

Elodie

In a world that it is run by adults, it seems that children's individual rights, particularly in relation to medical issues can be subservient to the wishes of parents and guardians. As children, we should be engaged in understanding the decisions taken regarding our own bodies. As an Anaphylaxis sufferer, having had interactions with both emergency departments and hospital outpatient centres, this issue is one that is close to my heart. We all have different levels of knowledge, some health conditions have names that are not even pronounceable by us, and the mechanisms and treatments of these illnesses may be hard to understand at any age but one thing that unites all people, regardless of our age, is our acute ability to feel pain as well as fear.

Every child has the right to the best possible health. The UN Convention on the Rights of the Child recognises that we as children have the right to express our views on all matters that affect us and surely there is no issue that may be considered as important as our own health. We as children recognise that the priority in every health decision must be in protection, to preserve life and health as the ethos of every practising physicians code of ethics and practice underpinned by the Hippocratic Oath and the Declaration of Geneva. We understand in that every interaction with children, the health of the patient must be the first consideration of any doctor, alongside their obligation to uphold our dignity as a patient whilst also ensuring that our age does not intervene between the duty of the doctor to us. This is a wide duty. There is a major difference in the medical understanding of a toddler to that of a 16-year-old, without even factoring in the nuanced differences of faiths, beliefs and hopes of children within that age range. But we as children believe it **is** possible to uphold both our protection as well as our autonomy.

We are so grateful to the Council of Europe for the steps that they have taken to promote our rights through their guidelines and strategies. But these are papers that are read by adults wearing smart suits with doctorates. Education on health is a pillar of the right to the best possible health that is enshrined under the UN Convention on the Rights of the

Child. This is why we have felt it is so important that we educate children, **us**, clearly and openly. The best way to do that is to consider our own experiences as children; what we want to know, how we want to be treated and to have faith that we, as children, have some control and autonomy over our own bodies, our health and treatment. Knowledge is power. I, along with Sara, Denis, Throstur, Lana, Nick, Molly, Leonardo, Christina, Rayan, Sarah and Jose who are all from different member states and backgrounds felt it was important to address health education in an accessible and sensitive manner.

Through online workshops we were able to air our own opinions and thoughts on how we could provide a universal written guide for children that children could read easily that would be supported through inviting yet calming illustrations and cartoons. We are grateful to our illustrators for so carefully taking our vision and putting friendly faces and characters to it and by so doing personifying and demystifying the often overwhelming process of attending with medical professionals. We are also grateful on a personal level for the encouragement given to our own artistic creativity in this process.

We understand the importance of this document in its universality, and we crystallised the crucial elements to address in the key messages through discussion and experience.

The first key element is that the **voice** of the child is prioritised. All children, no matter their age have the right to influence all decisions about their health. The child's opinion is so important in any health decision; ranging from a routine visit to a life-saving operation.

Secondly, **information**. It is crucial that every child can understand the details of their health situation. This acts as the foundation that will enable them to make any decisions on their health. Truthful, impartial information should be given in a way to suit a child's age and understanding. This is important as understanding varies considerably

regardless of age. Health professionals must take all steps to ensure that they are satisfied that each child has this understanding.

It is my belief that the four W's are important in breaking down each personal situation to the Child. Who? What? Where? and Why? Who is my physician and nurse? What are their roles? What is my condition? What are my treatment options? Where is my treatment going to be carried out? Why is this treatment required? Why do I have this condition? The child should be encouraged to ask questions. Their input is so important. If they cannot think of questions at the time, they should have a contact to provide these questions to outside of the hospital setting.

Spreading information is important, but so is the **transmission**. This information must be spread in a way that helps the child feel comfortable and safe. Adults should foster conversations in a way that is open and encouraging. Confidentiality of each person's medical status and treatment is a legal right, and this safeguard should be explained to the child to help them understand that doctors are under no obligation to share details of their illness or treatment. Also, although some information may be challenging to hear, the children must be fully aware of the whole process, even including pain or risk.

Disagreements are unfortunately inevitable in some cases, but the best interest of the child is always prioritised. For example, if a child does not want a treatment but it is needed for them to recover, the best interest of the child would be used. We recognise that we might have to sometimes undergo testing or examinations that do not feel good, the importance is that it is explained these are needed for the greater benefit for our health and to limit potential pain in the long run.

Before I pass over to Sarah, I just want give our heartfelt thanks to Child Rights Connect for her patience, kindness and support through the project as well as all the support from the Council of Europe in making our hopes to improve children's right to accessible health a reality.

Sarah

Thank you Elodie and I totally agree with you on that

The Role of Parents/Carers

Now we move on to look at the rest of the booklet, the role of parents/carers in regards to children's rights to Health and participation in their health. Their role is extremely significant as they are the people who support you and can offer appropriate guidance on certain medical situations, such as visiting the hospital or local doctor, but not just that, by discussing how you feel and expressing your views with your parents/carers they will be better informed and equipped to ensure your medical needs are met in a way that works best for you.

However, we must remember that parents/carers don't always get it right, which can result in them sometimes making the wrong decision, albeit for the right reasons. For example, some children can receive a diagnosis at an early age, but their parents/carers may choose not to tell them until they are older, in a sense trying to protect their child. Whilst at the same time the child may be struggling to understand what is happening to them or why they feel, or react in a certain way to certain things, which can cause a lot of anxiety for the child or develop a negative narrative self-image. As stated by James A. Garfield "The truth will set you free, but first it will make you miserable."

It is also important to remember that as a child you have the right to have your parents/carers alongside you during medical visits or treatments. If they are not able to be present a trusted adult or guardian can help.

Expressing your views

Most health professionals will usually ask you questions orally, although they can use other methods if required. You too can express your views verbally, however there are a range of different approaches you could choose. You can use body language, write it down or even draw, whichever method works best for you. For example, holding your arm out for an injection, is a way of demonstrating that you give consent, and you are willing to have the injection. Medical professionals due to their training should be able to pick up on body language and other forms of expression used to convey your views and opinions. Adhering to Article 12 of the convention on the rights of the child means that everyone, no matter their situation, should have a voice and have the right to be heard and respected. In some situations, you and/or your parents may be required to fill out forms of what you do and do not want. Your parents/carers can also advocate for you in these situations to express your views, remember it's okay to be unsure or uncertain sometimes, and ask your parents/cares to help.

Making Decisions

What can lead to a good decision being made?

Information is the key component in effective decision making, it is also important to analyse and discuss information thoroughly with all parties concerned the parents/carers, health professions and the child to ensure that the desired outcomes are achieved for the child and that the wants and the of voice the child are considered.

Therefore, adults should always listen to what young people have to say and take that young person's view seriously. Given this decision will affect the child now and, possibly in the future, it is essential that they have been given a voice and are okay with the potential outcomes, as they will be the ones who will ultimately have to live with it. Now as you age you will build on your knowledge and understanding and can be more involved in the decisions that will affect you. Though your opinion may weigh in more when you are an older teen that does not mean that the views and opinions of a younger child are not viable or as important.

How adults can implement this booklet

Now that we have looked at the all the chapters of our booklet and gained a bit more knowledge along the way we are posed with the question of how adults can implement this booklet. Adults whether parents/carers or health professionals alike would be required to read the booklet to gain an understanding of the importance of including young people in the decisions about their own health.

By adopting this approach Adults can encourage empowerment and autonomy in young people in relation to their health which can foster a sense of control and responsibility over their own well-being, promoting independence and self-advocacy.

This booklet needs to be promoted throughout health services, education and training and within communities to ensure that everyone is fully aware of this concept and encourages young people to become architects of their own futures.

I would also like to draw your attention to the annex included at the end of the publication It contains additional information that will prove useful for parents, educators, social workers, and healthcare professionals who wish to engage with young people and encourage their participation in their own health decisions.

I would also appeal to adults, if possible, to display this booklet and make it accessible to children as making these resources widely available, we can nurture a generation that feels heard, informed, and capable of advocating for their own well-being.

Let's work together to give every child a voice in their health journey!

To use a quote widely used by disability rights and youth advocacy movements "Nothing about us without us."