

MEDIA RELEASE

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NEW SERVICE HELPS PATIENTS WITH CHRONIC UROLOGICAL CONDITIONS TRANSITION FROM PAEDIATRIC TO ADULT CARE

Medical team in NUH's Adolescent Urology Service plans a transition process that enables children to move seamlessly from one care team to another

SINGAPORE — With improvements in care and outcomes, children with severe life-limiting illnesses live longer and mature into adulthood, bringing with them the chronic illnesses now influenced by the myriad of changes in adult life. It is well-observed that abruptly transferring care from the paediatric provider to a counterpart in adult practice often ends up with some patients quitting the follow-up appointments and suffering significant deterioration of their condition.

Chronic urological diseases in childhood affect a heterogeneous group of patients who require special expertise. With a deep understanding of the challenges surrounding the care of these patients as they enter adulthood, a team of healthcare professionals in the National University Hospital (NUH) set up the Adolescent Urology Service in September 2022, the first such service to be established formally in Singapore.

This service brings together doctors from different specialties to take care of patients in the outpatient and inpatient setting, with joint clinics and operations. The team has taken care of 55 patients since the service was established.

Many children with major congenital urogenital anomalies have lifelong medical needs. For example, children with spina bifida have a neurogenic bladder as the nerves in the spinal cord that control the bladder do not form properly, such that their bladders have trouble storing or emptying urine, or both.

When female patients with reconstructed bladders become pregnant, they may not be suitable for vaginal births and will require planned Caesarean section. This is one of several medical issues that patients with complex congenital urogenital anomalies may face when they reach adulthood.

Key to the transformation of care is the wholehearted adoption of the transition mindset, rather than forcing the transfer of care from one provider to another. While the setting up of a formal Adolescent Urology Clinic provided a “final” physical destination, the important change was a stronger partnership between specialists from two different disciplines to care for patients through their journey into adulthood.

Dr Melissa Tay, Consultant, Department of Urology, NUH, is usually introduced to the patient and the family in the Paediatric Surgery Clinic when the child is still being

followed up by Dr Nyo Yoke Lin, Senior Consultant, Department of Paediatric Surgery, Khoo Teck Puat – National University Children's Medical Institute, NUH.

Early participation in the care of these long-term patients builds rapport and gains trust for the eventual migration of the care setting to the Adolescent Urology Clinic, which is sited on the same Kent Ridge campus.

Dr Tay runs a weekly outpatient clinic under this new service and sees one to three patients each session. Once a month, she runs this clinic jointly with Dr Nyo, who, in a reversal of role, joins the adult care setting.

The clinic is also a space for doctors to discuss cases pending transition, review medical literature and train younger specialists in transition care urology.

Dr Tay is the only urologist in Singapore to be formally trained in the subspecialty of adolescent and transition care urology through a fellowship.

Patients under this service have conditions such as spina bifida with neurogenic bladder, congenital abnormalities of the genitourinary tract (which includes the urinary and reproductive systems), posterior urethral valve (a birth defect in boys involving an obstruction in the urethra caused by flaps of tissue) and hypospadias (an abnormality of the penis), among others.

Patients who were operated on in their childhood or have chronic conditions affecting their urinary system may develop complications as they grow older, hence they are closely followed up by the medical team. Issues may also arise with a change in the patients' size and physiology.

For example, those with spina bifida may encounter functional issues such as urinary leakage, develop urinary tract infections or stone formation, while men with hypospadias may develop urethral fistulas (an abnormal opening in the groin area where urine may leak out) or urethral strictures (narrowing of the tube that carries urine from the bladder out of the body).

Besides the physical shift of care setting, the adolescent and young adult patients are also gradually shifted from a care philosophy which is prescriptive, family focused with parental direction to one which allows for more autonomy, focusing on the individual fledgling adult. This care setting also allows for more candid discussions on emotions, sexuality and aspirations.

Dr Tay said: "The Adolescent Urology Service is dedicated to the long-term care of this unique group of patients, who will become effective partners in their own medical care as they mature and learn to be independent, not relying on their parents to direct their care."

Dr Nyo said: "The team adopts a flexible, coordinated and personalised approach to transitioning patients to the Adolescent Urology Service, depending on the patient's level of psychosocial development and medical needs.

"At NUH, paediatric care providers start to prepare their patients at an early age – as early as 12 years old – for the transition through discussions about their long-term care plan, which takes into account the surgical, endocrine, psychological, gynaecological and sexual needs of the patients," he added.

At times, particularly with patients who are staying in hospital for prolonged periods, Dr Tay may be required to start her involvement when they are hospitalised, beginning her long journey with them as an integral part of the paediatric care team.

Patient profile

When Janell Lim woke up one morning and realised she could not move her hands and legs, her parents whisked her off to the National University Hospital (NUH) in an ambulance. A battery of tests later, the 12-year-old was diagnosed with neuromyelitis optica, a rare autoimmune disease which damages the optic nerves and spinal cord.

The condition also affected the nerves that control bladder function, leaving Janell with an impaired ability to empty her bladder fully and requiring external drainage with a urinary catheter. Janell was taught to perform self-catheterisation, which involves inserting a thin, hollow tube through the urethra into her bladder to drain urine at regular intervals.

For six years since her diagnosis, Janell's urological needs were taken care of by Dr Nyo Yoke Lin, Senior Consultant, Department of Paediatric Surgery, Khoo Teck Puat – National University Children's Medical Institute, NUH.

Well before she turned 18, while Dr Melissa Tay was still completing her fellowship training, Dr Nyo broached the topic of involving a "jie jie (big sister in Mandarin) doctor" who will look after Janell in the longer term.

When Dr Tay returned to set up of the Adolescent Urology Service in 2022, Janelle was one of the first to transition to Dr Tay's care. As Janell grows, her physiology also changes from that of a child to an adult, together with the onset of new challenges and conditions that children face when they progress into adolescence and adulthood. She was transitioned to the new service over a series of combined consultations and procedures with Dr Nyo and Dr Tay.

Over the years, Janell has had her bladder pressure checked regularly with imaging and pressure volume studies to avoid the risk of excessive pressure affecting her kidneys. Despite the use of medication to slow deterioration, Janell's bladder progressed towards a high-pressure state over time, which posed a significant risk to her kidneys if left untreated.

In March last year, she underwent a bladder augmentation surgery which used a segment of her small intestine to attach to the walls of her bladder. This increased the volume of her bladder and reduced its internal pressure. The surgery was jointly performed by Dr Nyo and Dr Tay.

As Janell frequently acquired urinary tract infections and needed a caregiver to help her with self-catheterisation through her urethra, the doctors also created a Mitrofanoff appendicostomy, which is a new channel for catheterisation via an opening in her belly button. This way, Janell can put in a catheter through her belly button to empty her bladder independently, bypassing the urethra. This was done in the same sitting as the bladder augmentation.

After the surgery, Janell has not had any urinary tract infections. The 20-year-old is now more independent than ever – travelling around by public transport and attending lessons at Republic Polytechnic without her helper in tow. She has also started hydrotherapy in swimming pools.

Janell will continue to be taken care of under the Adolescent Urology Service. As she continues to progress through different life stages, issues pertaining to adulthood, such as her reproductive health, will also be managed under this dedicated service.

Chinese Glossary

National University Hospital (NUH)	国立大学医院(国大医院)
Dr Melissa Tay Consultant Department of Urology National University Hospital	郑惠文 顾问医生 泌尿科 国立大学医院
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About the National University Hospital

The National University Hospital (NUH) is Singapore's leading university hospital. While the hospital at Kent Ridge first received its patients on 24 June 1985, our legacy started from 1905, the date of the founding of what is today the NUS Yong Loo Lin School of Medicine. NUH is the principal teaching hospital of the medical school.

Our unique identity as a university hospital is a key attraction for healthcare professionals who aspire to do more than practise tertiary medical care. We offer an environment where research and teaching are an integral part of medicine, and continue to shape medicine and transform care for the community we care for.

We are an academic medical centre with over 1,200 beds, serving more than one million patients a year with over 50 medical, surgical and dental specialties. NUH is the only public and not-for-profit hospital in Singapore to provide trusted care for adults, women and children under one roof, including the only paediatric kidney and liver transplant programme in the country.

The NUH is a key member of the National University Health System (NUHS), one of three public healthcare clusters in Singapore.