difficult for them than it is for you and that they are not able to have too much of an influence on it. Of course, the journey doesn't end with puberty. Some will experience falling in love for the first time, break-ups, disappointments, euphoria, and giving themselves over to someone. They'll also have new

feelings associated with first sexual experiences, i.e. being touched in erogenous zones, orgasms, or also unpleasant feelings from sex that didn't work out, and partners with whom they didn't click. All these experiences are very important for a person's future life. They will emerge from these experiences and compare them with other, new experiences. Remember that everyone experiences a relationship differently and places different demands on it. Even though you'd certainly like to advise your child well, remember that what worked for you in life need not be right for them. Relationships take many forms and are solely a matter for the people between whom they occur. Therefore, we respect purely platonic, emotional relationships. On the other hand, we must also respect purely sexual relationships.

A parent of a child with disability, especially the mother, often literally sacrifices her life for her kid and cares for them. The mother sometimes loses friends and often even her partner, who cannot cope with the demands of care. The child then becomes the focal point of the mother's life and they can be a partial "substitute" for the relationships with people she's lost. For some mothers it is then difficult to detach themselves from the child and let them make their own way in life and experience their own relationships. This also occasionally happens to the parents of children without disabilities. Therefore let your child take their own path in life, and be a prepared and supportive witness to their experiences.

Remember also that some people need not emotionally experience sexuality and relationships in the way we'd generally assume. Some can be fine without a relationship and they don't suffer for it or miss it in any way. The priority is for the person to be satisfied and for them to be able to choose the path that leads to their happiness, whether this is through a relationship or not.



How parents can support the sexuality of their children

If you are the parent of a son or daughter with a disability, you will also have one important extra duty. Unlike the parents of a child without disabilities (who can find out many things for themselves and who will be in an environment where they will naturally come into contact with the information), you will have to provide sexual education and awareness to your child.

Remember that you are “the most powerful person in the world” to your child, and mostly you as parents can really help or hinder them.

Many things come naturally and arise automatically by themselves. There are some things that we have to help, to create or mediate, because the child will not attain them on their own or is not able to understand them without specialized input.

Being a parent is difficult in and of itself and being the parent of a child with a disability can be even more difficult in some respects. Under the weight of problems in your life, try not to lose sight of normal healthy communication and natural sexual behaviour. Don't lose the possibility of getting involved in society. Don't deny your own sexuality or that of your child. And try to find options that are in tune with intimacy and not at variance with social and legal norms. Try to abide by the following recommendations for developing a healthy sexuality in your child. Only you, the parents, can set up and influence many things.

What is in your power?

- Even though your child has been born with a disability, the main thing is that you have a daughter or a son. It is necessary for you to constantly see your child as a son or daughter and not to let the disability overshadow their sexuality, which will accompany them their whole life and will be just as important to them as it is to anyone without a disability.
- Dedicate yourself to actively supporting the sexual identity of your child. Toys, colours, clothes, the choice of words and gender in communication with them – these are all very important for children, so that they can self-identify and connect. Respect it when the child rejects some colours or toys – after all, there are always more options. Invest in sexual attributes even if it seems that the child is not responding to them. We don't want to raise some kind of sexless being without an identity, but we want to support their sexual identity.

- Share nudity with your child. This is not a problem in any way until the child is three years of age, and it is only a good thing that they discover there are two possibilities in this respect and they themselves can identify with one of them. Conversely, it is not good to share nudity in the family with older children or even adolescents. You would be disrupting the intimacy that the child needs for conceiving of his/her body (and the bodies of others). Naturally, it's not a problem to share nudity when changing into bathing togs at the swimming pool, for example, and similar places.
- Be aware that every child needs role models. Ideally, these roles should be fulfilled by the mother and father, but they can also be (and are) other people in the child's surroundings. If they live in a single-parent family, it's important that they can meet other people and find sexual role models among them. They need people with whom they will identify, but also those whom they will define themselves as different to. In this respect, same-sex couples are not a hindrance if the child is not living in isolation, and they find their sexual role models outside the family like how they would if they grew up in a single-parent family.
- Despite their disability, your children will not remain as small kids. Avoid the so-called infantilization of your child, i.e. any unnatural "undermining!" Even if a doctor during diagnosis tells you the estimated mental age of the child, e.g. 3 years, this does not mean that the child will be a 3-year-old kid all their life. Let them step out of the role of a child and support this outcome as well. Monitor how you talk to your child, what you offer them for activities, and also watch how your child looks. Forty-year-old "Hanička" with pigtails and a sweater with Mája the bee, who receives soft toys for

her birthday, is not a dignified look for a mature woman. There is no longer any place for the myth that disabled people are forever small kids!

- Avoid “uglification” (so-called de-attractivization). Devote attention to the child’s appearance. Don’t hesitate to invest in their hairstyle, clothes, cosmetics, etc. Our appearance is one of the basic expressions of our sexuality and, if we’re in tune with it, it strengthens our self-confidence and helps us know the ropes in social interactions with other people. How can a person whose femininity or masculinity is not underlined, whose clothes and hairstyle are sexless and often as cheap as possible, be able to feel and identify, thereby enabling them to behave and communicate socially? Even your child wants and needs to be attractive and to feel that it suits them and that they are sexually recognizable in the way they feel and wish themselves to be.
- Count on puberty! Whatever disability a child has, puberty will come. And beware, it can look completely different to what you experienced yourselves. Once again, it holds true that it’s not a good idea to compare your experiences of puberty and to consider them the norm. Be cognisant of the fact that puberty is a much more difficult period for the child than it is for you as parents/observers. Grant the young person more privacy and offer them the information that they need, and if necessary, also emphasize the boundaries that they may not cross. Respect their right to a sex life from the age of 15 onwards and give them responsibility for their actions and decisions. It’s normal for puberty to be a turbulent period in which the child revolts against the parent. Don’t be afraid to let this process run its course. Once again, it leads to further self-identification for the child and has a positive effect as a result.

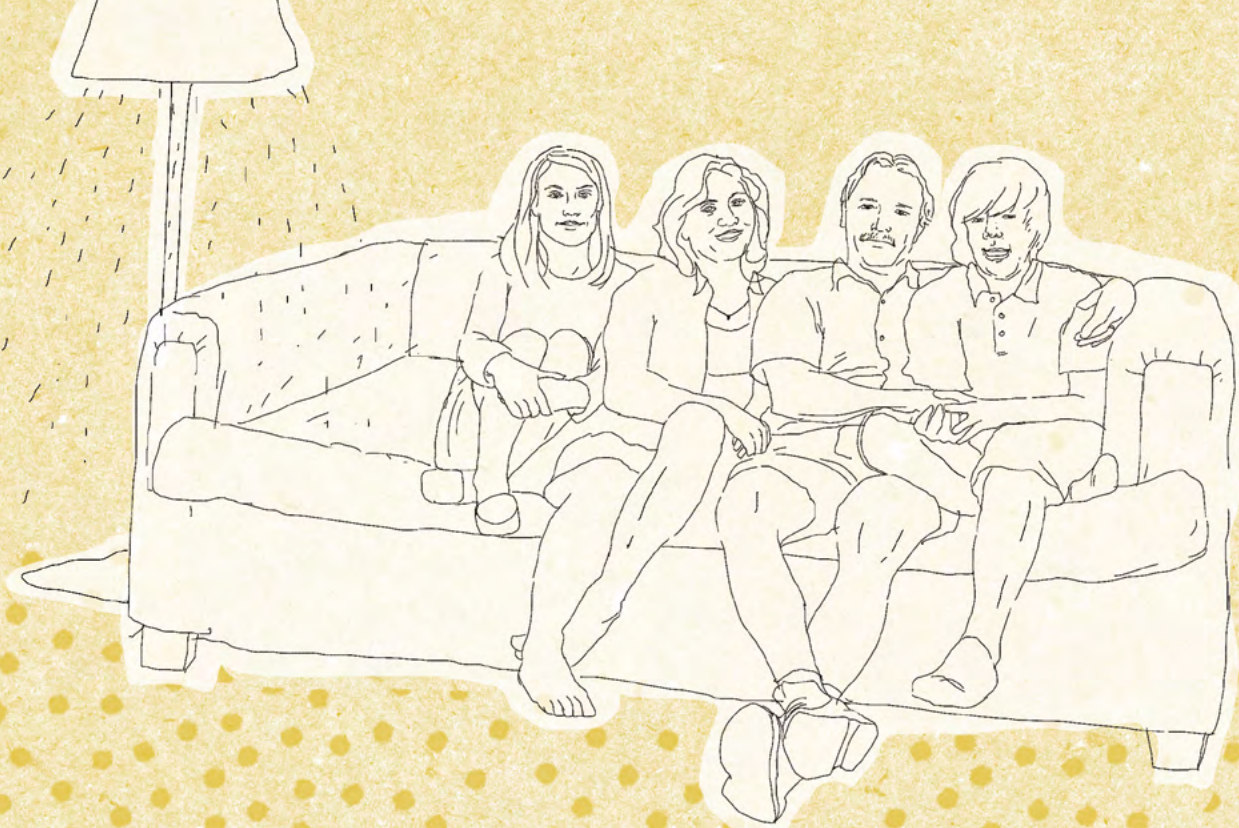
- As far as possible, avoid depressant drugs/medications. Many parents are frightened by manifestations of their children’s sexuality, particularly during puberty, and they demand medicines that would suppress these manifestations. Try out other possible solutions. Drugs should be a last resort, not the first thing you reach for. Moreover, drugs don’t solve the problem. They only suppress manifestations, but the needs of the young person remain unfulfilled and in time they will manifest themselves in different, possibly even worse, ways. Aggressiveness and explosive episodes can also occur. The children may also begin self-harming or overeating and drinking too much. Involuntary movements may also manifest themselves as an outlet for the tension that occurs in the body. Avoid falling into a vicious circle that it might not be possible to get out of.
- Do not isolate your children. Grant them as much social contact as possible, whether it be in the family or society as a whole. It can only be a good thing for them to witness ordinary life of different people, to meet new people, and to experience situations that they can learn from. Don’t be ashamed of your child. Whatever way they come across, they should be part of society and it is society’s moral duty to accept them.
- Grant your children intimacy. Particularly upon entering puberty, it’s important that they can be by themselves more, that the place where they can be naked (and possibly masturbate) is clearly defined and they can be certain that they will be genuinely alone. The last thing we want is for the young person to view their nakedness as a public thing and to then share it with other people. Respect their intimate zones and define yours in respect to them. Try to leave them space for secrets, so that

they are able to distinguish the nature of information that they can share with others and that which they can't. After all, not all information in our lives is public.

- Pass on information. Don't rely on something occurring to the child themselves or that they will find out what and how on their own. Continuously offer them understandable information about their body, sexuality, and relationships, so that this is something that they can draw on and use in practice. A child will get into many situations in life and it is always better if they are prepared and can find their bearings rather than making serious mistakes out of ignorance. You cannot rely on always being present and protecting them. Also don't rely on the internet. You must always check how your child understands information from the media and how they want to apply it in life.
- Set clear and understandable boundaries. Don't let a child's disability make you tolerate sexual behaviour that exceeds social and legal norms and don't demand this tolerance of your child from other people. Your child has the right to a sex life, but at the same time they must also observe the obligations that arise for them from the use of such rights. Avoid trivializing inappropriate sexual behaviour, but do not overstate it. Act in an adequate and calm manner. If you yourself are at a loss, there is no shame in consulting an expert, a clinic, etc.

Ivan had long been an adult man, but his family treated him like a child. Ivan liked women. Their breasts pleased him. It was normal in the family for "Iváněk" to cuddle with his aunts, female cousins, etc. It was

normal for him to hug them and rub his head against their breasts or put it in in their lap. Apparently, it was completely innocent and childish. Iváněk liked to cuddle. He wanted to cuddle in a similar manner with the assistants in the short-stay ward, but they rebuffed him. Ivan had fits of tears and rage. He complained to his mother with whom the assistants had consulted about his behaviour many times. The mother, however, described their approach as unprofessional and she commanded them to allow their son to have contact as a person with disability. Ivan's behaviour escalated and eventually the provision of services was terminated. About two years later, Ivan raped a woman he didn't know in a public place. He did not understand that he had done something wrong. It was natural for him to go and cuddle a woman who was near him and whom he liked. Ivan was ordered by the court to receive treatment and to stay in an institution. This event changed his life forever, but his mother still blames the situation on other people, including the raped woman and the social workers.

A line drawing illustration of four people (two women and two men) sitting on a couch. A floor lamp is positioned to the left of the couch. The entire illustration is cut out and placed on a background of yellow polka dots.

Support

Work with sexuality has been available in the Czech Republic for several years now, ranging from sexuality and education to sexual assistance, which is relatively controversial for now. Unfortunately, for the time being, work with sexuality is not automatic and standardized in social services or in school. Institutions may devote themselves to it, but they are also under no obligation to do so. Regrettably, it's not possible to rely on the healthcare system in this respect and unresolved issues also persist in sexual assistance.

- Family – Ensure a healthy approach to the sexuality of the child and keep an open mind on their sex life and relationships. Ideally, this should apply to all members of the family. Create options of privacy and intimacy for the child to experience their sexuality.
- Education – Seek the incorporation of comprehensible sex education into curricula and teaching plans. Make it your business to know the content of the classwork and what information the child receives, so that you can also work with it yourselves. Be prepared to explain to the child the things that escaped their attention at school. Schools may use special aids for sex education and learning. Ask for the school to purchase such aids and to arrange for a teacher who is trained to use them with the children. Caution: don't ask the school to create a space for the satisfaction of the child's sexual needs. This behaviour does not belong in school and should be carried out in the privacy of the home.
- Social services – In residential social services, in particular, (homes for people with disabilities, weekly wards, sheltered housing, etc.), ask about the possibilities for fulfilling the sexual needs of your child. Request that a system of sex education and intervention, which your child could use, is in operation in the service. Ask whether the facility has formulated a so-called "sexuality protocol," which deals with and defines this area and if there are so-called "sexual confidants" among the staff, i.e. workers who are competent to pursue this matter at a professional level. Social services also have the possibility of using specialist aids, such as prints, films, etc. Just like a teacher in school, a service worker may not use physical contact or demonstrations on their own body for sex education, training, or intervention. Everyone is dressed, nothing is shown, and nothing is practi-

sed directly, which is where the aforementioned aids come into play. If work with sexuality is not clearly defined in the description of the service or in the contract on the provision of the service and your child is younger than 18 years of age, social workers need the consent of a legal guardian for the provision of intervention. On the other hand, if the child is older than 18, they can decide on provision themselves, even if they have limited legal capacity and a parent is their guardian. Seek out clinics or links in your region that you can use flexibly.⁸

- Health service – Have a doctor genuinely examine your child. Demand that they pay them the same amount of attention as they would to a person without a disability. Ask about the need and reasons for the prescription of medication and about the side effects of drugs (e.g. psychopharmaceuticals or antiepileptics). Hold consultations on other possible options besides medication. Prepare your child (daughter) for a visit to the gynaecologist. Explain to her what will happen and possibly prepare the doctor and a nurse for the meeting as well.⁹ Find a doctor with a good practice, who you know can communicate with people with disabilities. Have the doctor speak with your child, not just with you.
- Sexual assistance/sexual services – Find a trained and professional service provider. Study their websites and offerings, which can vary. Try to verify that they are competent in communicating with a person with disability and that they have clear boundaries. Also check their prices. Ask for an invoice. Understand that a sexual assistant can (and probably will) use their own body and the body of your child for training or direct sexual satisfaction. Do not skip over the preceding pillars of support (fami-

⁸ If you live in the Czech Republic, You can contact the Consultancy Centre of Inclusion Czech Republic (Poradenské centrum SPMP ČR) www.spmpr.cz. They will put you in touch with the service that you need.

⁹ See easy-to-read booklet on Gynaecological Examination: http://www.zveza-sozitje.si/modules/uploader/uploads/system_menu/dokumenti/A_visit_to_the_gynaecologist.pdf

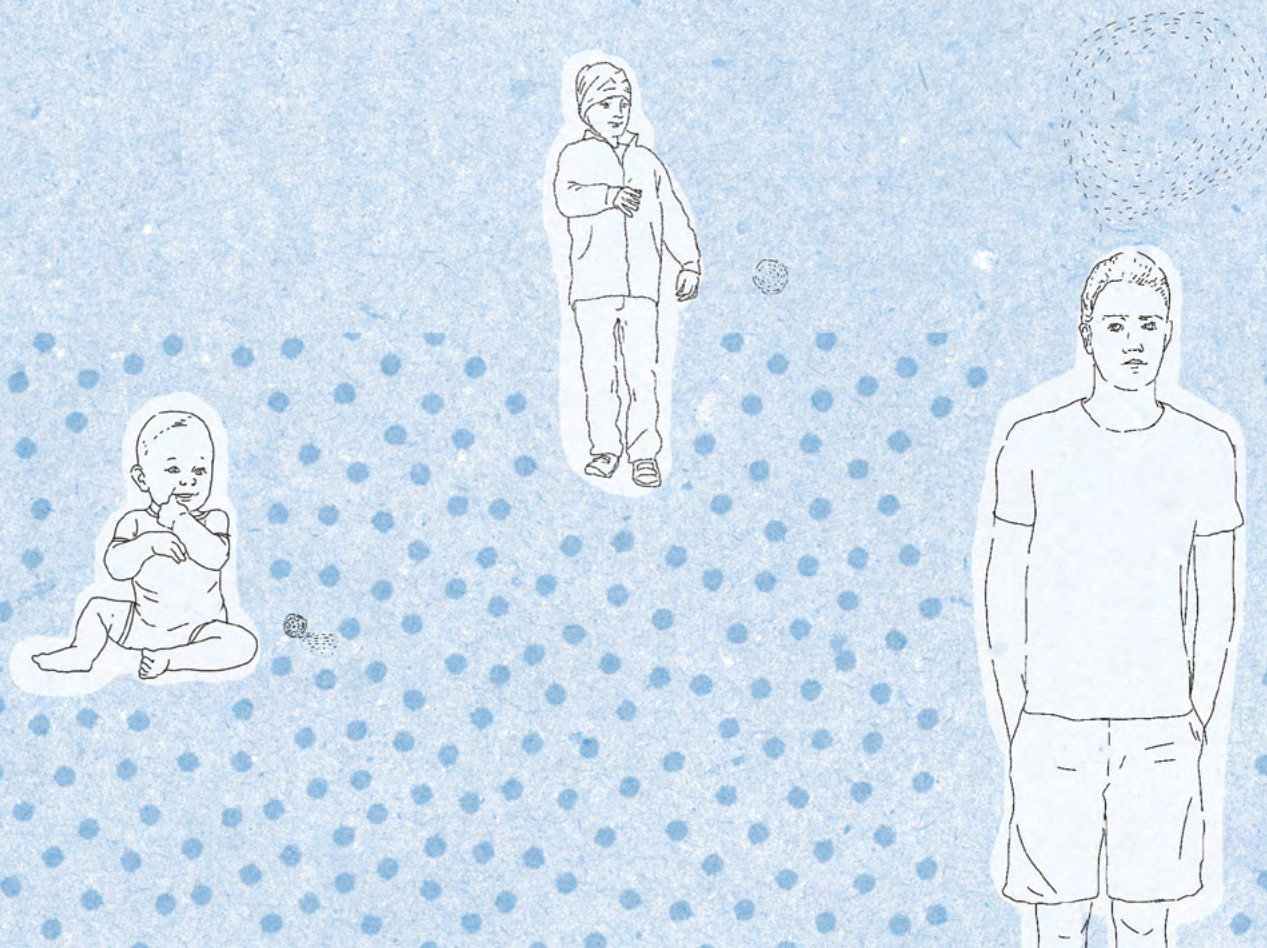
ly, schools, social services, the healthcare system). Use sexual assistance or sexual services only if no other solution to the situation is possible. A sexual assistant or sex worker cannot provide a service without the consent of the client, who must be capable of verifying them. Ask about the aim of the service and its significance for developing the sexuality of your child. Request a legal basis for the services, thereby giving you the option of checking their implementation. Find out the current legal framework for the situation, so that you are not procuring and soliciting prostitution during negotiations.

As a parent, however, you have a strong voice! Ask about work on sexuality in services or schools that your child attends. Challenge the behaviour and approach of the doctor. Some institutions need to register your request so that they purposefully devote themselves to the subject. And conversely – don't be afraid of services and institutions that work on sexuality. Ask about the details so that you properly understand the support in this area and can work on the objectives with the child in your home environment. It is always a good idea to check that real experts will be working on the subject.

If you can't find an alternative solution to your situation yourself, contact the Counselling Centre of Inclusion Czech Republic (Poradenské centrum SPMP ČR). We will try to help and advise you, and possibly direct you towards another organisation who deals with the subject in your region. It's okay to be interested in the topic and to ask about a solution to your situation.

"Every parent wants the best for their child!" If we abide by this motto as parents, we will have to think about our child's sexuality. This area cannot be taken away from them due to their disability. If we want the best for our child, we must also ensure that their sexual and relationship needs are fulfilled. At the same time, it also holds true that we are not responsible for these needs. Seeing your child miss out in this area or any other area is often painful. Sometimes, an ideal solution simply doesn't exist and we must reconcile ourselves with the best that can be possibly achieved with respect to the child's disability and their current living conditions.

Remember that everyone makes mistakes in life and that, if something doesn't work out or if you overlook something, it doesn't mean you're a bad parent. There is always room to remedy the situation.



**What can I
do specifically
as a parent
to support
the healthy
sexuality of
my child?**

For better orientation, these rules are divided up according to the age of the child. Remember that some are clearly tied to the child's age, but others hold true for their entire period of physical and sexual development, or literally for their entire life. Consequently, it is necessary to not just choose only one rule, but to view everything altogether as being interconnected and intertwined.

First stage – birth of the child up to roughly 3 years of age

- I address the child by their name, I speak about them in their gender, I choose appropriate words.
- I offer them toys, colours, activities, interests... Caution: I offer, I don't force. If the child rejects what is offered, I leave them to choose. I persist with the offer even though the child hasn't responded to it thus far.
- I ensure that the child is in contact with men and women of various ages. I ensure that they have enough role models.
- I bathe and change clothes with them up to around 3 years of age. This helps them with self-identification. It's okay for a small child to see their parents naked and to understand how they differ.

Second stage – roughly from 3 years to 10, up to the start of puberty

- I set clear boundaries for physical contact and social behaviour in a way that the child understands.
- I include the child in normal household tasks or in looking after themselves, so that they can see them and possibly try them out.
- I support the appearance that the child chooses. I invest in clothes and other things that help them to feel good about themselves and to define their sexuality in relation to their surroundings.
- I don't avoid the subject of sexuality even though the child is still small. If they ask a question, they should get an answer that they'll understand, and which will be truthful and useful. I won't lie to them. I don't tell fairy tales about storks delivering babies. On the other hand, I don't foist information on the child if they are not yet ready for it.

- I will seek out social services and schools where the subject of sexuality is worked on, or I will request this work from institutions.
- I will not make sexuality a taboo subject, but I will preserve boundaries of intimacy that I will not allow the child to cross.
- I will not share the nudity of my body with a child older than around 3 years of age. I will protect and demarcate my intimate zones so that the child understands that they have these on their body as well. Swimming pools and similar places are an exception.

Third stage – puberty

Caution: the age range can be very wide – from 10 to 20 years of age, but also more!

I avoid incestuous behaviour that could tend towards intense contact with an adolescent or even adult.

As soon as the child hits puberty and secondary sex characteristics appear, it is necessary for me to ensure their privacy. Other people should not have the option of seeing their naked body and the child should themselves demarcate whom they will share nudity with and whom they won't.

I won't enter the child's room without knocking and without their consent. I will not be insulted if the child doesn't want me in their room.

I give them the option of being alone in the bathroom or the toilet. I only assist with really essential tasks. I don't need to know everything. I give the child the opportunity to have secrets and they themselves can

decide with whom they want to share them. I want them to be able to distinguish between which information is public and which is private. I will not disclose intimate information about the child.

As a parent, I am never a sexual object for my child, and I will not try to satisfy their sexual needs with my own body.

I will not trivialize evident sexual behaviour from the child that goes beyond social or legal norms and I will not demand that those around me tolerate this behaviour because the child has a disability.

I will regularly and comprehensibly offer the child information/sex education and training, but I will to see if they want to accept it. I don't force information on the child. They themselves must assess whether they want to accept it.

I can employ special aids for educating the child, but it is necessary to consult with experts on their use. If I talk to the child about sexuality, I use a simple but not childish vocabulary without unnecessary specialist terms and complex formulations.

I use understandable examples. I can talk also talk about myself, but I still preserve intimacy (including my own).

I check that the child has understood the information correctly.

I always talk to the child about sexuality alone and in private, so they understand that it is an intimate matter, which can't be shared with just anyone.

I take the daughter to their first gynaecological examination and I prepare her for it and inform her about it as best I can beforehand.

I don't take the internet as a reliable source of information. Once again, I check how the child understands the information. Virtual dating sites and profiles on social networks can be very risky for a person with disability. I respect their privacy, but I strive to be aware of what's going on in this environment and if the child is being exposed to any risks.

I will not request that problems be resolved with depressant medications. I view drugs as a last resort. I respect the child's right to a sex life – I create space for masturbation, I enable them to use sexual aids, etc.

I respect and don't criticize the child's sexual orientation. I create an environment where the child can realize their sexual orientation and feel safe.

If deviant sexual behaviour manifests itself in the child, I will not be afraid of a diagnosis and of cooperation with experts in the field of sexology.

Fourth stage – end of puberty and adulthood

I don't decide on my son or daughter's relationship. They have the right to decide on and choose whom they want to have a sexual relationship with – from 15 years of age onwards, they already have the right to satisfy sexual needs with another consenting person.

I will not prevent my child from going to residential social services, for example, where they can live with their partner, or I will make space for them in my own household.

If the child speaks about the desire to become a parent, I speak with them about specific parental com-

petencies, so that they can envisage what parenthood entails and whether they can become a parent or not. I will acquaint them with the possible risk of a child being taken away from them. I ask them how they would behave as a mum or dad and how they would ensure a home and care for the child. I will speak frankly about what I don't intend/intend to do in terms of providing support as a grandparent.

From 18 years of age, the young person can avail of sexual services or use pornography.

I will find out detailed and up-to-date information on sexual assistance, or on a specific sexual assistant.

I always act in accordance with applicable legislation. I cannot procure or solicit prostitution.

I will enable the young person to use their financial resources for the purposes that they choose, i.e. even if they are used in connection with satisfying their sexual needs.

I will not needlessly restrict the child in their legal capacity. As a guardian, I don't decide on most matters pertaining to sex and relationships in any event. Sex and relationships are not legal acts. I correctly understand my role as a guardian, and I don't misuse my competencies for other purposes.

I will not let myself be misguided by a diagnosis of the child's so-called "mental age." I will not infantilize an adolescent or adult on this account.

If you want to learn more as parents about working on sexuality and to understand the topic in more depth, seek out lectures or courses, which are also available in most countries nowadays. You might also want to visit a clinic and obtain information on using sexual aids for sex education or training and intervention.

You also don't need to be ashamed of going into a "sex shop" and enquiring about specific sexual aids, which could be very beneficial for your child. You might not even know about all the things that exist and you will be pleasantly surprised to find out what sort of help is available. "Sex shop" staff tend to be very accommodating, discreet, and professional.

If you succeed in grasping and practically incorporating these rules and principles into your life and particularly into the life of your child, problems should arise only on very rare occasions. Don't forget that you are the most important person to them, just like your parents were (and possibly still are) the most important to you. Perhaps you found many mistakes in their approach. However, let's not waste time on needless criticism. On the contrary, let's learn from these mistakes. Now, let's make as few of these as possible.

Conclusion – the story of a mother and her daughter who has a intellectual disability

I'm the mother of Hanka, a 20-year-old woman with an intellectual disability. Our journey through her adolescence was long and difficult, but it was worth overcoming all those obstacles to get to where we are now.

*When Hanka started being interested in various differences between genders, I was unhappy and afraid. After all, this was something she could never understand in any event! Nonetheless, I tried to find aids and to provide explanations. I discovered the publication *Moje první knížka o sexu* (My First Book About Sex). When I began to read it, I cried at every page... I realized that I wasn't ready or reconciled to the fact that Hanka was growing up.*

Over time, however, it dawned on me that the best protection I could give Hanka against the pitfalls of adult life was if she knew the truth. After all, if we're knowledgeable and aware, we know how to protect ourselves. So, we began reading unusual fairy tales with drawings in which the people weren't dressed.

I discovered that my fears were unfounded and that Hanka was stronger than I thought. I ultimately became reconciled to the fact that I had an adolescent woman at home who deserved to live her life to the full. Only one task remained for me – to be on guard and to lend her a helping hand.

One day, Hanka took a fancy to Matěj, a fellow pupil from school. At first, Matěj's mother and I were embarrassed, and we had grave doubts. For example, it wasn't easy to explain when and where it is and isn't appropriate to hug and hold each other by the hand. But we discovered that their love is of benefit to them and helps them overcome hurdles, just as it does for people without disabilities.

Today, both families fully support Hanka and Matěj, and we are happy about their relationship. We are their confidants and comforters. Like every parent, I still have my concerns, but I don't want to prevent my child from living life to the full, even if it can lead to tears and disappointment. This is part of living and in this way it's just real life.

Growing up.

A booklet for parents of young people with intellectual disabilities.

Author: Petr Eisner

Co-authors: Sašo Kronegger, Nataša Zupan Cvetežar, Mateja Turk

Editors: Jitka Brchaňová, Xenie Dočkálková a Jana Stejskalová

Illustrations and graphic design: Helena Neubertová, www.prooko.cz

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