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“Patients often face a number of challenges, including accepting that they have a chronic, incurable condition and feeling lonely, isolated, and afraid”

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Q1 Could you tell us about your career journey and what led you to specialise in lupus care?

I qualified as a nurse with a First-Class Honours degree from the University of Birmingham in 2013. My final placement as a student nurse was on the renal medical ward at Queen Elizabeth Hospital Birmingham (QEHB), UK. At that time, I didn't know what I wanted to specialise in, but found myself really enjoying the placement and was subsequently offered a job as a Band 5 Staff Nurse upon qualification.

I was keen to experience all aspects of Nephrology nursing, so between 2013–2017, I rotated through renal medicine, renal surgery, dialysis, and transplantation. Advancement into a Clinical Nurse Specialist role appealed to me, and I began looking out for opportunities. In 2017, I saw an advert for a Lupus Clinical Nurse Specialist. This was a brand new, 5-year fixed-term post, funded by Lupus UK. The task, in summary, was to develop a cross-speciality (nephrology and rheumatology) nursing service for patients with systemic lupus erythematosus and to lead the lupus research portfolio. I was drawn to both the opportunities and challenges presented by this role, which included but were not limited to: advancing my knowledge and skills in the context of a highly specialised service; the variation of clinical and research work that aligned with my ambition to develop a clinical-academic career; and the future leadership opportunities which I hoped to use to support the development of services for

patients with lupus not only at University Hospitals Birmingham (UHB) but regionally/nationally.

Q2 You became University Hospital Birmingham's first Lupus Clinical Nurse Specialist in 2017. What were some of the biggest opportunities and challenges involved in establishing this role?

A significant opportunity in developing the Lupus Clinical Nurse Specialist role was securing charity funding. A grant from Lupus UK funded the role for the first 5 years, after which I was able to demonstrate its value and secure permanent Trust funding through the development of strategic business cases. I also receive funding from Lupus UK to support the delivery of educational meetings for members of the Lupus UK Nurse Network.

Another key opportunity has been working within an exceptionally experienced, friendly, and supportive multidisciplinary team. They have supported me in gaining the knowledge, skillset, and confidence necessary to carry out the role to a high standard and to strive continually to improve myself and the service. This includes both formal education (e.g., completing the non-medical prescribing course) and informal on-the-job training.

Developing strong relationships with industry partners has also provided valuable opportunities. These collaborations have led to invitations to attend and speak at regional and national meetings and conferences, facilitating my continuing professional development, expanding my

professional network, contributing to peer education, and showcasing the role and value of specialist Lupus nurses across the UK.

One of the greatest challenges has been managing the increasing demands on my time. My clinical caseload has approximately doubled between 2017–2026, and the care of these patients has become more complex as new treatment options and approaches have emerged. The time commitment involved in managing competing priorities has also increased substantially as I have become more established in the role.

Funding has presented another significant challenge. In 2024, I succeeded in securing Trust funding for a second lupus nurse. Sadly, this post became vacant in 2025, and the Trust revoked the funding. As one would imagine, this created significant challenges in terms of managing the workload, although I am hopeful that when the financial landscape improves, some funding may be reinstated.

I have also encountered stigma from patients, relatives, and colleagues, particularly during the early years of the role. This has mainly been based upon a widespread and longstanding belief that nurses are inferior to doctors. Challenging this takes years of hard work, determination, and collaboration to build trust, rapport,

respect, and awareness. Specialist nurse networks, including the one that I chair, have played a vital role in supporting this cultural change.

Finally, establishing a completely new service without an existing pathway or competency framework was a considerable challenge. As the first Lupus Clinical Nurse Specialist at UHB, I did not have a clear job plan or set of competencies to work towards, nor did I have a nurse mentor to train, support, and guide me in the role. There are not currently any formal pathways to support the development of lupus specialist nurses. The Royal College of Nursing¹ provides a competency framework for rheumatology nurses, but disease-specific competencies are currently lacking. The RCN does not currently provide a competency framework for nephrology nurses. These are unmet needs that specialist nurse networks (including the Lupus UK Nurse Network and Specialised Rheumatology Nurse Network [Spec-NET]) are currently working to address.

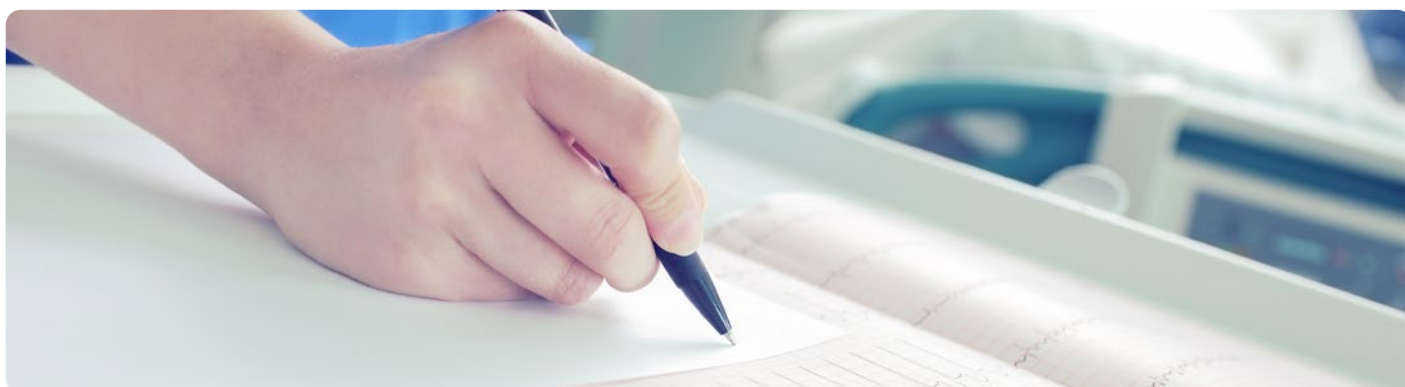
Q3 In your experience, what are the most common concerns or challenges patients with Lupus face, both at diagnosis and throughout their disease journey?

Patients often face a number of challenges, including accepting that they have a chronic, incurable

condition and feeling lonely, isolated, and afraid, particularly if they do not know anyone else with lupus. Having friends or family members who have also been diagnosed may influence their fears, expectations, or experience. Many have worries about medication side effects and pill burden, as well as difficulty managing their medications, for example by running out or forgetting to take them. Some patients also experience difficulty attending appointments due to competing demands on their time, such as work or family life, or logistical difficulties, including parking. Concerns about the potential impact of lupus and its treatments on fertility and family planning are common, as is healthcare anxiety, especially following an organ-threatening or life-threatening flare.

Q4 As lead nurse for the British Isles Lupus Assessment Group (BILAG) registry and a contributor to clinical research, how have you seen the lupus treatment landscape evolve over recent years?

There are now several more treatment options available than there were when I came to the post in 2017. Furthermore, there has been a shift towards the early use of combination therapies along with steroid minimisation, particularly in the treatment of lupus nephritis



(LN). This approach is consistent across all of the major guidelines, including the American College of Rheumatology (ACR),² the European Alliance of Associations for Rheumatology (EULAR),³ and the Kidney Disease: Improving Global Outcomes (KDIGO).⁴

Q5 There has been increasing attention on improving outcomes in LN. From a nursing perspective, what developments have been most impactful for patients?

LN is a cause of significant morbidity and mortality.⁵ Improving outcomes focuses upon rapid reduction of proteinuria using combinations of immunosuppressive medications and minimal quantities of glucocorticoids.⁶⁻⁸

From a nursing perspective, the development of new treatment options that supports the achievement of these outcomes can be summarised follows: patients now have a greater range of treatments to choose from, with the guidance of their clinician; they have greater confidence that treatment will be successful or, if it is not, that there are other options to explore; and they are less likely to experience steroid dependence or toxicity thanks to the introduction of lower-dose regimens and rapid tapering protocols.

Q6 Access to specialist lupus care can vary significantly across the UK. What inequalities currently exist, and what steps are needed to address them?

Access to clinicians with the relevant specialist knowledge/experience, access to specialist nursing support, and access to high-cost drugs are the main inequalities that currently exist in relation to lupus care across

the UK. Patients who are cared for at a tertiary/specialist centre are more likely to have access to these resources than those who are cared for at a District General Hospital (DGH).

Addressing these inequalities is challenging, but some practical steps that may be useful are cohorting patients with lupus into a dedicated clinic can provide a number of benefits, including enabling clinicians delivering these clinics to develop specialist knowledge and experience, which ultimately leads to improved patient care. It also improves continuity of care, gives patients with lupus the opportunity to meet others with the condition, and facilitates the collection of valuable data, such as patient numbers and outcomes, which can support service evaluation and business cases for additional resources. In addition, specialist centres should establish regional multidisciplinary team (MDT) meetings to discuss complex cases and ratify high-cost drugs, while clinicians in district general hospitals (DGHs) should be aware of referral pathways into these MDTs. Clinicians in specialist centres should also support colleagues in DGHs by facilitating access to MDTs and assisting with the implementation of recommendations, including the prescription, administration, and monitoring of high-cost drugs. Where it is not feasible to appoint a dedicated Lupus specialist nurse due to barriers such as limited patient numbers or funding, centres should consider supporting existing clinical nurse specialists to develop specialist knowledge and skills. This aligns with the objectives of the Department of Health and Social Care Rare Diseases Action Plan,⁹ which emphasises equitable access to specialist expertise.

Furthermore, all nurses involved in the care of patients with lupus are encouraged to attend one or both established specialist nurse networks: the Lupus UK Nurse Network and Spec-NET.

Q7 Education has been a major focus of your work through initiatives such as the Lupus UK Nurse Network and Spec-NET. Why is investing in nurse education so important for improving Lupus care nationally?

Patients with lupus are at high risk of morbidity and mortality.^{5,10} Access to prompt advice and treatment, ongoing monitoring of their condition, medicines counselling/prescribing/monitoring, psychosocial support, and co-ordination of multidisciplinary care all have a significant impact upon patient outcomes and experience. This includes improved patient satisfaction, reduced flares, and lower unplanned admission rates. Nurses are well placed to carry out these roles but require specialist knowledge and skills to do so effectively.

There are currently no formal career pathways or disease-specific competency documents to support nurses in becoming specialists in the care of patients with lupus. Furthermore, this tends to be a very isolated role as few centres have more than one dedicated Lupus specialist nurse. As a result, developing the knowledge and skills required to care for this complex patient group is challenging and can take a number of years. Even in centres where there are experienced specialist nurses, a lack of success planning means that the knowledge and skills developed are lost when these experienced nurses retire or decide to move on.¹¹

Some of the ways in which the Lupus UK Nurse Network and Spec-NET aim to address the issues raised above include: advocating for the value of Lupus specialist nurses, showcasing successful career pathways, developing disease-specific competency frameworks, and providing educational opportunities and peer support.

Q8 Looking ahead, what areas of Lupus care do you believe require the greatest attention from clinicians, researchers, policymakers, and patient organisations?

Priorities for clinicians should include: cohorting patients, ensuring that they have access to a regional MDT, advocating for the value of specialist nurses, and supporting the development of nurses within their centres.

Priorities for researchers should include developing new treatment options that support rapid proteinuria reduction and steroid minimisation whilst also being convenient for patients (e.g., reducing pill/appointment burden).

Priorities for policymakers should include strategic planning to urgently address the shortage of lupus specialist nurses in the UK.

Priorities for patient organisations should include developing patient support services that both complement specialist nurse services (where these exist) and help reduce the inequalities faced by patients who do not have access to these services.

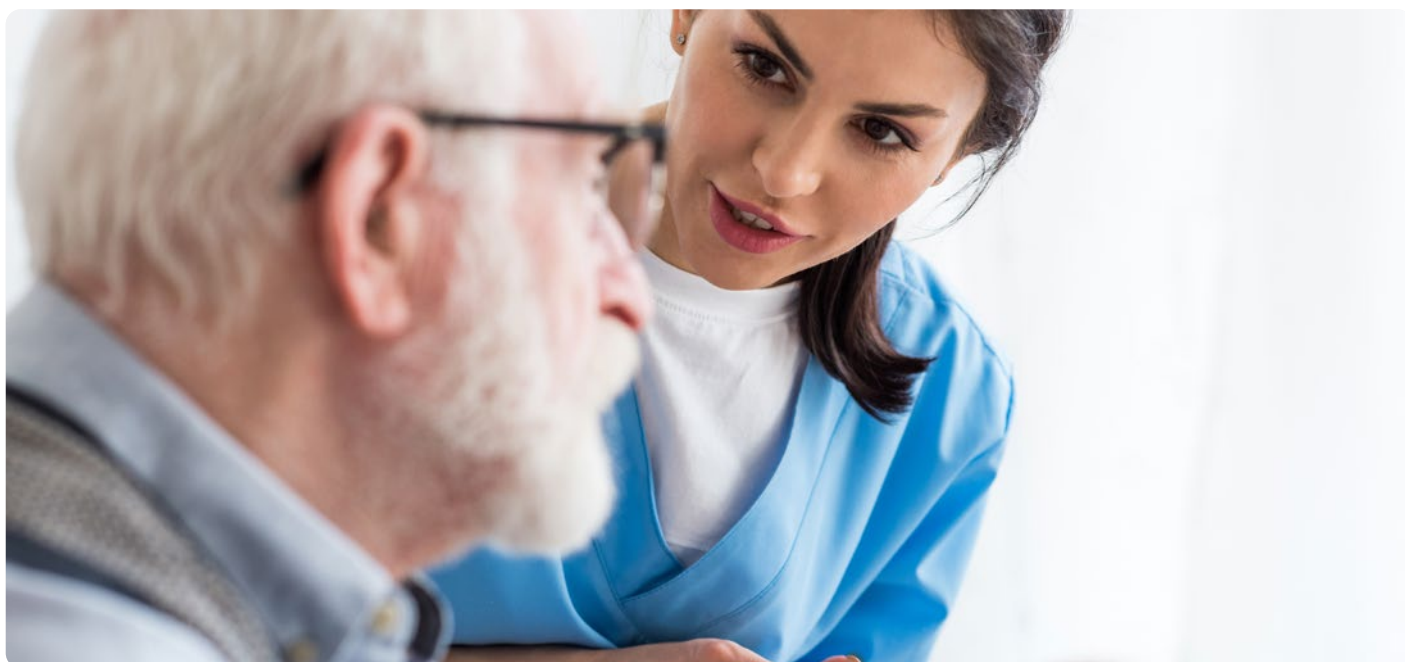
Q9 Finally, what message would you like healthcare professionals to take away about the value of specialist nursing in the management of lupus?

Specialist nursing in the management of lupus is a challenging, highly specialised but hugely rewarding role that makes a real difference to patients' experience and clinical outcomes.

The following quotes are from some of the patients whom I personally have cared for, with one patient stating, "Thank you for helping me receive the most suitable treatment and monitoring my situation, making me no longer

feel afraid and anxious." Others have commented, "You are always there and are supportive, caring, empathetic and reassuring," "Thank you for your time today. I really felt you listened to me," and "Thank you for all that you do, you truly go above and beyond." Another patient shared, "I have had fantastic service, support and clinical care since being diagnosed. I will always be eternally grateful."

Priorities for researchers should include developing new treatment options that support rapid proteinuria reduction and steroid minimisation



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