

**Breakthroughs in children's medicine**

**Nursing**





Welcome 

**Welcome to our breakthroughs in children's medicine guide, focusing on nursing.**

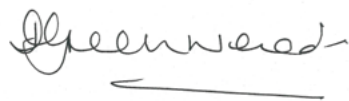
The roles of nurses at Great Ormond Street Hospital today are in stark contrast to those early days in the 19th century, when there was little regard for the profession. Now, they are experts in their well-respected fields.

Education and training have always been at the heart of nursing, from the appointment of the hospital's very first matron in 1852 to the award-winning programmes being led by nurses today. By advancing their skills and knowledge, our nurses are able to use new opportunities to advance their careers and educate medical professionals across the world.

Left: Ms Juliette Greenwood.

In addition, their work is enabling them to harness the full potential of technology and pioneer research studies that make the experience of our patients and families as comfortable as possible, at such a difficult and stressful time of their lives.

The dedication and determination of our nursing staff to always push the limitations of the care we offer to our patients and families have led to many exciting developments over the course of Great Ormond Street Hospital's history. I hope you enjoy reading about some of them in this guide, and that you continue to support our vital work. Thank you.

A handwritten signature in dark ink, reading "Juliette Greenwood". The signature is fluid and cursive, with a long horizontal line extending from the end of the name.

Ms Juliette Greenwood  
Chief Nurse  
Great Ormond Street Hospital

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Cover image: 12-year-old Ethan was born with bladder exstrophy and first came to Great Ormond Street Hospital when he was a day old to have surgery to put his bladder back in place.





Yesterday 



## The early days of nursing

Opportunities for nursing outside of the home were scarce in the early 19th century. Mothers were expected to care for their sick children at home, and housewives depended on well-established networks of support.

Most nurses were employed for their housekeeping skills rather than knowledge and experience of nursing. They were regarded by doctors as handmaidens, indistinguishable from servants or cleaners. According to Florence Nightingale, nursing was left to “those who were too old, too weak, too drunken, too dirty, too stupid or too bad to do anything else”.

When the Hospital for Sick Children – now Great Ormond Street Hospital – opened in 1852, it had employed its first matron, Mrs Frances Willey, who was

responsible for the housekeeping and nursing accommodation. Although the hospital committee set high standards for recruiting nurses, the focus was only on experience of caring for children and not medical knowledge.

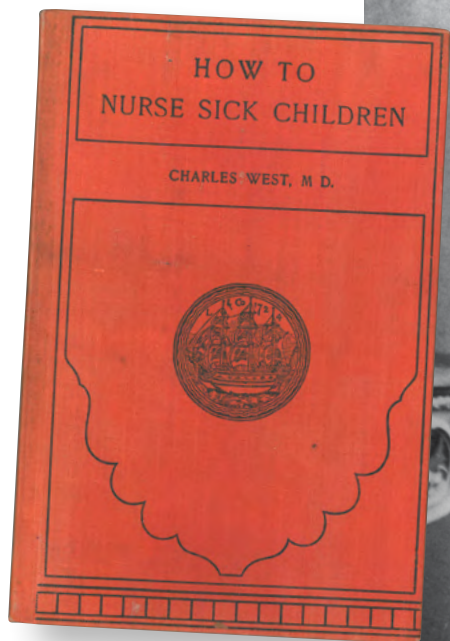
Two years later, the hospital’s founder, Dr Charles West, published his book *How to Nurse Sick Children*. He identified that nurses were “our best helpers... the real carriers-on of the hospital”. His views echoed those of Miss Nightingale, who had reorganised army hospital nursing during the Crimean War. They believed that by modernising and promoting nursing as a more respectable profession, they would be able to better serve the needs of the patients.

Right: Mrs Frances Willey.

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**1852** The Hospital for Sick Children opens on Great Ormond Street.





## Setting the standard

Developing attitudes towards nursing led Great Ormond Street Hospital to embark on improving standards. In 1862, the role of matron was replaced by the hospital's first Lady Superintendent, Isabella Babb, who introduced a new type of nurse: young, well-educated female volunteers, who worked as sisters and supervised regular nurses.

The most respected and influential of the hospital's Lady Superintendents was Miss Catherine Wood. She had been a lady visitor since the late 1850s, when she read to patients and undertook tasks that nurses were too busy to do. In 1863, she began working under the tutelage of Dr West.

Miss Wood believed that children thrived on love, and expected her nurses to act as motherly figures for the ill patients.

To her, toys and games were as important for a child's treatment as medicine.

Although not a nurse herself, Miss Wood believed in a proper training and certification scheme to regulate sick children's nursing, and introduced a specialist and rigorous training programme at the hospital. She thought it was essential for nurses to complete preliminary training – which included discipline, obedience, order, method and cleanliness – before moving on to the wards, where they would work for at least six months, learning to hold, feed, clothe and wash patients.

Working with Dr Charles West, Miss Wood helped to establish the hospital as a major centre for training nurses in the care of children.

Right: Miss Catherine Wood.

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**1888** Great Ormond Street Hospital offers a private nursing service, training private nurses to work in the community and treat children at home.

**1890s** Formal nurse training programmes are established at Great Ormond Street Hospital.





## Coming to Great Ormond Street Hospital

Nurses obtained professional status in the late 1800s, thanks in no small part to Miss Wood. She had continued to develop nursing at the hospital and beyond, and her campaigning took her to found the Royal British Nurses Association.

At Great Ormond Street Hospital, the developing structure of nursing had led to a hierarchy where the ward sister reigned supreme. If she was dissatisfied with the work of her staff, she would call them back after their shift had ended to finish the job properly. These duties included taking inventories of equipment and cleaning the cloth that was used for nappies. The ward sister viewed the children on the ward as her own. Nurses were expected to observe their patients at all times and know everything about them when questioned.

Sandie was a patient at the hospital in the 1950s, where she had an operation on her eye. “The nurses were caring and very kind to me...” says Sandie. “They went out of their way to make sure I was loved and cared for. I remember holding a nurse’s hand while standing by the window. She said that the Queen would be passing by soon in a carriage!

“My recollection of Great Ormond Street Hospital and the care I received from the nursing staff will stay in my mind forever. Of course, not being able to receive visitors was hard, but the nurses made that void bearable.

“I have very fond memories of a caring and dedicated team.”

Left: Sandie as a child.

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**1937** The inaugural meeting of the hospital’s Nurses’ League takes place.  
**1951** Matron Miss Gwendolen Kirby was the first nurse to attend board meetings at the hospital.



## The specialisation of nursing roles

The hospital began to radically change its ethos during the 1970s, moving from a focus on treatment solely for the patient to care for the whole family. The abolishment of restricted visiting hours for parents was almost complete by 1968, and now they were becoming more involved in their child's care. Accommodation was found wherever possible to allow them to be closer to their children.

These developments had a massive effect on nurses. They took on enhanced clinical roles, such as taking blood samples and inserting cannulas, and were responsible for developing personalised care plans with parents and patients, teaching them the necessary skills to look after their children.

The rising complexity of work and the specialisation of the hospital's wards

required additional nursing skills, which led to the establishment of clinical nurse specialists in the 1980s. This role expanded the areas of specialist care that nurses provided, from asthma and cystic fibrosis to neurology and pain relief. Gaining knowledge in a discipline meant that nurses could serve the rest of the hospital and pass on their expertise.

In 1980, Susan Macqueen was recruited as the hospital's first Infection Control Nurse after an outbreak of salmonella on one of the wards. This appointment led to increased staff education in hospital-acquired infection and the development of stricter controls for sterilisation and disinfection of equipment. Staff also began to adhere to new infection prevention guidelines.

Left: Susan Macqueen decontaminating a bedpan in the 1980s.

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**1960** The University of Edinburgh launches the first degree in nursing in the UK.  
**1978** The Charles West School of Nursing celebrates its centenary.





Today 



## Training patients and families in their own care

In order to deliver new and more effective ways of providing care to our patients and families, nursing professionals are constantly developing their advanced clinical skills and implementing innovative methods of care.

A team of advanced nurse practitioners in the Critical Care and Cardio-respiratory department have introduced a home-testing service for patients who take warfarin, a medication that prevents blood from clotting (also known as an anticoagulant). Some of our cardiac patients have artificial heart valves, which heightens the probability of producing a blood clot. These patients require daily warfarin medication, which needs to be consistently measured and monitored.

Usually, coming in to hospital or a clinic for a blood test takes half a day several times each week. However, by training families to use the device at home, the Cardiac Nurse Practitioner team are reducing the need for these appointments. In addition, the same group of experienced nurses dose the medication and monitor the patients, so they get to know them really well, providing individualised care.

Nochum is one patient who has benefitted from taking warfarin monitored at home. His mum, Ellen, says: “Nochum was cared for at the highest level. With the fantastic anticoagulation team looking after him, coupled with the self-testing machine that the hospital procured for us, Nochum can attend school and live his life like all other kids his age.”

Previous page: four-year-old Hassan on Lion Ward.  
Right: 12-year-old Nochum.

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**1994** The hospital's first Director of Nursing, Sally Nethercott, is appointed, responsible for the management of nursing services.







## Tailoring treatments for patients

One uncomfortable side effect of chemotherapy for patients with cancer is mouth infections. In the mid-1980s, a small group of junior nurses, including oncology nurse Faith Gibson, recognised that treatment for those infections was the same for every patient.

Instead of toothbrushes, all patients used pink sponges – thought to lessen the pain of cleaning one’s teeth – and took two oral medications. However, the sponges were ineffective at cleaning the gums, leading some patients to develop gum disease and consequently become more stressed and anxious.

After conducting their own research, the team of nurses discovered that the prescribed treatments were not based on any evidence. In response, they carried out studies with young patients and their families at the hospital and set

about creating a set of tools to assess the risk of oral infections, the first of their kind in the UK.

Thanks to this work, patients like Hattie, who came to Great Ormond Street Hospital after being diagnosed with a type of leukaemia, are able to receive the tailored treatments they need so that their experience is as comfortable as possible.

Since then, Faith (now Clinical Professor of Children and Young People’s Cancer Care) and her research team have refined international guidelines for delivering care to children with mouth infections. The tailored approach to treating these children means the risk of mouth infection is reduced, and they have a better patient experience.

Left: three-year-old Hattie with her mum Katie.





## Developing nurses to benefit patients

In 2003, Great Ormond Street Hospital introduced the role of consultant nurse, which allows senior expert nurses to remain in clinical practice rather than having to switch to management in order to progress their careers.

Consultant nurses use their advanced skills and knowledge to assess, treat and prescribe medicines, work that is traditionally associated with doctors. By educating nurses to take on more complex roles while retaining the core values of nursing, they are able to offer better care to our patients.

Sue Chapman was one of the hospital's first consultant nurses. She led the development of a number of different tools to help staff on wards identify when a child is beginning to deteriorate, including the Children's Early Warning Score (CEWS) system,

so that action can be taken as quickly as possible.

As Consultant Nurse, Sue could combine her clinical work with teaching. She also conducted research and is currently completing her PhD in Paediatric Early Warning Scores and the nurse's role in detecting deterioration in children.

“The patients and families I spoke to felt reassured that Great Ormond Street Hospital was looking out for them,” says Sue of her research. “Seeing a child experience a cardiac arrest is traumatic. If the CEWS system can help identify children and young people at an early stage, prompting staff to get senior help and potentially avoid the cardiac arrest happening, that can only be a good thing.”

Left: Sue Chapman.



## Helping dialysis patients return home

Patients who require dialysis treatment spend a lot of time coming in and out of hospital in order to use the equipment that keeps their kidneys functioning healthily. These visits mean they have to fit their lives around dialysis treatment, taking time out of school and away from the comfort of home. But a nurse-led programme at Great Ormond Street Hospital is helping to empower some of these patients and their families by offering a home haemodialysis (HHD) programme.

Clinical Nurse Specialist Lynsey Stronach worked with Consultant, Paediatric Nephrologist Dr Daljit Hothi to develop the programme. Lynsey and her colleague, Kate Sinnott, train children and their families on the wards, and follow up with home visits and weekly monitoring by phone and email when families return home.

The HHD programme has many benefits: the dialysis fits around the family so patients can go back to school full time and see their friends more often. The equipment is portable, so holidays are a possibility, and patients gain confidence and independence as they manage their own treatment.

Livia and her mum Annamarie were trained to use the HHD equipment within just five weeks. “Home haemodialysis has given us normality,” says Annamarie. “Livia has more energy and is growing again. She has learned to cycle and to swim, she walks to school with her friends and she plays netball. Our hopes are limitless now thanks to the programme.”

Left: 11-year-old Livia with mum Annamarie.

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**2010** Great Ormond Street Hospital launches first nurse-led UK programme for provision of home haemodialysis using portable dialysers to children.

**2012** *The Great Ormond Street Hospital Manual of Children's Nursing Practices* is published.

## Meet the team

Nurses are an integral part of the multidisciplinary teams delivering the very best care to our patients and families. The diversity of their skills and expertise is essential to the important breakthroughs taking place at Great Ormond Street Hospital.



“ As a newly qualified nurse, I’m extremely humbled to begin my career at such an incredible hospital. There’s no such thing as a typical day – each child is individual, which presents distinct moments and challenges.

The biggest difference we make to children, young people and their families is to ensure their journey is as comfortable as possible by offering emotional and clinical support. Being at hospital can be stressful and upsetting, and if I can put a smile on a young person’s face when they are at a low point, I feel that I’ve made a difference. ”

**Neil Gibbons, Staff Nurse, Bear Ward**

“ On Sky Ward, a lot of careful planning goes into children having orthopaedic and spinal surgery, involving many different members of the multidisciplinary team. By teaching children, young people and their families how to use the equipment they need, we can and do get them back to their home environment where they can be around their family and friends.

We also care for adolescent patients and, where appropriate, encourage them to be experts in their own care, involving them in the decision-making and helping them to understand their condition. We support these young people as they move into adult services, which can often be a difficult transitional period. ”

**Amanda Mooney, Ward Sister, Sky Ward**



“ I've been at GOSH for more than 20 years. We've had to get to grips with several pieces of new technology in that time, including an extra corporeal membrane oxygenation (ECMO) machine, which delivers oxygen into a patient's blood. The ECMO service is led by a specialist group of nurses. They know the physiology of the heart and lungs and use the equipment to maintain the output from those organs for patients who are unable to do so themselves.

I've also been involved with the Berlin Heart – a mechanical heart – which is used as a bridge to transplant for our cardiac patients. When it was first used here, the team from Berlin came over to train us. Now, we train other members of staff on the function of the equipment. ”

**Barbara Childs, Lead Nurse, Flamingo Ward**







## Nurses inspired to innovate

New technology is inspiring nurses to find ways to train and provide reassurance to patients and families both in and out of hospital.

In 2015, Endocrine Clinical Nurse Specialist Sally Tollerfield developed a smartphone app to help parents with children diagnosed with cortisol deficiency. The cortisol hormone acts as the body's natural steroid. Patients with a deficiency can take medication to control their cortisol levels, but if they become very stressed or unwell, they cannot increase the production of cortisol. This can lead to a life-threatening adrenal crisis, which requires urgent treatment with a life-saving intramuscular injection of hydrocortisone.

“Parents can get anxious about giving the injection in the stress of a crisis,”

says Sally. “We recorded a short, simple training film and put it on the website. However, we realised individuals could only access it on their phones if they had a signal.”

Sally worked with the hospital's Medical Illustration team to design a new app, ‘My Cortisol’, which would make the film available anywhere at any time. The staff use the app in clinic to train parents and patients, who can then use it outside of hospital.

As a result of her innovation, Sally was shortlisted for a prestigious Nursing Standard Nurse Award 2015. Her success has inspired other departments to consider how they can develop similar apps to help patients with other conditions.

Left: 16-year-old Monica and her mum Juliet watching the training film.

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**2015** Great Ormond Street Hospital Clinical Nurse Specialist Nicola Bennett-Rees receives an MBE for services to nursing.



## Research nurses: core to care

Research is essential to understand more about childhood conditions. At Great Ormond Street Hospital, support from clinical research nurses is key to helping embed research into all aspects of care.

Clinical research takes place across the whole hospital, although much of it is based in the hospital's Somers Clinical Research Facility. Having dedicated clinical research nurses gives children and their families the opportunity to participate in a clinical trial when there may be limited or no treatment options available. It also means they avoid lengthy waits to see the consultant, and nurses can spend time with patients to give them a better understanding of their condition and treatment.

The support provided by clinical research nurses includes recruiting children and

young people to a trial, administering the trial medication, and performing laboratory work. There are now more than 40 clinical research nurses working at the hospital. Thanks to their success, the amount of clinical research taking place at the hospital has increased. In addition, one of the first clinical research practice educators in the country has been appointed to work closely with other teams to raise the profile of research across the hospital.

This integrated approach to the clinical care of patients at the hospital means there will be more opportunities to provide access to the newest, cutting-edge treatments for our patients.

Right: Amy Jones,  
Senior Critical Care Research Nurse.



## Harrison's story

Harrison's family noticed something was wrong when he was three years old. His one-year-old brother, William, had started to walk independently, whereas Harrison was still using the furniture to pull himself up.

A genetic test revealed that Harrison had Duchenne muscular dystrophy, a condition that causes his muscles to gradually deteriorate. Sadly, his parents were told that there were no treatment options available.

Harrison's family came to Great Ormond Street Hospital in search for answers. Paediatric Neurologist Professor Francesco Muntoni offered help in the form of a clinical trial.

Harrison's trials take place in the hospital's Somers Research Clinical Facility, a state-of-the-art area that

provides specialist day care and accommodation for patients taking part in clinical research. Neuromuscular Research Nurse Katie Groves and Senior Research Nurse Naomi Antcliff help to deliver Harrison's trials.

"Katie and Naomi look after us as much as they look after Harrison," says dad Alex. "Nothing is too much. For example, they made sure that Harrison had an Xbox to distract him from the treatment. They appreciate we are in a challenging situation. It's very difficult watching your child become distressed. They understand that and support us."

Harrison's trial is ongoing, but Alex is hopeful that it will make a difference: "Getting on a trial is the Holy Grail. It's the only thing that can help Harrison."

Right: nine-year-old Harrison.





Caring for you today

Ward  
CLINICAL RESEARCH  
FACILITY

Date  
3<sup>rd</sup> Sept 2015

SHIFT

arrived to  
study today

10

We have  
on duty today

NIGHT

We should  
not duty





Tomorrow 

## Educating the nurses of tomorrow

Education and training have been vital to the development of nursing at Great Ormond Street Hospital since it opened its doors in 1852, and always in response to the needs of our patients. The hospital recently received recognition for the training it provides to nurses – for example, teaching those with limited paediatric experience how to communicate with children and helping patients to become active participants in their own care.

Renate Tulloh is an advanced nurse practitioner (ANP) who works with children who have been diagnosed with oncological and haematological conditions. ANPs like Renate support children and families throughout their cancer journey by providing expert clinical care, management plans and emotional support. ANPs also use their

breadth of knowledge and clinical experience to help nursing and medical teams.

“Part of my role is to lead advanced practice within the Haematology and Oncology division,” says Renate. “I support new doctors and nurses by working alongside them. I have a weekly nurse-led clinic where I focus on children with brain tumours and I often spend my time teaching doctors and nurses about the care of the child with a brain tumour.

“ANPs should not be seen as ‘mini doctors’: we’re nurses with advanced skills that we use to enhance patient care. Our roles are constantly evolving because education and development are a continuum.”





As ANPs advance their roles, many of the competencies once considered to be part of advanced practice are becoming essential to the role of everyday nursing. This is helping to expand the skills and

knowledge of nursing staff across the hospital, enabling nurses at all levels to better meet the complex needs of our patients.

Above: Renate Tulloh, Advanced Nurse Practitioner on Safari Ward.

## Harnessing the potential of technology

The advancement of nursing at Great Ormond Street Hospital is enabling nurses to harness the potential of the hospital's state-of-the-art equipment and become leaders of life-saving developments.

Babies with hypoplastic left heart syndrome undergo a three-stage surgical procedure over a period of up to three years. During the first two stages, these young patients are extremely vulnerable to common illnesses such as colds, which could lead to sudden death.

This high risk led a team of cardiac liaison nurses to create a fragile baby home monitoring programme, where parents are trained across three sessions of basic life support to use handheld portable monitors that collect sets of data on their child. They provide this data to the hospital's cardiac nurses,

and if those results indicate that a patient would need surgery sooner, the hospital is able to act accordingly.

As the programme has developed, it has expanded to include patients with other serious heart conditions. Nurses are now also planning to launch a lifelong programme that will continue to provide support and expertise for children with certain heart conditions well into their futures.

“We say to our families: ‘just because you are out of the building, doesn’t mean that you are out of our minds’,” says Cardiac Nurse Specialist Laura Jarocki. “They’re not alone – we’re always here to help them, and we’re just at the end of the phone.”

Right: eight-year-old Issy is being treated at Great Ormond Street Hospital for cerebral palsy and hydrocephalus.



## Advancing nursing through research

Research at Great Ormond Street Hospital is currently supported by a team of dedicated clinical research nurses. As the hospital looks to embed research into care for every patient, it will offer opportunities to other nurses.

“We’d like research to be everyone’s business,” says Lorraine Hodsdon, Head of Nursing for Clinical Research. “Our team of clinical research nurses will continue to facilitate research, but other nurses could be involved. For example, a bedside nurse would be able to collect samples from a consenting patient, which would give them experience they wouldn’t otherwise have.”

Training nurses to understand what is required when carrying out research will be a key element in the development of their roles. One approach to this goal is via clinical academic careers.

“After qualifying as a nurse, one can complete a master’s degree or PhD with an element of clinical practice,” says Professor Faith Gibson. “Once a nurse has completed their preceptorship, they’ll have gained a degree and clinical nursing skills.

“The experience that nurses will have gained from the research element of their degree will enable them to ask more clinical questions. Therefore, they will have a greater understanding of what is required in research studies, but also continue to deliver expert nursing care that they learned as part of their clinical practice.”

Right: Lorraine Hodsdon with Christy Rowley, Operations Manager for the Somers Clinical Research Facility at Great Ormond Street Hospital.



**NHS**  
Great Ormond Street  
Hospital for Children  
and Young People  
Head of Nursing

LORRAINE HOODON  
Nursing Professional Practice Lead

## Thank you

We have come a long way since the Hospital for Sick Children opened in 1852. Our dedicated and passionate staff have pioneered many new and better ways of treating children with some of the most life-threatening conditions. But we are yet to find a cure for all of the children and young people.

Throughout the hospital's history, it has been the continued and generous support of our donors that has helped to fund the research that provides new breakthroughs. With your ongoing generosity we seek to give hope to all children that need our specialist help.

Right: 12-year-old Alfie with nurse Charlie.









# Find out more

Our website has more information about the specialists, patients and treatments you've read about in this guide, as well as the pioneering research Great Ormond Street Hospital carries out.

If you'd like to find out more, or you have your own stories that you'd like to share with us, please visit **[gosh.org/breakthroughs](https://gosh.org/breakthroughs)**

We need to raise money to continue to support the legacy of breakthroughs

at the hospital. Your donations are used to rebuild and refurbish the hospital, to fund the most up-to-date equipment, to support research for breakthrough treatments and to provide accommodation and other support services for patients and families.

These are just some of the developments that have taken place since the hospital opened in 1852. Amazing things continue to happen at Great Ormond Street Hospital every day.