

Start	End	Topic	Speakers
10:30	10:45	The Four Boxes of medical ethics	William Gibson
10:45	11:05	Case 1	Marilena Gubbiotti
11:05	11:25	Case 2	Davina Richardson
11:25	11:45	Case 3	Ashani Couchman
11:45	12:00	Discussion	William Gibson Marilena Gubbiotti Ashani Couchman Davina Richardson

### Description

While incontinence is ubiquitous in neonates, for the vast majority of children both faecal and urinary continence is developed in the second or third year of life. However, for a myriad of reasons, for some children this milestone is delayed or missed.

Children and young people living with incontinence will experience challenges and difficulties in their lives, and these will often come with ethical challenges and dilemmas.

In this case-based workshops, the ICS Ethics Committee will explore the ethical issues that arise in children and young people living with incontinence, four ICS experts will present illustrative case studies to explore aspects of incontinence in children and young people, with a focus on the ethical issues which arise, including social impacts of continence, access to care, confidentiality, sexuality, and the transitions which occur as people living with incontinence develop from dependent child to independent adult.

### Learning Objectives

Following the workshop, attendees will 1) have an understanding of the guiding principles of medical ethics; autonomy, non-maleficence, beneficence, and justice, 2) be able to apply them to the unique challenges faced by children and young people with bladder and bowel dysfunction, and 3) understand the specific issues of confidentiality in this context.

This workshop, presented by the ICS Ethics Committee, will use a series of interactive case discussions to outline the challenges of delivering ethics-informed and person-centred care in children and young adults with different experiences of incontinence. Four speakers will cover the common issues with continence faced by children and young adults, the particular ethical challenges and dilemmas which arise in this group. Children and young adults experience incontinence for numerous reasons, including neurological conditions, neurodivergence, congenital. The workshop shall use a series of illustrative cases to explore the issues, and each will have an ethical conundrum to consider. The workshop will be interactive, encouraging discussion among attendees, and using online interactivity such as Mentimeter where possible, allowing the attendees to vote for their preferred course of action.

Bill Gibson, Workshop chair, will introduce the speakers present the 4 box model of medical ethics; Medical Indications, Patient Preferences, Quality of Life, and Contextual Features. This Paradigm will and discuss the general principles of medical ethics, with a focus on how they relate to children and young adults, and the concept of a "mature minor".

Marilena Gubbiotti (neurourologist) will present the case of a 10 year old child with Autism Spectrum Disorder (ASD) and mild cognitive impairment. The child had diurnal, continuous urinary incontinence and therefore the use of diapers during the day was necessary, without daytime symptoms. No therapy was ever performed due to the parents being "too busy". The child is a little embarrassed at school but the parents who would like to improve their child's urinary condition and are even more embarrassed. The child underwent toilet training with very good results.

Speaker 2 (TBC) will present a case of a 12 year old with faecal incontinence due to Hirschsprung's disease. The child is very embarrassed by his condition and wishes to keep it secret, but his parents wish to normalise discussion of bladder and bowel dysfunction and will often disclose the child's continence issue to friends. This case will discuss issues of confidentiality for young adults.

Ashani Couchman (urologist) will present a case of a 17yr old male with VACTERL and penoscrotal transposition and significant previous surgical history who is in the process of transitioning from paediatric to adult care. His ability to be autonomous is increasing however there is a significant developmental delay resulting in the inability to understand complex discussions or form an opinion based on the information provided. He catheterises intermittently but is irregular in undertaking this. He is

incontinent of urine and has embarked on his first sexual relationship. We would like to explore the alternative interpretations of his current clinical situation demonstrated by his parents and the patient himself, the considerations in planning management and support whilst ensuring he is empowered and safe.

### **Aims of Workshop**

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### **Educational Objectives**

While incontinence is ubiquitous in neonates, for the vast majority of children both faecal and urinary continence is developed in the second or third year of life. However, for a myriad of reasons, for some children this milestone is delayed or missed.

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### **Learning Objectives**

1. To develop an understanding of the guiding principles of medical ethics; autonomy, non-maleficence, beneficence, and justice,
2. To be able to apply them to the unique challenges faced by children and young people with bladder and bowel dysfunction
3. To understand the specific issues of confidentiality in this context.

### **Target Audience**

Urology, Urogynaecology and Female & Functional Urology, Bowel Dysfunction, Conservative Management

### **Advanced/Basic**

Intermediate

### **Suggested Learning before Workshop Attendance**

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