MEDVET

MedVET - VET programme for medical practitioners supporting parents of babies with disabilities and complex needs

Our LiveBooks.

TÜRKİYE ULUSAL AJANSI
TURKISH NATIONAL AGENCY
Co-funded by the
Erasmus+ Programme
of the European Union

These LiveBooks are the result of the collaborative work of:

- Marmara University, Physiotherapy Rehabilitation Department, Turkey
- Asociatia Unu si Unu Romania
- National Association Of Professionals Working With People With Disabilities “NARHU”, Bulgaria
- Specialised Hospital For Active Treatment Of Obstetrics And Gynaecology “Selena”, Bulgaria
- Spastic Children’s Foundation Of Turkey, Turkey
- Gazi Universitesi, Turkey
- PhoenixKM BVBA, Belgium

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You can download a PDF version at https://medvet-project.eu/outcomes-downloads/.

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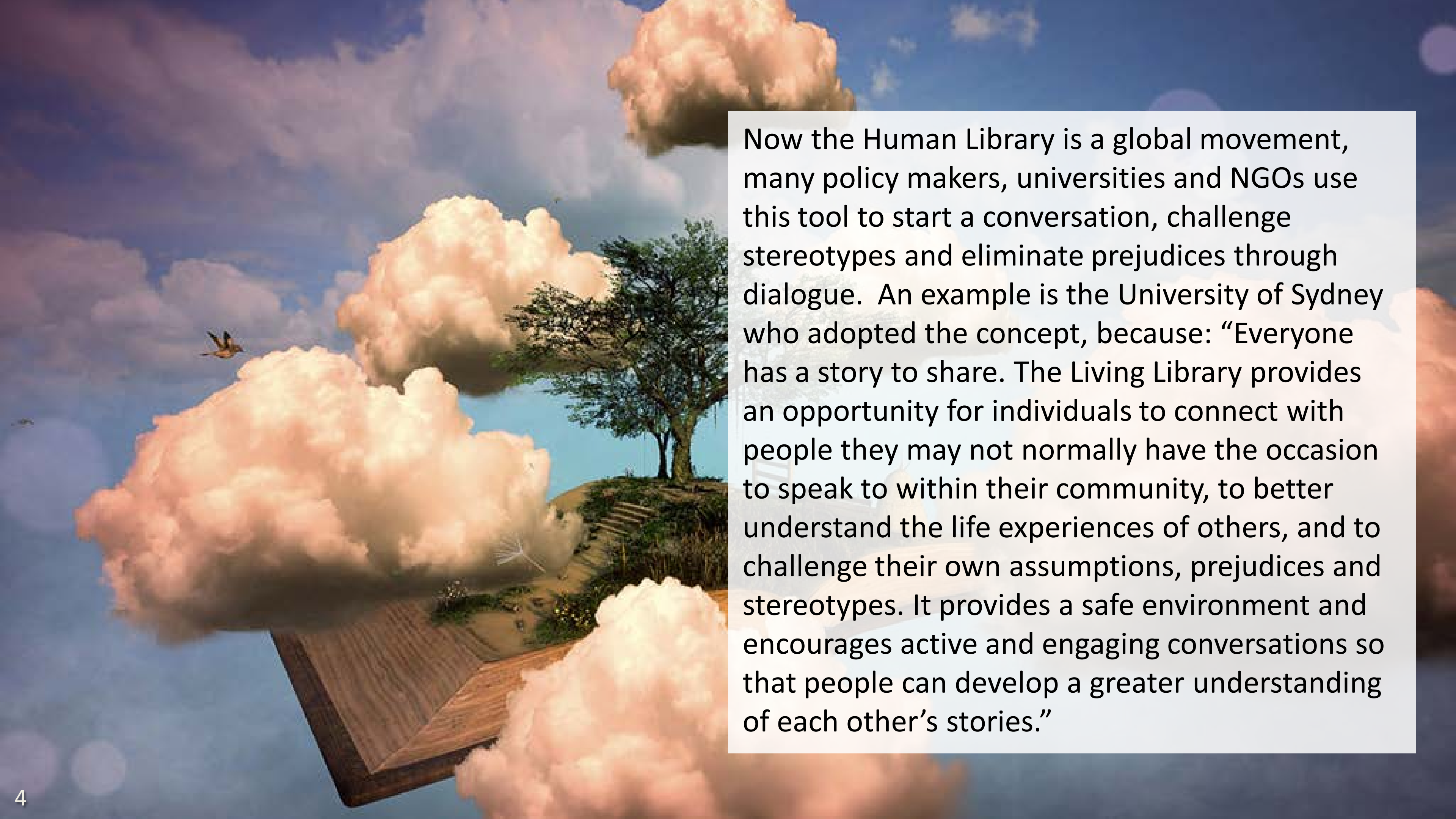
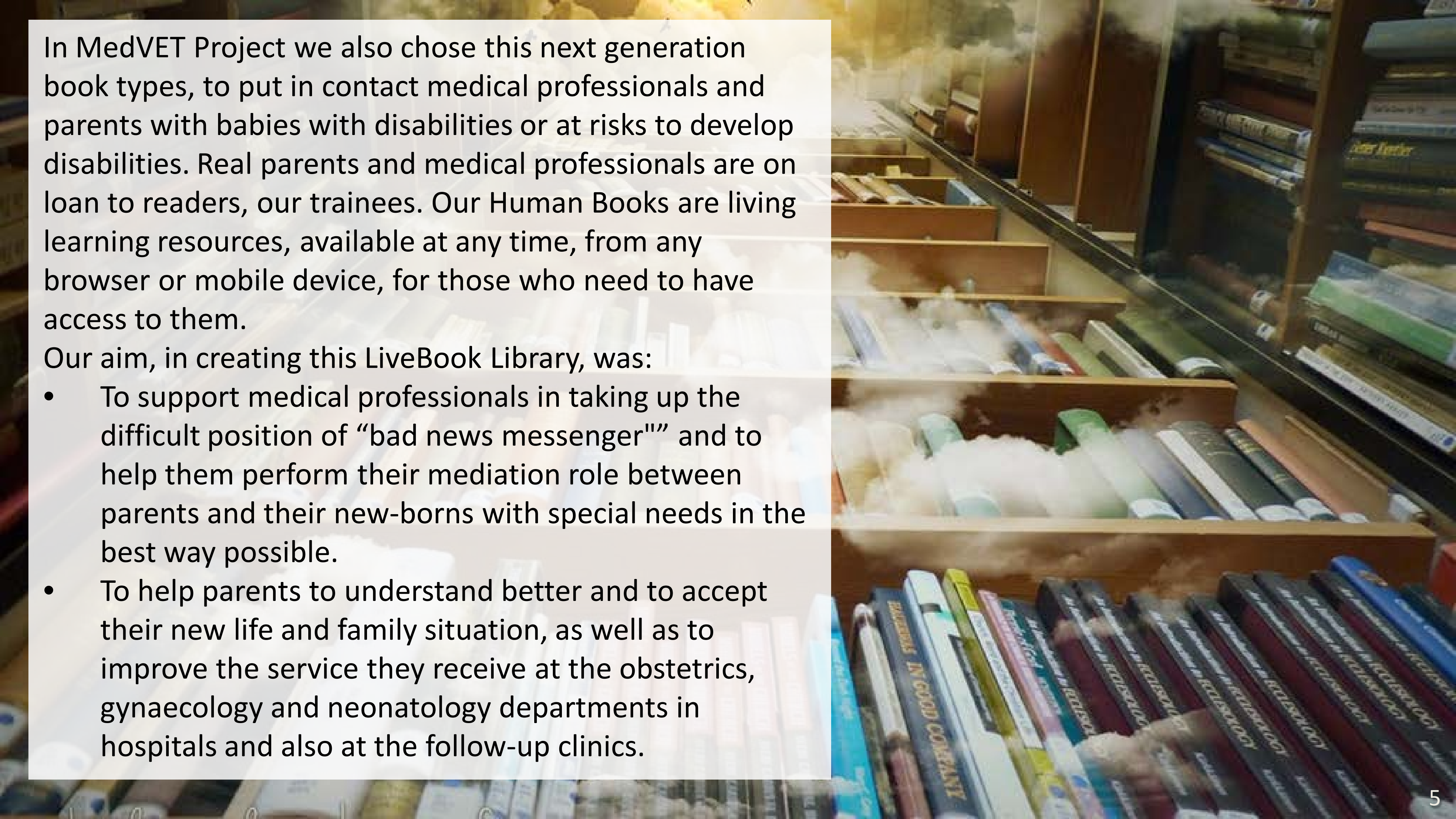
The concept of the Human Library was created in 2000 in Denmark and the first public event for "reading" human books was organized at Roskilde Festival. “The Living Library is an equalities tool that seeks to challenge prejudice and discrimination. It works just like a normal library: visitors can browse the catalogue for the available titles, choose the Book they want to read, and borrow it for a limited period of time. After reading, they return the Book to the library and, if they want, they can borrow another. The only difference is that in the Living Library, Books are people, and reading consists of a conversation” (Roskilde Festival Organizers).



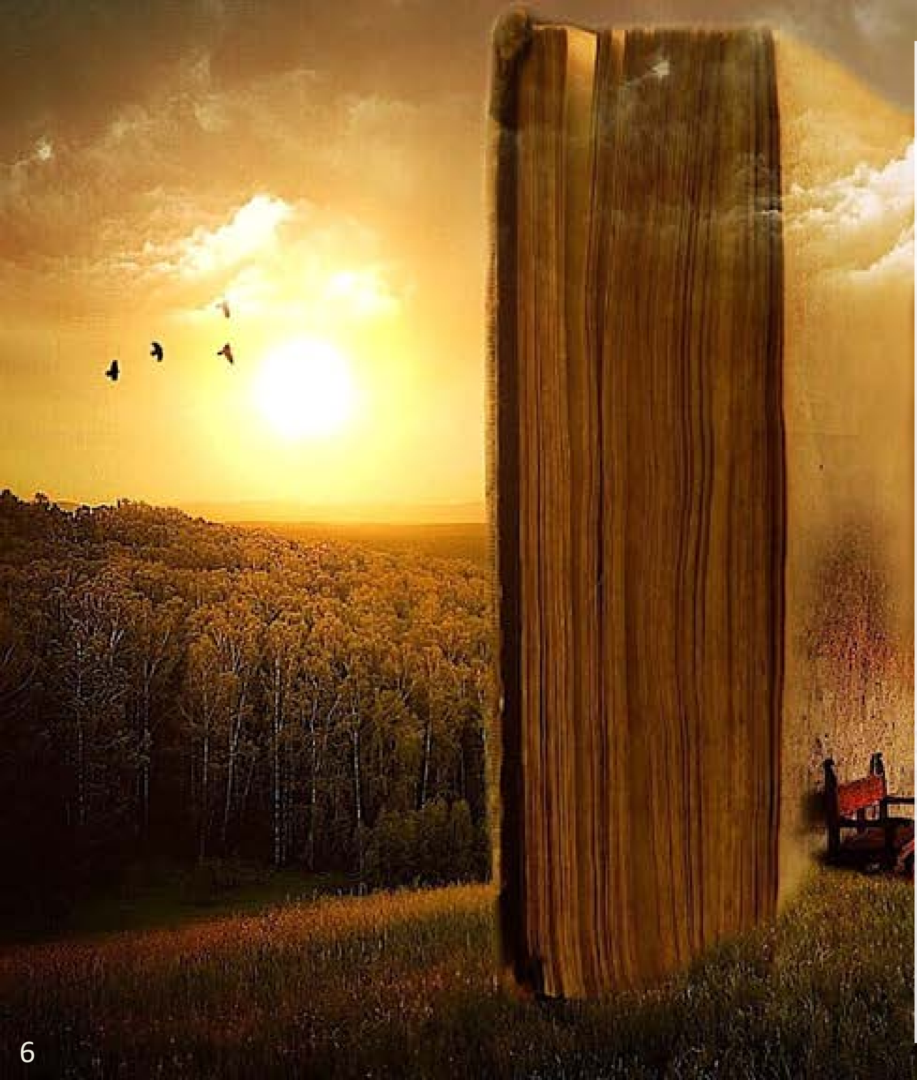
Now the Human Library is a global movement, many policy makers, universities and NGOs use this tool to start a conversation, challenge stereotypes and eliminate prejudices through dialogue. An example is the University of Sydney who adopted the concept, because: “Everyone has a story to share. The Living Library provides an opportunity for individuals to connect with people they may not normally have the occasion to speak to within their community, to better understand the life experiences of others, and to challenge their own assumptions, prejudices and stereotypes. It provides a safe environment and encourages active and engaging conversations so that people can develop a greater understanding of each other’s stories.”



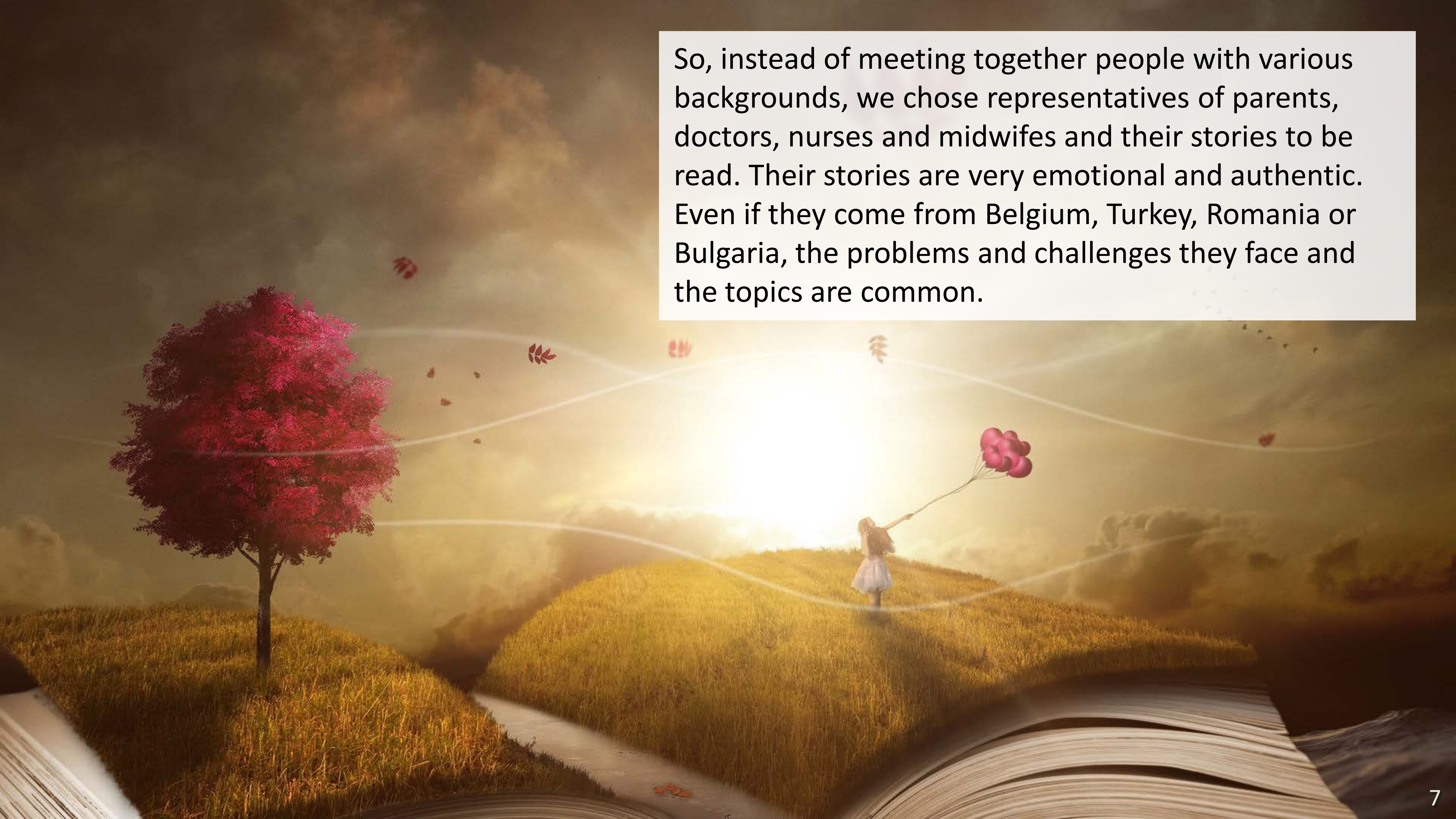
In MedVET Project we also chose this next generation book types, to put in contact medical professionals and parents with babies with disabilities or at risks to develop disabilities. Real parents and medical professionals are on loan to readers, our trainees. Our Human Books are living learning resources, available at any time, from any browser or mobile device, for those who need to have access to them.

Our aim, in creating this LiveBook Library, was:

- To support medical professionals in taking up the difficult position of “bad news messenger"” and to help them perform their mediation role between parents and their new-borns with special needs in the best way possible.
- To help parents to understand better and to accept their new life and family situation, as well as to improve the service they receive at the obstetrics, gynaecology and neonatology departments in hospitals and also at the follow-up clinics.



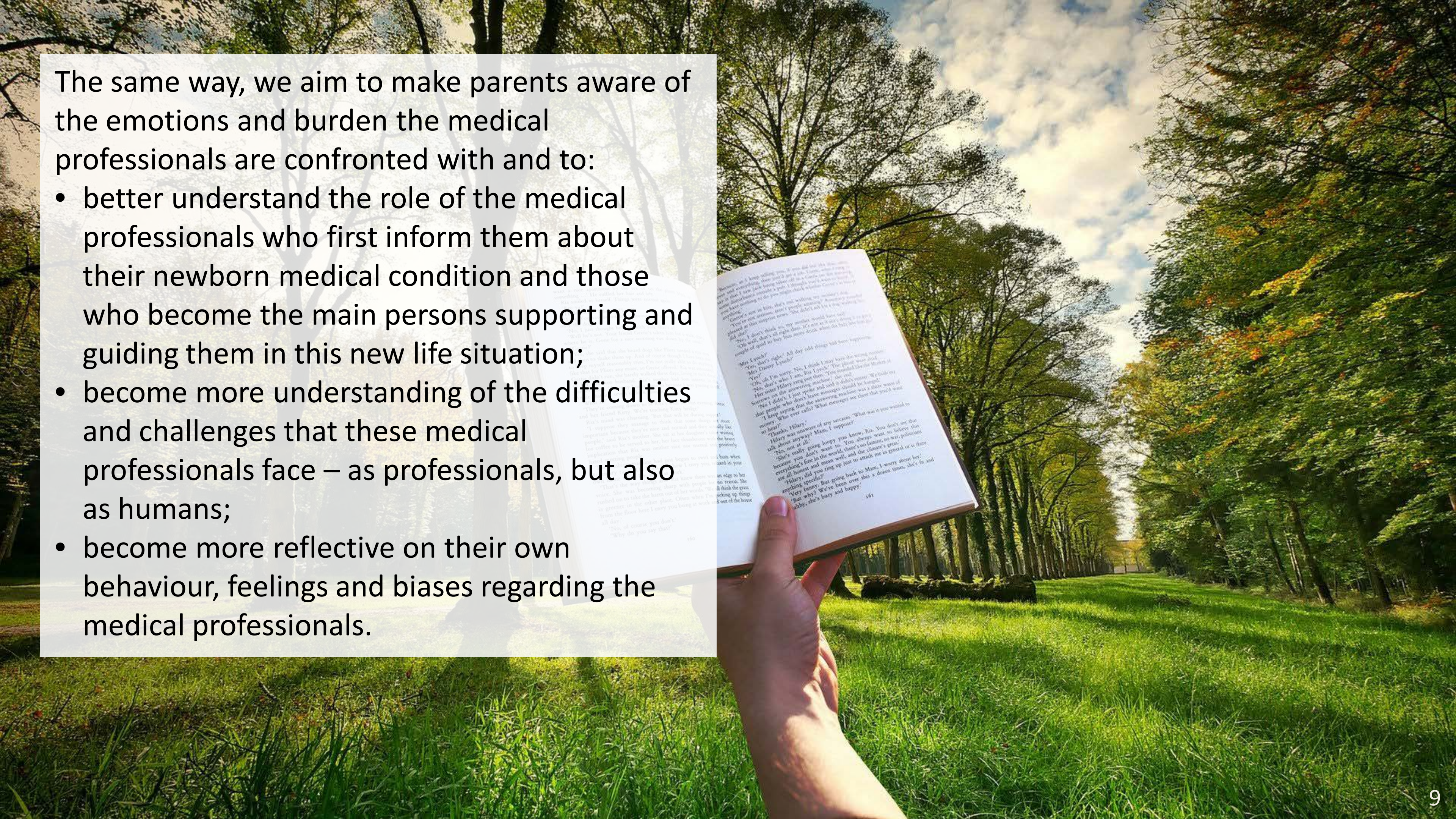
In order to choose the relevant Human Books, to make them available in the MedVET library, we made a small research: we had preliminary one-on-one interviews with potential volunteers, and we also organized focus groups with parents and medical professionals. We wanted to better understand which are the “blind spots” in the knowledge and understanding of medical professionals regarding the behaviour of parents who are expecting or have a newborn with special needs, their necessities, expectations and vice versa. During the analysis of the data, we identified what is general and repetitive in the expectations and experience of the participants. This way, we were able to define the profile of the most “problematic” participants and circumstances that impede the interaction between the parents and medical professionals and thus to choose the most useful “stories” about communication between them.



So, instead of meeting together people with various backgrounds, we chose representatives of parents, doctors, nurses and midwifes and their stories to be read. Their stories are very emotional and authentic. Even if they come from Belgium, Turkey, Romania or Bulgaria, the problems and challenges they face and the topics are common.

Creating this LiveBook Library, we hope that medical professionals (doctors, nurses, physiotherapists, midwives, doulas, social workers, care givers, etc.) will:

- understand better what parents of newborns with special needs feel (their fears, suffering and hopes);
- become more reflective towards their own behaviour, feelings and biases regarding the parents who are expecting or have newborns with special needs;
- share their unique experiences, achievements and failures in supporting and interacting with such parents;
- be motivated to communicate and interact more effectively and carefully with parents who are expecting or have newborns with disabilities.



The same way, we aim to make parents aware of the emotions and burden the medical professionals are confronted with and to:

- better understand the role of the medical professionals who first inform them about their newborn medical condition and those who become the main persons supporting and guiding them in this new life situation;
- become more understanding of the difficulties and challenges that these medical professionals face – as professionals, but also as humans;
- become more reflective on their own behaviour, feelings and biases regarding the medical professionals.

Welcome in MedVET's LiveBooks Library!

Sit comfortably in your armchair and enjoy the stories of the real people we put you in touch with! Get excited about their life experiences and learn how they need to be communicated with. Remember other similar stories and contexts from your work, and make plans for the future!

Printed edition: Do scan the QR Code below each video screenshot with your smartphone camera, to watch the movie of the story.

1. LiveBook of Doctor Mihaela Demetrian (Romania)

Neonatology doctor, with 27 years of experience, who shares about the stages of communication that a professional goes through during her career. She explains how she communicates with parents depending on the gestational age at which the child is born and depending on the severity of the condition. She also tells us how she communicates with parents with multiples, whose medical condition is different. Dr Mihaela Demetrian says a doctor should never communicate without empathy and she considers that the neonatologist should put him/herself in the parents' ”shoes”.

2. LiveBook of Mother Mihaela (Romania)

Mihaela is the mother of 6 years old twins. Even if they are healthy now, without sequelaes after the preterm birth, Mihaela is still fighting to find her equilibrium, to get rid of the deep depression she experienced. She has many examples of bad communication with medical professionals, during those vulnerable moments, when she needed to be strong… She should have needed complete medical information, but also a psychologist to accompany her, immediately after the birth of the children.

3. LiveBook of Mother Adela (Romania)

Adela is the mother of a 9 year old disabled girl, who has a rare genetic disorder, Sturge-Weber Syndrome. She is also a NGO professional, having and association for severely disabled children in Romania. She shares many good examples of communication, one of which is that a neurologist told her that raising a child with a disability is similar to caring for a bonsai (it only requires more attention and care). After a long process, she managed to balance and enjoy life with her special little girl.

4. LiveBook of Mother Maria (Bulgaria)

Maria is a mother with 3 boys conceived in vitro: a first pregnancy with twins and the second one with one boy. She tells us about her perfect pregnancy (the second one), how everything was going according to the initial plan, until the 6th month pregnancy when, during the foetal morphology, she and her partner found out that the child probably had Down Syndrome and that the foetus was also expected to have Tetralogy of Fallot. They searched for other opinions and they refused to abort the baby. Maria found the strength in the dialogue with an old yet very experienced cardiologist, who gave her hope.

5. LiveBook of Nadezda (Bulgaria)

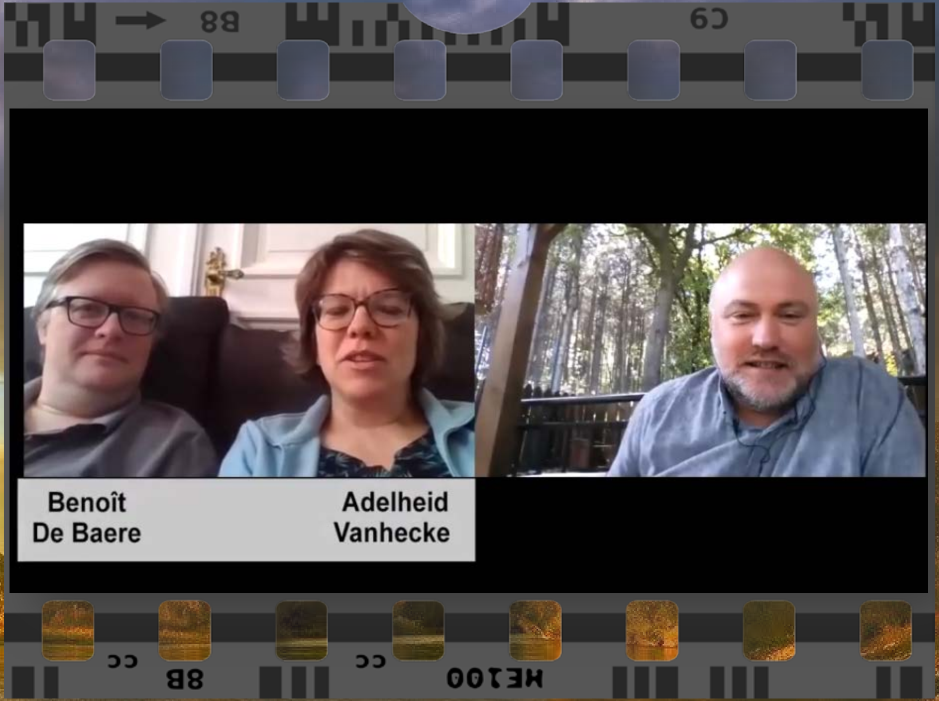
Nadezda is a mother of a 6 years old girl with Down syndrome - Vyara. She shares with us the story about her pregnancy especially when the doctors discovered that her baby will have Down syndrome. The mother speaks about the dehumanizing way of communicating the diagnoses while at the same time the doctors have done their work as medical professionals in the best possible way. It is a story about a consecution of communication challenges, not only during the pregnancy period but also during the delivery, as well as during the stay in the hospital.

6. LiveBook of Father Karel (Belgium)

Karel shares with us the emotional experience of a father (raised up in a catholic family), finding out, during the pregnancy of his partner, that the baby has Tetralogy of Fallot and the XYY syndrome. He fights for the right of the child to be born, and in the end, after birth, they discover that the heart problems were not that severe, as they anticipated. He also focuses what they, as parents, did for their son's ongoing rehabilitation, and how they overcome one step at a time.

7. LiveBook of Adelheid and Benoit (Belgium)

This is the story of a couple with a premature born in the 25th week of gestation. The parents, rational people, were very pleased with the informal and professional approach of the Belgian doctors and nurses, although many parents felt the lack of empathic communication. They believe that empathic communication can generate unrealistic, false expectations. The parents managed to take the situation as it was, because they realized that they had no choice, but just keep going.

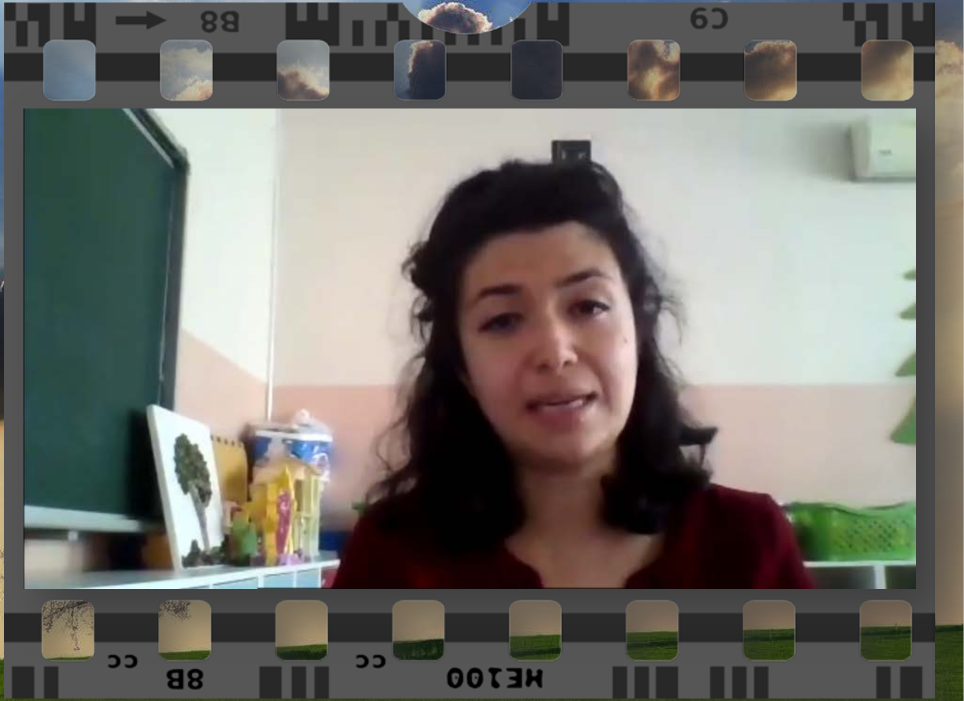


8. LiveBook of Professor Azime Sebnem Soysal Acar (Turkey)

From the testimony of Mrs. Professor Azime Sebnem Soysal Acar, we find out that burn-out refers to the cases in which it is insufficient to control ourselves to continue the daily work. Especially doctors, nurses and other service workers, working in the NICU, are at very high risk. The solution could be group support, but also individual support must be provided.

9. LiveBook of Mother Tuğba (Turkey)

This is the story of a mother who gave birth at an early stage because of toxaemia of the pregnancy. She was separated from her baby, immediately after delivery, because there was no available bed in the intensive care unit of the hospital. She describes the shock of seeing the baby boy for the first time in the incubator. She also explains how her perception level was very low, and she couldn’t understand the doctors’ explanations long after the birth. Tuğba found out that her son will be affected on the right side of the body, and she tells us how difficult it was to start his rehabilitation process because of the lack of information.



10. LiveBook of Professor Derya Buyukkayhan (Turkey)

Professor Derya Buyukkayhan is a neonatology and paediatric specialist. She explains how a multidisciplinary team should work in the NICU and emphasises on the essential role of early intervention. She considers that communication with parents is vital for the baby and also the more you prepare and empower a mother at this point, the more the baby gets support from the mother later at home.

11. LiveBook of Mother Beyza Sengun (Turkey)

Beyza is a mother who was unable to carry the pregnancy to term because of cervical stenosis. Unfortunately, during her pregnancy, she wasn't aware of the possible risks, due to the preterm birth. For the last 6 years, she and her husband have struggled a lot, financially and mentally, in order to support their son. She tells us how painful it was how doctors communicate with her and how she had one choice, in order to survive: either she had to destroy herself or reconstruct herself. Then she learned how to become the mother of her son and not the expert trying constantly to fix the children's health.

12. LiveBook of Mother Deyyan Altinsoy (Turkey)

Deyyan is a mother with a 9 year old boy with Down Syndrome and a typical 5 year old boy. Her husband works abroad and she tell us how difficult it was to take care of her children, alone, during the COVID-19 pandemic. Even if she was doing her son's therapies since the beginning of his rehabilitation, this pandemic forced her to change and adapt the rehabilitation methods to her son's medical condition. Despite of the quarantine, what matters is the longing for their father…

13. LiveBook of Doctor Maria Neshterova, head of the neonatology department at Selena Hospital (Bulgaria)

Doctor Neshterova is the head of a neonatology department with 10 years of experience. She considers that, even during the COVID-19 lock-down, doctors should make an attempt so that the parents can communicate with their babies via video telecommunication. She feels that every mother comes every day with a huge hope, and “asking eyes”, hoping to hear something good about the child’s medical condition. Unfortunately, sometimes much more time is needed for doctors to make them happy. If a child loses the battle, when the mothers cry, they hug each other and cry together.

14. LiveBook of Midwife Dinka Negalova (Bulgaria)

Dinka is midwife for 24 years and she is still happy with the choice she made when she was young. She shares the joy of the mothers but also, she shares their suffering as well. Dinka learned how to convey the bad news in a very delicate way, speaking like a mother to her daughter. She also encourages mothers with premature babies, giving them hope, and teaching them how to take care of their small baby.

15. LiveBook of Seyhan Firat (Turkey)

Another story of a Turkish father tells us how difficult is the bureaucratic part of obtaining medical documents yearly, and how serious it is that there is no communication between doctors and parents (one of his children was diagnosed with cerebral palsy at 13-14 months and the second one at the age of 4).

16. LiveBook of Physiotherapist Ayça Elbasan (Turkey)

From a recovery Centre in Turkey we learn how they approach the family as a whole, have medical recovery services in several areas, for the child, therapists and doctors who work together, and also how they educate parents about how to support their children at home. It is also very important for physiotherapists to love working in this field, with the disabled children and their family.

My notes

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More information at:

- https://www.medvet-project.eu/
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