An out-patient service

One of the biggest changes in St John’s 150 year history has occurred within the last decade – the closure of its in-patient wards. Instead of admitting patients to hospital for six to eight weeks at a time – a frequent occurrence in the past – today the department manages the vast majority as outpatients, thanks to advances in drug treatments and phototherapy.

In turn this has transformed the role from primarily ward based healthcare workers to the highly skilled specialised nurses of today. These specialised nurses may manage cases, administer day treatment or phototherapy, prescribe medicines, carry out surgery, and look after patients with highly complex needs who are living at home. They set national standards and guidelines and have conducted training courses across the globe.

Nowhere is the transformation in the way patients are cared for – and the role of the nurses caring for them – clearer than in the treatment of inflammatory skin diseases such as psoriasis, eczema and blistering conditions. Patients with severe
psoriasis comprised most of the in-patient population in the past.

St John’s had two 28 bedded wards at one point. Patients could be admitted for many weeks and receive daily topical treatments to control their skin condition.

Today, patients are still treated with lotions, creams and ointments in much the same way as in past decades but in a day centre rather than a ward. Applying lotions to the skin is a laborious, time consuming process but can provide remission. Care is provided by dermatologically trained Registered Nurses and Nursing Assistants, who all play crucial roles in the out-patient setting.

The last in-patient ward was closed in 2005. Today, the Dermatology Day Centre provides the same treatment with one difference – at night the patients go home. Some come three times a week and spend two to three hours having topical treatments and complicated wound dressings applied by the skilled nurses, most of whom have undertaken specialist training on caring for severe skin conditions. Occasionally, the patients worst affected will spend a week or two in the unit, staying in hospital accommodation if they live far away. But the real transformation in the treatment of psoriasis and some skin blistering conditions has been achieved through the introduction of the new biologic drugs. This can be seen in the figures. In 2003-4 there were over 120 in-patient admissions for psoriasis. Three years later there were fewer than 10. The impact on patients has been dramatic. But it presented new challenges for nurses.
Karina Jackson, nurse consultant and clinical lead for the day centre, said: “We are keeping psoriasis patients out of hospital by using highly effective but potentially dangerous drugs. But finding the right therapy can take months. Some people fail on one drug and need to try another. They start with standard therapy – ciclosporin and methotrexate – and if these are not helpful, then may move on to the biologics. Much of our work now is running drug initiation and monitoring clinics, supporting and coordinating patient care. We take at least 50 calls a day from patients who need advice about their treatment or are worried about side effects or concerned about their progress.”

The Dermatology Day Centre is open seven days a week and the nursing team treat patients with a range of inflammatory or blistering skin conditions, some requiring woundcare. Those worst affected are still admitted as in-patients, if they are acutely unwell. But today they will be treated on an acute ward in the Trust, visited by clinical nurse specialists from St John’s who will develop their skin treatment plan alongside other specialists, prescribe drugs such as steroids for eczema, and ensure they receive the best multidisciplinary care. The specialist nurses who do this also train other hospital nurses on caring for people with a skin condition.

Longstanding treatments such as coal tar ointment and paste bandages are still used in the Dermatology Day Centre with good effect.
The six specialties

Records show that the first matron of St John’s – Fanny Edwards – was appointed in 1869. Thousands have followed in her footsteps and today the Institute has 63 nurses (including a nurse consultant, three matrons and a head of nursing) of whom 25 are clinical nurse specialists. They are divided between six specialties: medical dermatology, skin cancer, cutaneous allergy, surgery and laser treatment, photodermatology and paediatrics. They also support two nationally-commissioned services for rare but severe conditions: Epidermolysis Bullosa and Xeroderma Pigmentosa.

While the nurse specialists in medical dermatology treat mainly patients with severe eczema, psoriasis and blistering conditions, in skin cancer they have taken on some of the tasks formerly performed by doctors.

The clinical nurse specialist for minor surgical procedures at St John’s operates on patients with suspicious moles or other lesions, and helps to train junior doctors in biopsy technique. Biopsies are samples of tissue taken for examination in the laboratory.

Skin cancer screening clinics at St John’s are run on the one-stop-shop principle so patients with a suspect skin lesion do not have to make multiple appointments.

Patients who come to the skin cancer screening clinic are assessed by a dermatologist or a skin cancer clinical nurse specialist first. If the patient has a suspicious lesion it can be biopsied or removed on the same day.
In the case of patients with disorders such as *Xeroderma Pigmentosum* and *Epidermolysis Bullosa* – both conditions that are extremely challenging to manage, especially in children - clinical nurse specialists will travel to the patients’ home to give advice on clothing, dressing blisters, feeding and how to protect them from the sun and other sources of ultra violet light, as appropriate. They also advise teachers on how to support affected pupils. In the rare cases when the condition deteriorates and patients are admitted to hospital, they provide care.

Nurse specialists operate lasers for the removal of birthmarks and port wine stains. They deliver phototherapy for the treatment of *psoriasis* and other conditions. In paediatrics, nurses face an additional challenge - supporting the whole family. Working alongside the clinical nurses are a team of research nurses who play a key role in recruiting patients to research studies and clinical trials, which leads to the development of new treatments for skin disease.
A nurse administering iontophoresis treatment (a weak electric current) to a patient with hyperhidrosis (excessive sweating). The nurse’s role has been transformed from ward-based healthcare to highly skilled specialised work.
Maija Hansen, deputy head of nursing, said: “In paediatrics, nurses support children and their parents and teach them how to use the medicines. They must make sure the child understands what they can do for themselves and that they feel comfortable doing so and at the same time empower their parents to help.”

A major growth area in the nursing workload has been in the use of extra corporeal photopheresis (ECP) for treating cutaneous lymphoma and graft vs host disease (a serious complication that can follow a bone marrow or stem cell transplant). This procedure involves withdrawing blood from the patient after the patient has taken a medicine called Psoralen. This medicine photo-sensitises the
white blood cells and they are then exposed to UVA light within the ECP machine. The patient’s blood is then re-infused back to the patient.

Ms Hansen, said: “There has been an increase in patients with graft vs host disease in the last six years following bone marrow transplants. We are now treating 125 patients a month who have two sessions each, lasting 2-4 hours per treatment.”

A big growth area has been in extra corporeal photopheresis (ECP): a treatment which involves withdrawing the blood from a patient who has been treated with a drug, psoralen, then exposing the blood to UV light to trigger a response before re-infusing it into the body.
From lotions to potent skin creams

There has been a big change in the skin creams and topical treatments used in recent decades. The St John's pharmacy once featured hundreds of items, including *hamamelis* (witch hazel) used to produce a soothing ointment, oil of bergamot, the main ingredient of eau de cologne which was used to mask unpleasant smells and *hydrargyrum* (mercury) used in ointments, now known to be toxic. All these have been superseded today.

Some concoctions were specially made up for a single patient, to a recipe their doctor felt would be most appropriate. Small batches of medication with a short shelf life proved expensive and made achieving quality standards challenging. In recent times the British Association of Dermatologists has dramatically narrowed the list of approved treatments. Topical steroids and emollients – moisturisers that prevent water loss – are the mainstay today.

Skin conditions can be disfiguring and there is high demand for help with cosmetic camouflage to disguise the effects. Patients are assisted to select the right products, find the right mixture for their skin tone and are taught to apply them. For those with *alopecia* (hair loss) there is a hair clinic where they are helped to choose wigs.
Four-year-old Jaiden from Chelmsford started losing her hair 18 months ago. Her mum Sarah said: “She had no hair at all at one point. The GP wasn’t sure what it was and we were eventually referred to St John’s. Jaiden had a biopsy taken and was diagnosed with alopecia areata in March this year.

“The condition is normally caused by stress, but we’re not sure what set it off. Her head is now covered in hair thanks to the treatment which involved a special type of shampoo that is only available through the clinic. She’s starting school in September so it’s brilliant that her hair has come back in time, as some of her friends had started to say things about her lack of hair.

“The children’s hair loss clinic is brilliant. I don’t know what we would have done if we hadn’t been referred to it, as no one seemed to know what was causing her hair loss or how we could stop it.”

The psychological and social impact of a disease that affects a patient’s appearance can be severe. Some suffer a catastrophic effect on their ability to function and lead a normal life.

Lynette Stone, former head of nursing at St. John’s oversaw the move of in-patient wards from east London to St Thomas’ in the 1990’s and she worked hard to ensure that patients’ psychological needs were addressed by doctors and nurses.

Today the need for psychological support has been formally recognised with the appointment of a clinical psychologist to medical dermatology (most recently in February 2014), who provides therapy to patients and helps staff better understand and support patients’ psychological needs.

“In the past nurses would often see patient distress and did what they could to provide emotional support but there was limited access to expert help. Now having trained psychologists in the department helps us provide support more confidently and we can refer patients for therapy if necessary,” said Karina Jackson.

St John’s nursing team has also established a course for parents of children with eczema, the first of its kind in the country. Parents are taught about the disease and available treatments, how to recognise infections and what triggers outbreaks. Anecdotal results suggest parents are more confident, the quality of life of their children has improved and GP visits have reduced.

“We are hoping to run a UK wide clinical trial,” Ms Jackson said.
**Education and training**

Lynette Stone, with co-authors Stuart Robertson and Helen Lindfield, published the first textbook on dermatological nursing entitled “Colour Atlas of Nursing Procedures in Skin Disorders” in 1989. She was a founder member of the British Dermatology Nursing Group, which fostered the development of specialist skills and there is an annual Stone Award to celebrate dermatology nurses of distinction.

St John’s established a course for nurses which was recognised by the English National Board in the 1990s as the first dermatology course in the UK. Short courses were also set up and nurse visitors started coming from abroad. An annual phototherapy training course for nurses is long established, led by Sister Trish Garibaldinos.

In 2006, Karina Jackson started a new dermatology care course, which was accredited by Kings College London and is offered at degree and MSc level. Ten to 15 nurses and others, such as podiatrists, undertake the course each year, drawn from London, the south east and further afield.

St John’s also runs a number of short courses including pharmacology and prescribing, long term conditions and dermatology, phototherapy, and biologics.

Research Nurses play a key role in implementing and managing a large portfolio of research studies and clinical trials within St John’s Institute of Dermatology which support the further development of treatments for skin disease.
All St John’s nurses are encouraged to undertake specialist training courses to advance their knowledge and skills.
St John’s outpatient and specialist day care services moved into a state-of-the-art new home at Guy’s Hospital in summer 2015. Part of the new Bermondsey Centre, dermatology services will be co-located with academic colleagues and research teams, as well as other specialties including allergy, lupus and rheumatology. They will also be located close to the new Cancer Centre and clinical genetics service, also at Guy’s.
The Bermondsey Centre at Guy’s has improved the experience of dermatology patients needing specialist treatment.
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