



Making hospital a happier place for children through play and advocacy

## **Children in Hospital Ireland Annual Lecture 2019**

### **The experience of teens in hospital - challenges and responses**

#### **A summary of the evening**



### Why this theme?

- Working with teens arose as a priority area from our recent consultations with stakeholders around the development of our three year strategic plan and the work priorities for that period of time
- Feedback from the consultations carried out by the Ombudsman for Children's Office (OCO) and the New Children's Hospital Group in 2018 highlighted this as an area for further consideration for hospitals
- The development of the New Children's Hospital and on-going work with the Youth Advisory Council to hear the views of young people who have experience of being in hospital
- Children in Hospital Ireland's pilot project in 2019 to work with our volunteers to bring new ideas for activities for working with teens in hospitals

Our keynote speaker for the evening was **Adam Harris from AsIAM** – Ireland’s national autism charity and advocacy organisation. Adam’s input was insightful, informative and very engaging and it provided a lot of food for thought in terms of how we should be aware of the many different perspectives of a hospital experience for a young person.

**These are a selection of key points that Adam highlighted for consideration to create inclusive and accessible hospital settings for autistic people:**

- A person may not speak but can understand (or vice versa)
- Consider what tools or skills you have to communicate with those who communicate in a manner other than speaking
- Processing time may be longer for an autistic teenager
- Be clear in your communication
- Don’t make promises you can’t keep
- Consider the importance of body language and tone of voice

**Adam spoke about how we might be aware of the signs of sensory processing differences and what the implications of these might be. There are ways that the sensory environment in hospitals can be improved:**

- Pillow breaks
- Have a sensory check list
- Hospital garments
- Demo-kits / de-sensitising opportunities
- Use anaesthetic cream
- Relation Boxes
- Quiet waiting area
- Quiet appointment times
- Awareness if how we use lights and pen lights
- Sensory map
- Keep spaces tidy and clear
- Less is more

### Top tips for Communication

- Don't use unnecessary words
- Use the person's name when speaking to them
- Say exactly what you mean
- Be mindful of the volume and tone of your speech
- Avoid negative language or phrasing
- Use interests to initiate and promote interaction
- Break instructions into steps
- Try not to generalise when praising or criticising



*Fiona Brennan, Assistant Director of Nursing, DLCHC, Adam Harris, Founder and CEO of AsIAM, Ashleigh Kiernan, member of the Youth Advisory Council, Margaret Burns, Chairperson, Children in Hospital Ireland, Anna Gunning, CEO, Children in Hospital Ireland, Eilish Hardiman, Group CEO, Children's Hospital Group and Rory Tallon, patient advocate with Cystic Fibrosis, Ireland.*

Following Adam’s input, there were three short inputs to give a perspective on a teenager’s experience of hospital, and the transitioning from paediatric care to the adult health care system.

**Rory Tallon: Patient Advocate with Cystic Fibrosis Ireland**

**Ashleigh Kiernan: Former patient of OLCHC and member of the Youth Advisory Council**

**Fiona Brennan: Assistant Director of Nursing at Our Lady's Children's Hospital Crumlin**

## Rory Tallon, Patient Advocate with Cystic Fibrosis Ireland

CF is predominantly a respiratory illness resulting in progressive deterioration of lungs over your lifetime. It is a genetically inherited illness. 95% of people with CF die of respiratory failure. You are born with healthy lungs. The journey from healthy lungs at birth to respiratory failure is your life. Every CF experience is different. Paediatric deaths in CF are becoming rarer now, where as they were the norm 30 years ago.



### Key areas of note for CF teens in hospital:

- Education is important. Technological approaches may be required for interconnected distance learning or similar.
- Hospital parking costs and availability as this impacts the teen's family support / carer support network visiting the teen, bringing fresh clothes and necessities
- Availability and cost of hospital snacks - there is very poor choice of healthy snacks outside of the in-patient hospital food menu. Patients with CF have huge energy requirements due to the nature of the illness and must snack regularly in addition to a regular meal routine. The hospital meal routine does not meet the nutritional needs of a person with CF. While daily calorie intake must be achieved - there must be a focus on achieving this through healthy eating
- Isolation in hospital due to risk of cross infection - important to have good quality WIFI to ensure that the young person can connect virtually with friends and family.

Transition strategies must involve education of the teen with CF about their CF and their management so that they can advocate for themselves, become proficient in discussing their health and have meaningful discussions with their healthcare professionals by themselves independent of adult careers- so that they will be ready for adult clinic and adult hospital.

Transition from child to adult services should depend on each individual case to a point in time that fits for the individual- based on how sick the individual with CF currently is (on lung health spectrum), how mature they are, age, and what's going on in their life, such as if they are due to sit a state exam etc.

Resulting teen challenges from CF are multifactorial- especially psychological and psychosocial- dealing with anxiety, illness literacy, body image, self-worth, delayed puberty, sexuality and sexual function.

A teen with CF admitted as inpatient is a very good opportunity for the specialist Multi-Disciplinary Team to spend the extra clinical time with the individual to discuss all above listed multi-factorial impacts of CF that the person with CF probably does not get the opportunity to learn about or discuss during the very short outpatient consultancies.



Anna Gunning, CEO, CHI



Margaret Burns, Chair, CHI



Eilish Hardiman, Group CEO, Children's Health Ireland



Play volunteers Evelyn Quinlan and Rosemary Murnane



Play volunteers Marie Staunton and Mairead McNamara

## Ashleigh Kiernan: Youth Advisory Council

Ashleigh presented her personal story of being diagnosed with cancer in 2010 and her experience of being in hospital. She spoke about the disruption that hospitalisation causes to your life and some of the challenges that she faced in hospital. She also spoke about the need for those who are caring for you in hospital to be aware that at times they just want to be left alone and need space for themselves. Ashleigh also spoke about the many positive experiences in the hospital and the friends that she made there.



Ashleigh is a member of the Youth Advisory Council which comprises young people who have all had the experience of being in hospital. The young people have experience from a range of hospitals in which they were cared for. Ashleigh spoke about how members of YAC provide details of their experiences with junior doctors and nurses and liaise with paediatric groups involved in the new hospital and urgent care centres sharing their experiences both positive and negative to help shape services into the future. They have been involved in providing valuable feedback to policy makers and to senior management in hospitals, as well as the New Children's Hospital Group on how the facilities and the overall experience of teens in hospital could be enhanced.

**Fionna Brennan: Assistant Director of Nursing at Our Lady's Hospital, Crumlin**

Fionna gave information on some initiatives which the hospital has taken around improving communication through the ACE initiative (**Accessible Communication for Everyone**).



**Objectives of ACE**

- To improve the quality and confidence of staff interactions with patients and families where there are additional communication needs
- To provide departments with a consistent approach to support communication
- To positively affect change on the culture of how services are currently delivered

Valuable feedback from hospital staff included suggestions in the following areas:

- Adapting Clinical Practice
- Improving Information
- Improved Identification of needs
- Staff Training
- Environmental Changes
- Multi Disciplinary Team Access



**Fionna highlighted the Three E's to note while working with teenagers in hospital:**

- Engage:** with child about their illness from a young age
- Equip:** knowledge and information to allow them ask the questions they want the answers to
- Empower:** to be autonomous during transition to adult centres

**Transition not transfer - more positive and inclusive**

In the past we transferred children to adult services but now we look at this as a period of transition where the individual young person is supported over a period of time. National clinical care programme has developed guidance for healthcare professionals. This is an area of growing interest.

Transferring care to adult physicians should be a **'guided educational and therapeutic process rather than an administrative event'**.

(Quote from the National Clinical Care Programme).

The Annual Lecture 2019 was a great opportunity for CHI to open a conversation around the experience of teens in hospitals and to include the perspectives of patients, hospital staff and advocates. The lecture was attended by a cross section of people including CHI volunteers, staff and board members, clinical and non clinical hospital staff, policy makers and other voluntary organisations working in the area. The evening was chaired by the CHI chairperson Ms Margaret Burns and included some time at the end for audience members to ask questions of the panel members.

The annual lecture provided a space for us to hear from the experts - those with experience; and we will now use this in moving forward with developing our practical supports and services in the hospitals and also our advocacy work to support the children and young people using the hospitals and their wider family.

A special thanks must go to our hosts in the Royal Victoria Eye and Ear Hospital for the use of their conference room on the evening. Also our gratitude to Commissary Catering for contributing the delicious refreshments. Thanks also to everyone who attended on the evening and we look forward to continue working with our partners and meeting you all again next year.