The Queen's Nursing Institute

Community Nurse Stories

Bringing Health and Wellbeing Closer to Home

Edited by
Suzanne Gordon

Contents

** All names have been changed*

Foreword

Suzanne Gordon

In the spring of 2018, when the QNI invited me to London to give a lecture at their annual conference, and hold two workshops following it, I don't think either I or the organisation imagined that this new relationship would result in this collection of stories that illustrate the power and importance of the work of community nurses. Over the past thirty years, I have given countless lectures to nurses all over the world. I have encouraged them to give voice to their work by moving beyond discussions of nurses' caring and trustworthiness and explaining how much skill, knowledge, experience, and expertise is involved in nursing practice.

I have also followed up these lectures with hands-on workshops that teach nurses to tell their stories in lay language so that their families and friends, as well as members of the media, policy makers and politicians get a vivid picture of their important work. More often than not, I parachute in and inspire a few nurses to tell their stories. Periodically, when I encourage their professional organisations, the hospitals for which they work, or the educational institutions in which they study, to truly support nurses as they tell their stories, people nod politely and then give nurses awards that portray them in the most gendered and stereotypical fashion. They are depicted as daisies linked in a chain, or angels executing spiritual commands from some higher being – whether a physician, hospital or nursing executive, or cabinet minister.

The QNI was different. My lecture was greeted with great enthusiasm. People came up to me in the reception that followed brimful of stories which they excitedly relayed in actual lay language. I'd expected that a few nurses who attended the two workshops that followed this lecture would produce some useful and interesting stories. I was, however, surprised by the alacrity with which participants grasped the message and recounted very detailed stories – again in comprehensible language – about their work.

What was even more surprising was how quickly the nurses in these workshops began not only to craft compelling stories but to encourage one another to acknowledge and take pride in their accomplishments. At lunch at the first workshop, a nurse who works with people experiencing homelessness told a story about her work. Four of us listened, awestruck not only by her caring and compassion but by her skill, grit, and persistence dealing with this particular rough sleeper. The nurse concluded her story by insisting that, 'Well, really all I did was use my common sense.' Before I could disagree, one of the attendees jumped in, 'What do you mean common sense?' Everyone at the table proceeded to laud her considerable achievements and insist that none of her work was a matter of commonsense. Instead, it was the result of years of study, knowledge, curiosity, reflection, and experience on the job. They all urged her never to downplay her skill and I know she took their words to heart.

After my workshops, the QNI arranged for me to follow a district nurse, Liz Alderton QN, for a day. Liz and I visited numerous patients in their homes. She coordinated care with other team members including the GPs with whom she works. In just one day, I estimated that she must have saved the NHS literally thousands of pounds – not to mention delivering high quality healthcare services and preventing pain and suffering for her patients. I was so moved and impressed that I decided I had to write up the experience and share it with the public. Thanks to the QNI, the article was published in the I (Independent online).

After my week in London, I was convinced that the stories of community nurses deserved a much wider audience. The QNI totally agreed. We decided to launch a much larger story telling project. The QNI asked me to return to London in June of 2019 to do two more workshops that would help recruit more nurses whose stories we would then publish. One workshop was for community nurses and another focused on the work of school nurses. During this time, the QNI videoed an abbreviated version of my lecture so that nurses all over the UK could learn how they too could move from silence to voice and explain the value of their work to the public. I was also thrilled when Crystal Oldman told me I would receive the highest of honors – becoming a Fellow of the Queen's Nursing Institute, an award I received at the June 2019 induction of a new cohort of Queens' Nurses at the QNI's annual Awards Ceremony.

I have been very privileged to help lead this Voice and Value project. The QNI was an amazing partner. Their leaders and staff – particularly Crystal Oldman and Matthew Bradby – devoted a huge amount of work to solicit the stories collected here. To do this, the QNI reached out to a variety of Queen's Nurses, asking for their participation, prodding and cajoling until we had the wonderful stories I then edited to eliminate any nursing or medical jargon that might make the narrative less clear or comprehensible to lay readers.

Although we wanted to launch the result of this project in the Spring of 2020, the Covid-19 pandemic interrupted this effort. Now, after a year in which community nurses have worked so hard to keep patients out of hospital and care for those suffering from long Covid, the QNI is launching a project which will help you see the value of nursing during more normal times. Just imagine how difficult this work has become during the pandemic.

The QNI has posted these stories on its website and compiled them into a short book that can be downloaded and made available to members of the media, policy makers, healthcare administrators, politicians and even other nurses who may not understand the value of community nursing. What is more the QNI is determined that this project is not a one-off event and we will be working together to collect the stories of community nurses during the pandemic.

When I do story telling work with nurses, I always learn an enormous amount about what it means to be a nurse, think like a nurse, and look at the world of sickness and health through the educated eyes of a nurse. The stories we have chosen illustrates how the National Health Service – and the patients it serves -- benefits from the work of community nurses. Yes, each of these nurses is very caring, committed to – and as nurses consistently tell me, 'passionate' – about their work. As these nurses make clear, nursing practice is not only heart work, but brain work.

The British healthcare system is very lucky to have nurses like the ones you will meet here. Every day they prevent pain and suffering, save lives and also, if you do the maths, save money. Community nursing in the UK is, I am convinced, a unique national treasure. Although nurses in my country, the United States, work in schools, in the home, community, and in care homes and long-term care, we lack anything like the well-elaborated models of community nursing that have been developed, over decades (and thanks to organisations like the QNI), in the UK. It has been both an honor and a pleasure to help nurses write about their work. I hope that more members of the public, policy makers, hospital and healthcare administrators, and even other nurses will listen to their voices and value their work.

Introduction

Dr Crystal Oldman CBE, Chief Executive, The QNI

I am delighted to introduce this book of community nurses' stories. The nurses who have written these stories are representatives of many different community specialisms and work in wide variety of contexts. The stories show the vast range of work that these expert practitioners undertake in people's homes and communities, with patients of all ages, carers and families, in town and country, every single day.

Most (though not all) of the stories have been written by our Queen's Nurses, following a workshop with the author Suzanne Gordon that took place in summer 2019. We intended to publish these stories in 2020 but were overtaken by the Covid-19 pandemic. We are thus publishing them a year later. If you believe, as we do, and as these stories illustrate, that community nursing is critical, imagine how much more important it is, and how much harder to accomplish, because of the impact of the pandemic.

Yet nurses are out there every day, caring for patients in homes, communities and nursing homes under even more challenging circumstances. We hope, in the near future, to work with Suzanne to document the work nurses have done and are doing, as they work to keep patients out of the hospital, care for patients with Covid-19, and with those suffering from Long Covid.

A word about our work with Suzanne Gordon. I first heard of Suzanne from QNI Fellow and former District Nurse Ann Keen, who spoke about Suzanne's passion to bring the real work of nurses to a wider audience. Suzanne has studied and written about healthcare for decades, not only in the USA but in many other parts of the world. She has campaigned for greater recognition and appreciation of the role of nurses in our society. She is also convinced that nurses need to be able to tell their own stories in a way that the public and the media understands. Too often we are told that community nursing is 'not well understood', even by people who have worked in health services for years. This book of stories is one way in which the QNI is helping to increase understanding of the vital nursing work taking place in every village, town and city every day, twenty-four hours a day.

Suzanne first came to the UK as a guest of the QNI in 2018 and thus began a process of tailoring her insights to a British audience. In 2019, Suzanne led a workshop for Queen's Nurses with the aim of producing a collection of stories about the value of their work in the community and over the following months, the QNs worked with Suzanne to produce the final versions you see in this collection

By presenting these stories our goal is to bring the incredibly diverse, complex and challenging work of community nurses to a much wider audience. We also aim to dispel some of the myths around community nursing and to support the case for improved resources for these vital services. To give one example, a nurse worked with an elderly couple to understand why they called out ambulances and went to the Emergency Department (ED) of the local hospital so frequently – more than 78 times in one year. By getting to the root of their concerns, this community nurse saved a vast amount of NHS resources, and the patient made no visits to the ED in the year that followed her interventions. Time and again in these stories we read about nurses who understand the bigger picture, who use their skills and expertise to work with people and the wider health, charitable and social care services to find a solution to their health problems. This can only be done with appropriate education, training, and experience.

We are incredibly grateful to Suzanne Gordon, who was awarded a QNI Fellowship in 2019, and to the nurses who have shared their time, skill and storytelling with us. I hope you enjoy their stories.

1. Finding Out What Matters

Anonymous

As a District Nurse, I am very aware of the importance of meeting not only clinical and diagnostic needs, but of helping patients – particularly those at the end of life or suffering from very serious illnesses – attain their goals and maintain a high quality of life. I did this recently when I was caring for a woman with motor neurone disease or ALS.

Because neither I nor anyone else on our team had ever cared for a patient with ALS (amyotrophic lateral sclerosis), the very first thing I did was contact the Motor Neurone Disease Association and learn more about the illness. Then I, as a District Nurse, went and visited the patient at home. The ostensible reason for the visit was to manage pressure sores. Clearly when a person is totally immobile, they are at a huge risk for developing pressure sores.

As soon as I entered the home, I recognised that there was a lot more to do than pressure sore prevention. The home was beautifully decorated and in impeccable taste. The kitchen was stunning, with exquisite wooden cabinets. Yet, there were dirty dishes and washing strewn about the house. This did not look like a house that typically had washing hanging off chairs, or stacks of dishes piled up near the kitchen sink. The woman – my patient – was sitting in a wheelchair and had mascara on her eyes. Since she could not have put the mascara on herself, I recognised that her husband must have done it for her. It became clear to me that having make up on was very important to her.

I talked to the patient and her husband about pressure sores and then asked them if there was anything else that concerned them. I discovered a whole host of other problems. For example, the woman had no friends and the couple was socially isolated. They had children but they did not live nearby. I and my team were their sole social supports. Over the course of the next few weeks, we made sure that our patient did not develop pressure ulcers.

I also learned that she was having a lot of trouble with saliva – oral secretions – and she was at risk of aspirating and developing pneumonia, which would have required a hospitalisation. Because I am an independent prescriber, I was able to prescribe medication to prevent that complication of her disease and hospitalisation due to it.

I also learned that her son was getting married and it was very important for her to wear the right dress with the right matching tights. Her husband, I learned, had chosen an outfit for her but she didn't like his choice of either dress or tights. I made sure she was able to wear what she wanted to the wedding.

At one point, my patient bit her tongue and was bleeding profusely. Paramedics were called in but had a hard time communicating with her and her husband. I was called in, was able to come to the home and help.

My patient eventually died of her disease but we were able to make sure she died peacefully. Her husband still sends me emails with pictures of their grandchildren.

Although I have moved out of a direct care role and am now managing a team of nurses, I am committed to making sure that I constantly acknowledge the nurses I lead for the excellent work they do. Just the other day, I received an email from a family. The mother had received wonderful end of life care from one of our nurses. I made sure to relay this to the nurse who worked with the family. Now I also make sure that in team meetings, we share our stories with one another. This empowers us and helps us all maintain a commitment to our critical work.

https://www.mndassociation.org/

2. Clinical Director for a Championship Football Club Medical Service

Professor Alison Leary MBE

I work as the Clinical Director of the Millwall Match Day Medical Service. Millwall F.C., located in Bermondsey, south east London, is one of the 92 clubs in the English Football League. I was the first Registered Nurse – indeed the first woman – to lead such a service. Most match day medical services are run by physicians – the majority of whom are male.

I never expected to embark on a career running a match day service for a football club. But in 1997, I was first asked to help someone out at the club on a locum basis. I ended up being the clinical director of the service in around 2008. When I began working for the football club, I was working in thoracic oncology. I am now Chair of Healthcare and Workforce Modelling at London South Bank University and the University of South Eastern Norway.

Our team is made up of different health care agencies and healthcare professionals. We have doctors and nurses. We have paramedics from the London Ambulance Service and volunteers from the St. John Ambulance. The number of people we have on the team varies depending on the risk of the game. The stadium is quite small, only holding about 23,000 people. If the stadium is full and the police have deemed the game to be high risk, then we need more people. So, depending on the game, we can have between 10 and 30 people on our team. We also do emergency planning and participate in public health initiatives, for example, prostate cancer or mental health awareness campaigns.

In football, clinical match day services really began with the Hillsborough Stadium disaster in 1989. Until about 2001 football medical services were organised primarily around disaster management. When I started to lead the service, my team and I began to collect data on the kinds of problems that we dealt with on match days. The majority of people we treated had exacerbations of chronic disease or minor injuries. They would have heart attacks or strokes, or epileptic seizures. They would fall down and get injured. About half of the things we see are problems that arise from pre-existing conditions.

However, post-Hillsborough, services were still organised around disaster management. The rules said that you had to hire emergency people on your team. They also said that you could hire a doctor as long as they had a three-day course from the Football Association. We found that, despite doing this course, doctors were not prepared for the work. We documented that this wasn't meeting demand because most of the problems we see do not stem from disasters but from exacerbations of chronic conditions or minor injuries. We knew that we had to change the make-up of the team.

My scientific background in healthcare modelling and mathematics helped us conduct the research and mount some robust arguments for change. Our data clearly showed policy makers that the configuration of the services needed to be revised and that we were running an unnecessarily high risk by not having the right people with the right skills in place. In fact, we had some near misses. The most important thing was to document that the policy of the regulator was not optimal, and the rules didn't work in real life.

Although we knew that change was needed, it was a very contentious thing to do. Some people were supportive but there were areas of resistance. But by gathering evidence and making a case, we were able to change the national policy of the English Football League, regulated by the Sports Ground Safety Authority. That change in policy meant that we were able to transform our team. We dispensed with the crowd doctor role and started to hire more general practitioners and nurse practitioners. We also work closely with senior paramedics, who have the best skills for managing an emergent disaster. A lot of the things we were seeing were better suited to that workforce.

I am at the stadium every time there is a match. Although the service meets demand better, we are never complacent. With a wide range of skills on our team, we are now well prepared for the routine work of dealing with emergencies like a cardiac arrest as well as disasters and mass casualties. And we are also constantly anticipating the next challenges. You never know where the next disaster is coming from. The world has changed and we now face threats not only from issues such as disorder but also from terrorism. We have to prepare for the routine as well as for these new threats. One of the ways we do this is by involving our supporters in all our initiatives, service redesign, and delivery. Every year we look at our service and review it to make sure it is still meeting the need and we do this with the input of our supporters.

Although I never expected to be in this role, I discovered that it is a very good opportunity for nurses because a lot of my work is in leadership. And leadership is a hidden facet of nursing.

3. Caring for a Man at Home during the Final Days of Life

Anonymous

Working in the community means you are managing a wide range of health needs, building relationships with patients and their families and working with other health professionals to adjust your care plan according to the changing needs of the patients over time. This role not only provides holistic care to those who need it but also provides integrated care, which ensures better value and outcomes for patients and the taxpayer.

I would like to tell you about a patient, whom I will call David, who had recently been discharged from hospital following vascular surgery. David needed ongoing care of his postoperative wound, which I provided.

As I entered David's house for the first time and followed him into the kitchen to do his dressings, I was struck by the number of paintings hung on the wall and books lining the shelves. In his mid 80s and following major surgery, David moved slowly but with focus and determination. He seemed determined to keep moving.

Sometimes the information we receive about a patient is limited when it comes to helping us understand their background history, so I asked David what had been happening. With a long history of vascular disease, he had had surgery to try to address the blocked vessels in his legs, which were causing significant pain as well as damage to his lower extremities.

As he talked I started to take off his bandages and became aware of the smell of necrotic flesh. He apologised because he could also smell the odour and I reassured him that I was used to this and that my concern was that he was not in too much discomfort whilst I dressed the wound. He told me that he was very conscious of the smell and so had stopped going out. We explored what impact that was having on his mental health and he shared that he was becoming quite depressed.

Now widowed, David had a son, with whom he was close but who nonetheless lived a long way away, which meant that David was quite isolated. He had been active until recently and was a painter but, due to his illness, was struggling to continue any activities.

As I dressed the wound, I could see this was not going well. I explained what the underlying pathology was and why things were happening. I also reviewed the list of medications he was on, reminding him of their functions and how to take them properly.

We agreed a care plan and after he was settled I left.

We visited him regularly over the weeks liaising with the specialist team at the hospital to prevent any unnecessary outpatient appointments or admissions. In spite of our care and close monitoring, the wound was not improving. We talked with the vascular team about the longer-term plans. It was agreed that there was nothing else they could do and that the only option was palliative care. Because his infection could not be cured, David would eventually succumb to it and die.

I contacted the palliative care team so we could do a joint visit and plan with David how to manage his pain effectively and agree where he wanted to die. He was clear he wanted to die at home surrounded by his books and his paintings.

He was aware of the prognosis but his main desire was to keep reading and exploring ideas and being with people. I knew of a centre nearby that ran art classes for older people and so went to see them to see if they provided transport for patients like David. They did. I brought David some leaflets about the centre and we agreed to sort out a visit to the centre.

When I saw him next, he told me he had been to the centre and was keen to continue going there as this had lifted his mood. In a very poignant moment, he told me that even though he knew he was dying, visiting the centre allowed him to focus on what mattered to him.

The leg deteriorated further and after one visit I was particularly concerned about his condition. After a discussion with my GP colleague, we asked the hospital to book him in for an urgent review. He was admitted and then developed sepsis, which they treated. When he left the hospital, he was frail and deteriorating more rapidly. Working with the palliative care team, we nursed him through managing his pain, palliative dressings of his leg and all aspects of care until he died peacefully at home with his son by his side.

4. End of Life Nursing in the Care Home Sector

Charlotte Hudd, Queen's Nurse

I am an older person's nurse and I have worked in the Care Home setting for eight years. In a 48-bed nursing home, I support people with complex physical and mental health needs, some with high dependency needs requiring one-to-one care. Nursing in this community sector is a privilege but its complexity requires great knowledge and skill in order to keep patients safe.

The kind of end-of-life care that nurses like myself deliver also requires critical analysis of the situation, the environment, and action to ensure resources are made available at the bedside. Carpets and curtains offer a home-like atmosphere. Underneath this thoughtfully constructed veneer lies a clinical environment in which unexpected surprises can, if not met with skill and creativity, defeat all our forward planning and jeopardize our patients, causing unnecessary distress to their families. Let me give you an example of the kind of challenges I face by relating the story of one of my patients – whom I will, to maintain confidentiality, give a pseudonym, Bob.

Bob arrived in the Home with advancing cancer and a poor prognosis. He was too ill to return to his own home and his wife was exhausted. The team monitored Bob's condition. He deteriorated more quickly than anticipated and became bed bound within a week. When I assessed Bob's condition on the day in question, I determined that he had days rather than weeks to live. He already had a 'do not attempt cardiopulmonary resuscitation' (DNACPR) directive. This means Bob wanted a natural death without invasive attempts at life support or defibrillation to start his heart if he had a cardiac arrest. Bob did not, however, have an advance care plan (ACP).

Patients are at risk of inappropriate and unwanted treatments and hospital admissions if an ACP is not developed in a timely manner. Expert nursing knowledge and courageous conversations in an equally timely manner prevent inappropriate hospital admissions every day from the nursing home sector. Inappropriate admissions take their toll, not only on the wellbeing of the individual, but represent a great financial cost to the NHS in travel, bed space, and resources. Relatives may also have to leave their work to visit hospitalised loved ones, not to mention that the hospital environment can be extremely stressful to families.

I met with Bob and his wife to have what is, for many people, a difficult conversation about death and end-of-life care. I explained that advance care planning involves making decisions about the kind of healthcare Bob wanted to receive both at the present and if and when he became unable to speak for himself. We discussed Bob's options, basing decisions on his personal values, preferences, beliefs, including medical and nursing care and treatment. Bob said he wanted conservative care with no more hospital interventions. Bob's wish was to remain in the home with the main goal of comfort and symptom management to ensure a dignified death. I documented our conversation. His wife and I signed the record as Bob was too unwell to hold a pen. Afterward I spoke with Bob's wife; she seemed relieved to have had the conversation.

I contacted the GP to communicate the care plan. I told her about my clinical assessment, the end-of-life discussion with Bob and asked for the necessary anticipatory medication that would relieve any pain, nausea, or agitation Bob might experience. The doctor agreed with my assessment and she prescribed the medication, which would be delivered through a small catheter below the skin. She said that she would also attend Bob on her ward round the following day. This couple were unassuming, quiet and rarely asked for help. They needed a lot of nursing support to ensure both were well cared for and so that they understood what was happening. Bob's wife came to visit every day. Two days after our first meeting, I met her again. I knew that Bob would die soon, perhaps within hours. When I explained this to Bob's wife she said that should Bob die when she wasn't present, she wanted to be called, no matter the time of day. She thanked me for our conversations and confided that they had buried their daughter earlier that year.

As Bob lay dying, we made sure that he did not suffer any distress. Everyone in the home team was communicated his wishes in our plan of care. There were no gaps between shifts of staff. I continued to support Bob's wife, who would now have to deal with the loss of two of the most important people in her life.

On the Sunday evening, two weeks post admission, after his wife left to go home for much needed rest, my patient died. I was not surprised that Bob died shortly after his wife went home. In my experiences in ward-based and community palliative care, I have learned that some people will die with company and others may wait until they are alone (even when there has been a 24/7 bedside family vigil). What did surprise me was that when my patient breathed his last breath, he died smiling. I had not seen Bob smile once during the days I cared for him; he was also grieving for his daughter. Of course, I will never know for sure, but it seemed that this quiet and pain free death had, in some way, brought Bob a measure of joy.

5. A School Nurse Intervenes for a Boy with Suicidal Thoughts

Chris McDermott, Queen's Nurse

Recent headlines around male teenage suicides have made me reflect on the school nurse role in supporting the emotional wellbeing of teenagers.

Some years ago, I held a well-publicised and well attended weekly lunchtime 'Drop In' clinic for students in a large secondary school. One day towards the end of the summer term, the school was unusually quiet because the older pupils had already finished exams and thus the school term. The rest of the students were hanging around in the playground and school games field enjoying the sunshine over the lunch hour.

The clinic room door was propped open. As I was sitting catching up on some paperwork, I could hear footsteps coming down the corridor; I looked up and saw a boy glance into my room and then walk by. The footsteps faded and then returned. Again, the boy looked into the room and walked by. My curiosity aroused I walked to the doorway, looking down the empty corridor I could see him standing 10 yards away. He turned towards me.

'Hello', I said, 'You okay?' I asked, 'Can I help'?

He walked slowly towards me, made eye contact in the doorway, and walked in. We sat side by side on two low chairs, facing towards the now closed door. He hunched forward in his chair, forearms leaning on his legs, hair hiding his face. Expressionless, motionless, he stared at the floor.

We sat in silence.

'You had lunch?' I asked.

He shook his head.

'Fancy a cup of tea? I'm having one, I'll get you one'.

The distraction of making and drinking tea appeared to reduce the silence. He appeared to relax.

'You seem sad,' I ventured, 'Is there anything I can do to help?'

He shrugged.

'Is this a bad day, or is every day like this?' I persisted gently.

At last some spoken words: 'Always like this.'

'Do you want to talk about it; sometimes just sharing how you feel can help?'

I was now duty bound to launch into my duty of confidentiality and information sharing statement, which I always make if I think someone is at risk. It is, however, always a conversation stopper. It was today.

He leant forward again and shifted in his chair. Time passed. I filled the void with reassuring words. Finally, he sat back in the chair, still staring at the floor, 'I just don't want to be here anymore!'

‘Do you mean at school or on this planet?’ I asked.

‘Anywhere, I can’t do this anymore!’ he exclaimed.

Finally, we were having a conversation, albeit one filled with monosyllabic comments that were stilted at times. The end of lunch bell rang. He looked about to leave but I told him he didn’t have to go.

With further prompting and responding to non-verbal cues, I finally asked the question, ‘Have you got a plan?’

Yes, he had a plan, he was going to jump. He had even researched sites including the school roof and how he could get up there. I further explored his feelings, and how I could get him some help. Together we thought about key people in the school we should tell. He chose the Head of School.

So now I explained my plan. I told him how I could get support to make him feel better. He nodded his head, and passively agreed to it. Together we walked to the Head’s office. To my relief he was in and available. With the boy’s permission I told his story. The Head was superb in his reaction, remained calm in his approach, and supportive of the boy’s feelings.

The boy remained with the head teacher. The school invited the parents to come in within the hour. I called the local child and adolescent mental health team and sought advice and arranged appointments.

I participated in the subsequent conversation with his mother, at which the boy was present but non-communicative. He was visibly struggling with the disclosure of his feelings to his parents. His mother was also upset. She recounted that she had been increasingly concerned about his behaviour and the fact that he was becoming more withdrawn from his family and friends over the last few months.

With key people in place to support him and keep him safe until his Child and Adolescent Mental Health appointment, my role was completed. He never visited ‘Drop In’ again but from conversations with the Head I know he engaged with treatment for low mood and depression. He returned to school in September in a much better place.

School Nurses support young people’s emotional wellbeing every day. They have the ability to be non-judgemental in their approach, have professional curiosity, are skilled at providing prompts to encourage conversations, and to read non-verbal cues. All this creates a safe place for young people to seek support. This kind of support improves children and young people’s health outcomes and life opportunities.

I wonder how the story would have ended if I hadn’t been in school that day. I have no idea why this young man picked that particular day to come looking for help. Nor do I know why his problems hadn’t been picked up earlier by family, friends or teachers.

I will probably never know, but I’m glad he did.

6. A Complex Presentation in Primary Care

Debbie Brown, Queen's Nurse

It was a usual busy Monday surgery. Since 7am in the morning, I had been in clinic seeing patients who came in for scheduled appointments and emergency book-on-the-day appointments.

Mr. T was the last patient of the day. I have known him, as well as his wife and family, for 13 years. During this time, I had built strong trusting relationship with both patient and family. Mr. T has high blood pressure, high cholesterol levels, chronic kidney disease, and Type 2 Diabetes for which I recently started him on Insulin injections. He also has bowel cancer, which is in remission.

When he came to see me that day it was a routine appointment to check his blood glucose levels and manage insulin doses accordingly. He was accompanied by his wife, daughter and granddaughter.

It was quickly very clear to me that this would be no routine visit. Mr T appeared short of breath. His face was taught and he was sitting uncomfortably, leaning slightly forward. I asked Mr T how he was feeling; Mr T is the head of his family as well as a leader in his local church. He is a very proud Jamaican gentleman and I wasn't surprised when he quickly denied having any problems. As an experienced nurse I knew this was far from the case and gently encouraged him to tell me what was wrong.

Mr. T explained that he had indigestion, lower back pain, had been unable to do even routine activities because of his shortness of breath. As he explained what was happening, his wife and daughter became distressed, and told me they were worried his cancer had come back. Being mindful of the dynamics in the room, I explained further tests would need to be undertaken as well as the rationale for each test. As an Advanced Nurse Practitioner (ANP), I am able to complete a full examination. I drew blood form his veins and sent it to the lab. I received the results quickly and after reviewing them, I suspected that Mr. T could be suffering from a number of things – a cardiac problem (a problem with his heart) that also affected his lungs, or anaemia – low red blood cells. More worrying, he might have cancer of the liver or pancreas.

Mr. T's chest X-ray was normal and did not show any problems. But his electrocardiogram and echocardiogram were abnormal. These tests of his heart showed that his heart was enlarged. A liver scan also showed a problem with his liver. The only good news was that there were no abnormalities with his pancreas.

I told Mr. T and his family that there was a possibility that he had developed liver cancer and that he had a new episode of heart failure. I explained that heart failure is a condition in which the heart is no longer able to pump oxygen-rich blood to the rest of the body efficiently. This causes fluid to build up in the body. I needed to start a new medication to reduce the extra fluid that had built up and set up an urgent referral for an appointment with a gastroenterologist and cardiologist.

Mr. T was able to get the care he needed because I recognised that his assurances that ‘nothing was wrong’ indicated precisely the opposite. I knew Mr. T was so afraid that he would be no longer able to be the main support for his family and leader of the church, that he would deny his own needs. Because I had a longstanding relationship with Mr. T, I was able to overcome his reluctance to admit to what he considered to be weakness and his resistance to getting care for himself. As an expert nurse, I was able to recognise the signs and symptoms of a serious change in his condition and to act early to deal help my patient.

As a result, Mr. T had a partial liver resection which excised the cancer from his liver. I work closely with the community heart failure nurses in a shared care approach. Although Mr. T is getting treatment for his liver cancer, he has a terminal illness that will eventually lead to his death. We discussed his options and openly discussed when the time comes, where he would like to die.

I will continue to see Mr. T and will do so until the day he dies.

7. Protecting a Vulnerable Young Mother and her Baby

Debbie Nash, Queen's Nurse

Sabina* was 14 years old when we first met in a local children's home. The Runaways Team found her after she had fled from her family. She and her siblings were known to social care because their mother had a long history of substance misuse and was currently a heroin user. Their extended family was Hindu and did not live locally. Although he did maintain some contact, her father had left the family several years ago, moving to another city, where he remarried and had other children.

The crisis happened because Sabina had become pregnant. Sabina's parents did not approve of her boyfriend and had taken her to the local hospital for a termination of pregnancy. The nurse in charge advised a delay in the process because Sabina had confided to her that this was not what she wanted. On their arrival back home her father said, 'if they won't get rid of it, I will!' and kicked her repeatedly in the stomach.

Both Sabina and her unborn baby were placed on a Child Protection Plan and a multi-agency team including the Social Worker, Educational Welfare Officer and myself worked closely with her and her boyfriend's family, who took her in and gave her a home. Throughout the pregnancy, both members of this young couple were very engaged in the Family Nurse Partnership (FNP), a home visiting programme for young parents and their babies. Together we explored many aspects of parenting and soon both parents-to-be were ardent to become good parents to their baby. Her partner was keen to provide for his family and we also discussed his options for the future.

As she was now living in a more stable home environment, Sabina could now eat a healthier diet. School had always been a 'safe haven' for her and she continued to attend, even though she now lived across the city. The team arranged to get her a bus pass and later, when her baby arrived, a taxi.

Sabina was now a few days overdue and it was my last visit before baby's arrival. We were alone and, as a midwife, I know that sometimes fear or anxiety can prevent labour from beginning. I used an activity developed by the Partners in Parenting Education (PIPE) program called 'Rocks in the Road.' PIPE is a tool used within FNP to encourage attachment between parents and their baby by promoting emotional availability and emotional connectedness.

I combined this activity with a motivational interviewing technique. Using Playdough to express the size of the issues in relationship to each other, we explored any concerns or problems she had. Because of the complex relationship she had with her own mother and siblings (whom she had cared for before she moved in with her boyfriend), relationship and communications skills were an area we had already worked on. Sabina also needed to come to terms with the guilt she felt because she was now prioritising her own and her baby's safety.

As was to be expected by any new mum-to-be, fears about her upcoming labour, caring for her baby, and how she and her boyfriend would support their new family were her main concerns. As she rolled a small piece of play dough between her fingers, Sabina paused, and eventually, in almost a whisper, and, with tears rolling down her cheeks, asked, 'What if he doesn't want me anymore?' As she wept quietly, she continued to articulate what was clearly troubling her the most. She had nowhere else to go that was safe for her and her baby, she told me.

I resisted the urge to say, 'don't worry, it will all be fine'. From experience, I know young men can be unpredictable at these transitional times in their lives. I was curious to explore if she would be happy to stay with her boyfriend's family, even if they were no longer romantically together? 'Yes,' she said, I don't think his mum would make me leave'.

As she talked, Sabina stopped crying and looked positively relieved. She had voiced her innermost fear and asked and answered the most pressing question she had. For her it was a very empowering experience. My communications training had taught me not to rush in to try to solve her problems or, through false reassurances, dismiss her fears. I sat alongside her and gave her the confidence to recognise she had the answer for her and her baby's future.

Supported by her partner and his mum, Sabina went into labour that night and her beautiful baby boy was born. Sabina was a natural mum. As she had planned, she exclusively breastfed her baby for six months. She resumed her education after three months, putting her baby in a nursery that was close to school and returning to feed him at lunchtime. She completed school and went to college.

When I left them, Sabina's baby was two years old. Sabina was still only 16 years old and was using an effective long acting contraception (LARC). There had been lots of ups and downs but her partner was now working and they were comfortable in their own flat. Working with the whole family, I had suggested a service to her mother, who was then able to successfully deal with her addiction and was more supportive and reliable as a grandmother. Sabina had developed a resilience that would stand her in good stead for the future and, as a couple, she and her boyfriend had created their own family unit.

I was able to be the consistent professional to work alongside her to empower her as a mother, and offer information as required around health, nutrition, and emotional and physical development for both her and her baby. I always 'held her in mind', modelling what I hoped she would do for her baby. My thoughts and actions were not intended to be judgmental; I explained the consequences of any poor choices in the long-term. She knew I saw the best in her and her baby but that did not prevent me from gently challenging some of her relationship issues. Our relationship allowed her to feel comfortable asking for and accepting help when she needed it. She aspired to always be the best Mum she could, strived to be economically self-sufficient. In fact, her long-term plan was to be a midwife and help other young women achieve their goals.

When I consider my work with Sabina, I often think about the way the work of community nurses saves both money and distress and provides empowerment and inspiration. The cost to the local council for mother and child foster placements and court proceedings were all averted for this family. There were some costs for social care and safeguarding procedures. These were, however, minimal in comparison, particularly when I think about how well the family responded to the Family Nurse Partnership.

Having both a stable home environment and relationship made it easier for the parents to put the baby's needs before their own and make better decisions about their own and their baby's future. The family became economically self-sufficient and the child was ready for school himself. I am confident that Sabina's son will have a far easier time navigating his journey through childhood and adolescence than his mother had, until that is, she reached out and received help herself.

8. A New Approach to Care for a Couple with Complex Needs

Emma Swarbrick, Queen's Nurse

My name is Emma Swarbrick. I have been a community nurse for 12 years and I qualified as District Nurse 6 years ago. District Nurses save lives, pain and suffering, and save money. I'd like to tell you a story – one that is routine for my practice – that illustrates how we do all three.

Several years ago, I, as a District Nurse, attended a multi-disciplinary team meeting where we discussed patients whom we cared for as a team. One of the team members discussed problems they were having caring for a couple, I'll call them Mr. and Mrs. Smith. In the past twelve months, Mr. and Mrs. Smith had called an ambulance 148 times and Mrs. Smith had been admitted to the hospital 78 times. The problem was a mysterious abdominal pain from which Mrs. Smith was suffering. Mrs. Smith had been examined and undergone many tests to figure out the origins of the pain. But no one was able to discover a physical problem that explained the pain. Mental health practitioners had gone into the home and found that Mrs. Smith was not mentally ill. The local GP was pulling his hair out because the couple were phoning up demanding home visits at least three or four times a week. They lived in a very rural, isolated bungalow so not a quick visit.

I went out to visit the couple to try to find out what was happening and why. I spent an hour and a half listening to their story and trying to determine what issues were of greatest concern to them. Over the next few weeks, I met weekly with the couple.

I realized that even though there seemed to be no physical reason for it, Mrs. Smith was genuinely experiencing chronic pain. The multidisciplinary team that also visited the couple in their home also agreed with my assessment. The problem had to do with the fact that Mrs. Smith felt pain, with no identifiable cause. So I had to do a lot of education with the couple to help them.

Mr. Smith was terrified that his wife's pain signalled a disaster about to happen – like undiagnosed cancer. Mr. Smith was very worried that his wife was, in fact, very ill and that people were missing something critical. I had to explain that people may experience pain even though there is nothing physically wrong. This doesn't mean the patient is mad – as Mrs. Smith feared. Pain is generated and perceived by the brain. It looked likely in Mrs. Smith's case that the brain was getting its messages wrong.

Once both Mr. and Mrs. Smith began to trust me and relax, we could address some things that might influence Mrs. Smith's perception of pain. One was that she had become malnourished. She had become convinced that eating made her pain worse and had lost all enjoyment in food. After becoming dangerously slim and losing strength and muscle mass, she had even fallen and broken her hip.

We began to explore Mrs. Smith's relationship with food. When she got more strength and confidence, we explored giving her more choices about food. Before we started talking, her husband was going out and buying food. Unfortunately, she just didn't fancy some of the things he brought home. When she felt better and stronger, I made a shopping trip with her. I actually got her to reengage, not only with eating, but with being back in the community and doing activities such as shopping.

Three years later, I was in a meeting, when someone suddenly said, "Emma, what's happened with the Smiths, we haven't heard from them in five months." I was happy to report that Mrs. Smith had gained weight and was no longer on the dietician's hit list. She was going out shopping with her husband at least once a week. This was a significant effort as they relied on public transport and it was a mile walk to the bus stop. The Smiths now understand that sometimes she may experience pain but it's not due to something that is catastrophically wrong. They were reassured because I told them the sort of things they should worry about if they did happen to show up.

There were no more ambulance calls and visits to A&E and no more frantic calls to the GP.

Over a number of visits, I was able to save the NHS thousands of pounds. Consider, for example, the cost of 148 ambulance calls and 78 visits to A&E*. Then consider how much an individual District Nurse visit costs the NHS, and how many other situations like this she may prevent from happening during the course of a year. And of course, the anxiety, anguish, and pain we were able to save this couple is incalculable.

*Ambulance call out estimated at £155; being taken to hospital £255. Estimated total = £30,740 for ambulance call outs and hospital admissions alone. A District Nurse's annual salary range is around £26,000 to £35,000 (2019).

9. ‘Thinking Outside the Box’: Better Care for a Man with Complex Needs

Gail Goddard, Queen’s Nurse

I have been a Community Nurse for 29 years and a Specialist Practitioner in District Nursing for 21 years. I am very privileged to be able to make a positive difference to a wide range of people in their own home. I have been able to get to know the person, their family, friends, carers – even pets – and build positive meaningful relationships every day I go to work.

As an autonomous practitioner I assess, diagnose, problem-solve, treat and evaluate patients. No patient is ever the same and I have to constantly think outside the box. Of course, I am always guided by the best practices and evidence. But because you can never anticipate the challenges that patients present, I also have to be flexible and creative and use my imagination to solve complex problems.

My care of a patient I will call John illustrates what ‘thinking outside the box’ means in my work.

I have known John for approximately five years. He has a very complex neurological condition which has resulted in paralysis of both legs. John uses a wheelchair for mobility and his flat has been adapted with ceiling hoists to allow him to transfer independently to the bed, toilet, and into the bath. John lives alone but his elderly parents live nearby. His mum is a retired nurse who used to be John’s main carer. Recently she broke her hip and hasn’t been able to care for him.

John is underweight and his sacrum, hips, and other areas are very vulnerable and he is at high risk of pressure ulcers, which are one of the most serious complications of immobility.

He has tried several different types of pressure relieving mattresses and cushions but finds most of them uncomfortable. For his wheelchair, he uses a cushion which is not particularly effective, but I have had to compromise on the issue. In this case, the cushion is better than nothing. John’s bottom is especially vulnerable, and his skin periodically breaks down and a pressure ulcer develops. Although John is in constant daily discomfort from this area when sitting, it becomes extremely painful when a wound develops. Throughout the years we have tried many different dressings and have concluded that at present there is only one available which meets John’s exact needs. Unfortunately, the dressing is not covered in our organisational formulary, so I can’t prescribe it without a very good clinical reason. John has brought many of these dressings himself but can no longer afford to pay for them. John has a bath every day and changes the dressing himself while he is suspended in the ceiling hoist. He uses one hand to complete this task. John uses the dressings for pain relief as well as wound care as the area is less painful when covered by a dressing, even when the skin is intact. One day, I received a message from our Administrator to say John had been abusive and aggressive on the phone. He wanted to complain and was extremely upset and angry. I telephoned John who was so angry he was very difficult to understand. He was unable to tell me what had happened, so I agreed to visit later that day.

When I arrived, John was still very angry and agitated. He was shouting at me in his frustration and it was difficult to follow the thread of his conversation. By remaining calm, allowing him to vent his frustration, and then asking simple questions, I was able to gather what had happened.

The GP had referred John to another community service for assessment and a Senior Nurse from that team had visited the home. As part of her assessment she had told John that he was using the wound dressings incorrectly and said he could not be prescribed any more of the dressings. This nurse had informed the local pharmacy, as well as the GP, that John was not to be given any more of these dressings. He also said that she would tell the District Nursing team not to prescribe any more. John had been left with no choice other than to try to buy dressings himself online. This had not worked, and he was panicking as he had no dressings to use and was in pain.

On examination I found that John's skin had deteriorated and he had a serious – category two – pressure ulcer on his sacrum. I negotiated with John, gave the correct assessment and care for the wound and agreed that I would liaise with the GP and the Tissue Viability service to see how we could meet John's needs. He refused to allow me to speak to the other Senior Nurse about this. He would never allow her into his house again, he exclaimed. I left him calm and more comfortable.

I discussed John's individual situation and needs with his GP and the Tissue Viability Nursing Team and we all agreed on a plan: the District Nursing team would visit three times a week to care for his wound until it healed. Then we would reduce visits to monitor his pressure ulcers as he cannot see them himself. I would also prescribe one of John's preferred dressings – which are not in the formulary – per day. I was able to make a case for this, explaining why John was unable to use the similar dressing which is preferred in our formulary.

As John has to apply the dressing with one hand and there are three removable backing sections on each of the suggested dressings, he cannot do this independently. With his preferred dressing there is only one backing section to remove so he can do this on his own. John would apply this dressing in the morning to provide pain relief and protection whilst John was sitting in the wheelchair. John would remove the dressing before his bath and then apply a barrier cream leaving the area exposed overnight while in bed. I visited John next day and described the plan, which he was willing to try. A week later the wound had healed, and we were able to reduce visits to weekly and then fortnightly.

John is now using one dressing a day at a cost of about £2.50 and barrier cream which costs approximately £10 per tube, lasting 2-3 weeks. This is a total cost of less than £100 a month. The Community Health Care Assistant (HCA)* visits once a fortnight at a cost of approximately £80 per month. This is more cost-effective than a Registered Nurse (RN) visiting three times a week redressing the wound for John. Our plan has also reduced the risk of a new wound developing. This would lead to the use of more products and more lengthy nurse visits.

When John had a wound, he was unable to bathe, as sitting in the bath was too painful. This had a negative impact on his wellbeing. His pain had also increased when sitting in his wheelchair, so he was taking pain medication which made him constipated.

Being willing and able to move beyond formularies and guidelines to deliver personalised care to patients like John not only saves money but allows patients who face chronic challenges to live as comfortably and independently as possible.

**A Health Care Assistant is not a trained Nurse, although they do receive training in order to complete their role. They do not make clinical decisions but complete clinical tasks under the supervision of a Registered Nurse.*


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10. Making a Difference in General Pratice

Gill Beardmore, Queen's Nurse

What do you do?' is a question I'm frequently asked. 'I no longer work in clinical practice,' is often my reply - I'm almost apologetic. Given the growing number of nurse vacancies, particularly in my area of General Practice Nursing, it sometimes feels as though I should be working in a clinical setting. Let me tell you why, after 35 years in and around General Practice, I no longer do.

It's because I recognise the critical importance of General Practice Nursing and want to make sure there are enough general practice nurses in the future who can provide the kind of high-quality care I delivered. I've learned through experience the important role General Practice Nurses (GPNs) play in helping patients to understand their symptoms: for example, helping to keep high blood pressure under control, teaching people what to do in the event of persistent chest pain, and assisting them as they try to take control over their lifestyle choices.

Nurses who, like me, earned a non-medical prescribing qualification also treat patients with sore throats, infections, bites, stings, sprains and other minor illnesses where they offer appropriate advice and, when necessary, prescribe medication. In addition, they irrigate ears, dress wounds, take cervical samples, supervise more junior nurses and health care assistants and ensure that they deliver high quality care through auditing their own practice. These nurses treat older people, teenagers, men and women all from different backgrounds and walks of life including people with mental health problems and learning disabilities. Theirs is a diverse role, fast moving and dynamic. When I played that role, I found that I was continually learning to ensure I was basing my expertise on the latest guidance and scientific evidence. Without the kind of work GPNs do in the community, GPs, pharmacists, and community nurses would have a harder time providing local services.

The problem is there are not enough GPNs entering the field to continue delivering this kind of critical care and support. That's why I've chosen to make a difference for the many nurses who elect to make general practice their career destination. I am now working for Health Education England where I focus on ensuring there are enough GPNs now and in the future in GP surgeries in the East Midlands and that they are equipped with the knowledge and skill needed to deliver high quality services to patients.
This work is critical because it's not easy to navigate the route into General Practice Nursing and never has been. People have known about and tried to solve this problem for years. For years, they have ended up throwing the problem on the 'too difficult pile'.

Simply put, the problem is that GPNs are getting older and there are fewer of them in practice with the requisite experience. When one of these nurses retires (a third of them across England will be eligible for retirement in 5 years' time) the General Practice employer advertises for an experienced nurse to replace the outgoing one. Since experience is in short supply, practices have to poach or recycle nurses who may be working at a practice down the road or across town. A particular practice might want to grow a new GPN, but this takes time and resources and if there's no current nurse to train the new one, it generally doesn't happen. Newly qualified nurses or nurses wanting to make a move into General Practice are massively frustrated as all they see are doors closed in their faces. GP employers only want experience. Experienced GPNs could soon become extinct – unless a new model of training nurses is developed.

Case Study

My encounter in April 2018 with a student nurse called Kate illustrates the problem and inspired me to try to come up with a solution. I met Kate in her last year at a university careers fair and she emailed to ask if we could meet to discuss her future. Recognising her motivation and enthusiasm I agreed. In her final undergraduate year and due to become a Registered Nurse in just a few short months, Kate told me she had decided upon her career destination on day one of her studies. Her choice was General Practice Nursing.

During our hour-long conversation, Kate's focus and single mindedness thoroughly impressed me. I asked where her placements had been during the last three years and I learned that despite her requests, General Practice was not among them. Neither of us were sure if that was due to there being so few placements in General Practice or because placement arrangements were not able to reflect personal student choice. She was fortunate in having had her university fees paid via a bursary, but she told me that if she had been funding her own studies, she would not have been satisfied with the selection of placements she had experienced. She would have expected to tailor her placements around her choice of career destination. It became clear through our conversation that this hugely motivated student would have many barriers to overcome if she was to navigate a path to General Practice Nursing.

Firstly, she would have to apply multiple times to vacancies that more often than not were advertised as requiring 'experience'. In a classic Catch-22, she would be unable to get this vital experience without first getting a job. Since practices don't advertise their vacancies through a single portal and many don't even advertise through NHS Jobs, I knew that finding a match would be tricky. Her motivation to keep going would be tested.

Next, she would need to keep her sights set firmly on her first choice of career. Kate told me her colleagues had mostly chosen to embark on a career in hospital nursing and many had already received job offers. Kate was already feeling anxious that she hadn't yet secured a position and I feared that she might easily default to one of many roles that were on offer in other areas. She would have to remain focussed.

I also knew that she would need to maintain her confidence levels at a time when many newly qualified nurses feel vulnerable – the point of registration. The transition from student to registered nurse must never be underestimated. In general practice this leap is possibly even bigger, as there is limited support from other nurses in small General Practices as opposed to large hospitals. Kate would need to get to grips with working in a room on her own rather than on a busy, bustling ward. At the time of my conversation with Kate, there were few preceptorship programmes designed to support newly qualified nurses in General Practice. Perhaps this was because most General Practices simply don't consider employing newly qualified nurses; Kate already knew this because she had telephoned a number of practices and asked the question. I suspected that she would be tempted to see other areas of nursing as easier career options.

Finally, Kate had no idea about what made a practice 'good' or 'not so good' and didn't necessarily recognise what would make for a positive first experience in general practice. She was surprised when I told her about the lack of alignment of terms and conditions. When I mentioned that she may want to find out about holidays, sick pay and maternity pay she was genuinely surprised as these entitlements are generally standard in NHS hospitals and large trusts. Despite all this, I passionately shared my own experience of my GPN career and sincerely hoped that her first-choice career delivered the same positive experience as mine had done.

Kate assured me that she was keeping her sights firmly set on her first choice of career destination. She told me she knew what she wanted, and I promised to do whatever I could to help. I knew that if she could secure a GPN role she would be able to embark on a Fundamentals programme that would equip her with the knowledge and skill she would need for her first months as a GPN and that this would form a firm foundation for her future career. I imagined, having met her, that she would succeed. When she does, the team she joins will be enhanced by her motivation, determination and enthusiasm.

There are many hundreds of students, every year, who will find themselves in similar positions, but their outcomes might be very different. They may be more easily attracted by an immediate job offer, the appealing support of colleagues, the robust structure of a large organisation and the exciting opportunities to develop. I know that if General Practice is to attract the very best, the barriers that prevent newly qualified nurses embarking on careers in General Practice Nursing must be broken down.

My encounter with Kate energised me to once again tackle the enormous challenge that nurses face when they attempt to embark on a career in General Practice Nursing. Something more radical was needed. I found myself designing a new route into General Practice Nursing, developing the business case, securing funding and finally carefully choosing sites to prove the concept would work. I connected with colleagues who supported my vision and together, during 2019, we witnessed the implementation phase of what had long been my dream. Work is now underway to roll out this newly tested route into the specialism and to encourage its prioritisation locally. Kate had inspired me to make a difference on her behalf and on behalf of the countless other Kates.

Planning for the future and making sure there are nurses in the right place, at the right time with the right skills, who are able to competently to deliver quality services to local people is immensely important. I know that those who are diligently delivering services don’t always have the time or resources to think past today, let alone about whether there will be a protected route into General Practice Nursing in the future. But these nurses will be playing their part in preventing illness, helping people manage their own long-term conditions and avoiding unnecessary hospital admission. We desperately need more of them.

So, although I’m no longer working clinically, I know I am making a difference for those who are.

11. Helping a Patient to Regain Control of her own Health

Hattie Taylor, Queen's Nurse

I have been working as a community nurse for 17 years. I've worked in many different teams across towns, cities and rural settings. I've loved the variety involved in moving to different places and healthcare trusts, taking the best ways of working with me. Working across cultures and communities has given me a rich experience that I value immensely.

I am now Lead District Nurse for Purbeck in Dorset.

Over these years, as pressures in the NHS have increased, community nursing has changed beyond recognition. Meanwhile, people are being cared for 'closer to home'. With earlier discharges now more common and hospital admissions avoided, people are able to be safe at home because of the work of community teams. In order to use our resources wisely, we try to work smarter all the time.

One way we do this is to make sure that there is continuity of care when we take care of patients. I try to assure continuity of care in community nursing because I know that developing extensive knowledge of the patient, especially between episodes of care, helps build trusting relationships and allows my colleagues and I to positively influence health behaviours over time.

To do this, I started a 'named nursing' system in my team six years ago. This means that the named nurses in the team act as a single point of contact for other professionals, the person and their family. The named nurse visits more often than other nurses, attends any multi-disciplinary team meetings and plans and evaluates their care (more timely care often means shorter episodes of care due to correct treatment and healthier behaviours). At times, the named nurse will plan pro-actively, for example liaising directly with other healthcare professionals and referring to relevant services. We are now working on named nursing being supported on the electronic notes system in my Trust. The data shows that the frequency of visits and number of different nurses visiting is reduced with named nursing in place.

Let me explain how named nursing helped me approach a dilemma I recently had when taking care of a lady who had poorly controlled diabetes and leg ulcers that refused to heal.

I was asked to see Mrs. W at home because the community nurses who had tried to care for her were getting exasperated when they arrived to re-dress her leg ulcers. Sometimes she would be out. She didn't appear to follow the advice she was given and would remove her dressings and bandages. The ulcers were so bad (and getting worse) that a nurse had to visit her at home every day.

I could see straight away that the lady was frustrated with her situation. I spent some time getting to know her really well so I could understand more about her. She had lost trust in the community nurses and felt suspicious because she believed that they didn't know how to treat her ulcers properly. She felt that she had lost control of her life and that all the nurses did was invade her home and tell her what to do. She also had no idea that diabetes and high blood sugar levels were affecting her leg ulcers.

Mrs. W had become less mobile as her legs had swollen up with fluid. She had stopped driving, but her sister would come and pick her up and take her out to lunch. She didn't want to be rude to her sister, so she would go out even if she knew the nurse was due to visit. Because Mrs. W lived in a rural area that was quite remote, this would result in a wasted journey and lost time that the nurse could have spent with other patients. Mrs. W could have theoretically come in to the local practice to have her dressing changed by a General Practice Nurse, but the fact that she couldn't drive ruled out this option. So, community nurse teams, who usually only see housebound patients, had to return to her house to change the dressings on the suppurating leg ulcers. This caused even more tension for the team.

To complicate matters, we also received telephone calls from one of her sons. She had complained to them about her wariness of community nurses and conveyed her considerable anxiety about the fact that her ulcers were not healing.

As I listened to both the team members and Mrs. W, I could see how it was disheartening for the team to spend so much time on her care without seeing any progress. I could also understand how Mrs. W felt. She wanted to go out to lunch when she felt like it and didn't want the fact that nurses were supposed to come and visit to stop her from doing just that. Clearly, we needed better communication and to find some compromises that would allow her to do this.

I continued to see Mrs. W for daily visits for a few weeks. I found out that she loved to garden and cook. When I was with her, I tried to find out what mattered to her and to understand what stopped her from elevating her legs and exercising better control of her blood sugar levels.

Meanwhile, I also contacted her doctor and discussed the complexities of her care, and I talked with the General Practice Nurse about whether we could organise some shared care with her team. Mrs. W also allowed me to talk to her son about her care. I was able to reassure him that all members of the team had knowledge and skill and were trying to help his mother get well. I helped him understand that tighter control of diabetes would help her legs heal.

I organised a meeting with Mrs. W and her family, the Doctor and Practice nurse at the medical centre to discuss how we could plan the best care and discuss any concerns. This meeting was pivotal to finding the right solutions for her. Members of the team were frustrated and this also needed to be addressed. We gently explained as a team that her behaviours were having a negative effect on her health. We emphasised the fact that we wanted to continue to provide her with high quality care but that, with our support, she also needed to make changes.

One of the first things I did after the meeting was to make sure she could get to the medical centre once a week (with local patient transport) for care in the treatment room. This was a first step to arranging more appointments out of the house. Mrs. W agreed to elevate her legs for short periods during the day, and all night. She had previously said that she elevated her legs all the time, but it was clear to me that she wasn't doing that. So, this was an important admission and compromise. I encouraged her to continue gardening and cooking, but reminded her to remember to elevate her legs whenever possible. I also talked regularly with the General Practice Nurse. Together we coached about how to maintain a healthy diet and a daily routine to improve her health.

One of the frustrations of community nursing is getting the right dressings quickly for their patients. Because the team work remotely away from the medical centre, they usually send an electronic message to a GP asking for a prescription. Busy GPs often fail to respond in a timely manner, which means that nurses may not have the right dressings with them when they visit patients like Mrs. W. This in turn produces the kind of frustration and suspicion that Mrs. W displayed. As a nurse prescriber, I was able to issue written prescriptions without these constraints and delays. As a result, Mrs. W became less frustrated and more trusting of the nurses who were now visiting with the right equipment at hand.

This holistic approach started to produce positive results. Mrs W's ulcers started to reduce in size and wetness. I could see changes every time I saw her. Continuity of care also improved health behaviours. She had better control of her diet and blood sugar levels. Over several weeks we slowly changed to less frequent dressings, as well as more visits to the medical centre. As she became more mobile she was keen to have appointments at the medical centre rather than at home and we discharged her from our care. To maintain our rapport, I have kept in touch with her and I reinforce how happy I am about the positive outcomes we achieved together. She is very happy to be well again.

12. Helping a Rough Sleeper in Crisis

Anonymous

I'd like to tell you that caring for people experiencing homelessness is simply a matter of treating people with respect and dignity and that it's easy. I'd like to say that it's just my job. In truth, it's the sum of the experience and knowledge of nearly forty years of working as a nurse that allows me to do this difficult, complex and challenging work. It helps me to deal with those who are isolated and marginalised and to take calculated risks to provide safe and effective care for people like 'Ray'.

Ray's story

The colour was an iridescent blue-green that shimmered in the late afternoon sun as if he was wearing a coat. Everything was still. So still, that I wondered if it was not him but, rather, a pile of ragged clothes. I called out his name and he shifted slightly. The sparkling coat flew up in the air, scattered momentarily, and then settled again on his body. I stood horrified then ran towards him.

Ray was sixty-six and had been homeless for over a year. His gambling debts had spiralled out of control and he had left his accommodation, unable to pay the large rent arrears. As a rough sleeper, he had found solace in drinking and the company of other street drinkers.

Today I had been called to his aid by a housing officer. His tent was sited close to some properties and there were concerns about the smell, empty bottles, and flies. He was to be evicted and served with a court order. However, when the officers arrived, they had found Ray covered in faeces and flies. They had called an ambulance, but he refused to leave his belongings. He didn't want to see his GP. He felt that they would only say that his symptoms were drink related. The housing officer asked if he could call the nurse to help clean him up. Reluctantly he had agreed.

The ambulance crew and the housing officers stood on a rise some distance from Ray's tent, talking quietly, eyes averted from the scene.

'Hello Ray. How can I help?' I asked. He was laid on his side and even with all of his clothes on I could see that he was extremely thin with waxy skin. "I'm sorry," he mumbled, "I've got myself in a bit of a mess".

It was evident from the smell and the dark blood-streaked splashes of faecal matter all around that this was not diarrhoea borne of alcohol abuse. 'How long has this been happening Ray?' His reply was non- comital but seemed to suggest that it was many months rather than days. I put on some gloves and an apron and he crawled into his fly filled tent.

Using my jacket to give him some dignity I cleaned his soiled, raw and dehydrated skin and then gently helped him into an incontinence pad and the clean clothes I had brought with me. He drank thirstily when he was given a bottle of water. He told me that he'd not eaten for weeks because of the diarrhoea.

I asked him when he'd last had any alcohol. He'd been too weak to get to the shop to buy any. Mindful that his lack of alcohol would soon be potentially life-threatening it was important to get Ray to hospital. He had more important things on his mind. He held my hand tightly. 'I think I've got cancer', he said.

It certainly seemed that he was right. Should I say this? Did he want me to concur with his self-diagnosis or was I supposed to offer false reassurance that it was it probably just an infection? In the end, I decided that he trusted me to tell him the truth. 'I think that you're probably right Ray but it's important that you go to hospital for some tests. You are really unwell today and you need to be looked after in a nice warm bed, not sleeping in a tent.' He squeezed my hand. We sat quietly for a few minutes.

'Shall we collect together your belongings that you want to keep and clean them up?'

Together we packed up some coins, his cigarettes and lighter, some family photographs and a few envelopes before the ambulance crew quietly helped him down the hill and into the vehicle.

13. Supporting a Young Person to Return to School

Jane Mulcahy, Queen's Nurse

I have been working as a Community Children's Nurse (CCN) for the last 15 years.

During this time the caseload has changed dramatically as children are living with increasingly complex clinical care needs in the community. A typical day may include giving an injection to manage a long-term health condition; managing a complex wound with a vacuum pump that removes fluid and infection; identifying deterioration in the child's clinical condition requiring emergency transfer to hospital; administering intravenous antibiotics to a baby who has a blood stream infection; making sure a dying child is not in pain at the end of their life.

I work in close collaboration with specialist doctors, nurses and therapists to help children and their families deal with their everyday clinical care needs at home. Freddie is one of those children.

Freddie had had just started at secondary school. He had previously been fit and healthy. Suddenly he found it hard to breathe if he ran or walked quickly or even climbed the stairs. During a routine Ear, Nose & Throat examination he collapsed. His airway had narrowed dramatically and to save his life, surgeons had to place a permanent breathing tube in his neck. Freddie now had to master a whole new way of being in the world.

He couldn't speak because the tube impinged on normal vocal cord speech production. He couldn't manage normal secretions he would previously have coughed up on his own. These had to be removed through a vacuum device he that his parents had to learn to use. He was suddenly dependent on having an adult with him constantly who knew how to care for his breathing tube, could suction the tube as needed throughout the day and could change the tube in an emergency. Failure to suction or change a tube could be life threatening.

Before he left the hospital, Freddie's parents had to learn to do all this themselves. I was involved in delivering this training and helped his parents deal with the fear of caring for such a vulnerable young person at home. In the hospital, Freddie was surrounded by competent medical professionals. At home, his parents would be on their own and were terrified that they would make a mistake that would kill their son. I helped Freddie's parents learn to manage complex medical equipment and how to manage the sleeping arrangements so Freddie was safe overnight. Initially I needed to visit daily to help his parents gain confidence in dealing with all the details of his care. We practiced changing the breathing tube in different positions and found Freddie preferred to sit upright rather than lie down for this procedure. Soon he began helping himself.

I was able to reduce my visits to weekly and as the family gained confidence this became monthly.

Once Freddie was home, I also trained his grandmother in his care needs so she could offer additional support to the family. I actively included Freddie in this training. He had been too ill to be involved in his parents training but I knew it would help his understanding of his condition as well as increase his confidence in his grandmother's competence if he was involved. Freddie also learnt to perform his own suction thus increasing his own confidence and independence.

A crucial element of Freddie's recovery was helping him to find his voice, both literally and figuratively. Freddie was initially very withdrawn following the emotional trauma of requiring an unplanned tracheostomy. This was compounded by the fact that he could not speak. Working in collaboration with the Speech and Language Team at the specialist children's hospital, I supported Freddie to try out different types of speaking valves until he decided which one he liked best. With practice Freddie was able to speak with a weak voice and over time this became strong and clear.

Understandably, Freddie's struggled with intense emotions including anger and anxiety. He stopped seeing friends and refused to go to school. To move through this, I knew he needed to accept his changed circumstances. Returning to school was a crucial part of this process. Staying at home would severely limit his future prospects in life but also limit his opportunities to socialise with his peers as a normal teenager. The latter was crucial to his emotional recovery.

To help Freddie return to school, I met with the school leadership team. They were very worried about their ability to support such a sick child resume their studies. I had to convince Freddie, his family and school staff that attending school was both possible and in his best interests. To do this, I set up an information sharing session with school staff and the family to explain what was involved. I included Freddie in this process and I asked him to help me explain the equipment and demonstrate what was needed to deal with it. Following the session, four staff members volunteered to learn how to care for Freddie in school.

Using manikins and then practicing on Freddie himself, I trained the staff to cope with scenarios that might occur in school. Freddie was able to give direct feedback to the staff on the experience of having suction or his tube changed. This supported staff learning and Freddie's confidence in their skills as they developed. I helped develop a plan for Freddie to be able to move around the school for his different classes with heavy and bulky emergency equipment needed to manage secretions and an emergency breathing tube change.

I did not sign off any staff as being competent to care for Freddie until I had fully assessed them in practice; Freddie was confident in them; and they themselves said they believed they were both competent and confident to care for Freddie. I provided on-going support to these trained staff on an ad hoc basis and delivered updates regarding tube changes to maintain skill and confidence.

As a result of all this, Freddie was able to go to school on a regular basis, and reconnect with his friends and fellow students. He recently sat his GCSEs. It was my absolute pleasure to cover short notice school staff sickness and act as Freddie's 'tracheostomy trained adult' in school for one of his GCSE exams. He sat the exam, with his peers. He not only passed that exam but many others and has gone on to attend college. I couldn't be more proud and happy for him.

I cannot emphasise enough the positive value of helping a child or young person return to their life. Attendance at school is a normal part of childhood and must be facilitated in any way possible. It is priceless in terms of the emotional health and well-being of the child and family.

14. Controlling Diabetes in a Prison Population

Lesley Mills, Queen's Nurse

I am a Registered Nurse and have worked in diabetes care for the past 25 years. I currently work as a Consultant Diabetes Nurse.

One day, I was called to the emergency department to review the case of a gentleman – we'll call him Arthur, who had been brought in from the local prison following an episode of hypoglycaemia or low blood glucose levels. I noted that his birthday was the following day and wished him a happy birthday. To my surprise, he told me that he, 'likes to make sure he is in hospital on his birthday so he can have a proper breakfast'. It seemed clear that he had carefully manipulated his glucose levels so he could be brought into hospital for an overnight stay until he was safe to be discharged back to the prison. He had managed to control his diabetes this way for the past several years – enjoying his birthday breakfast in a hospital bed.

This encounter prompted me to review other hospital admissions from the prison and the reasons for those admissions. What I found was not a group of offenders with diabetes who were deliberately manipulating their blood glucose levels so they could enjoy a birthday meal in a hospital, but rather men who were not receiving the highest standard of care. Many admissions resulted from uncontrolled glucose levels and the lack of regular reviews of each person's diabetes control in the out-patient department or community clinic. Some admissions were due to very high glucose levels, others to infections that had not been managed in a timely manner. One of the reasons for this was the fact that staff were not available to bring those men from prison to their clinic appointments. Another was lack of transport or poor communication between the health care clinic and the prison wing.

It is well documented that many people who are in prison, do not engage with health care professionals when they leave. In this 'hard-to-reach' population, many people do not understand how to manage their condition or get good follow-up care. The men who were currently being held within the prison system, should be given the same standard of care for their diabetes as anyone else. They were not. Practice was not going to change if everyone did not share the same agenda.

Although I tried to encourage the health care clinic to ensure that appointments were attended, we were not seeing any improvements in attendance rates. I didn't feel that I was making any difference to the needs of this very hard to reach group of people with diabetes.

I decided to work out the financial cost to the NHS of bringing a prisoner to a hospital out-patient clinic – a trip that requires two prison officers and transport for several hours. I compared this with the cost of poor diabetes control, which can lead to long term complications such as blindness, kidney failure, and foot or leg amputations. It can also lead to acute complications such as hypoglycaemia and diabetic ketoacidosis. Both of these conditions can cause death very quickly if not treated.

The total cost to review the care of all these men three times a year in the out-patient clinic was around £60,000. If I moved that clinic to the grounds of the prison, delivering care within their residential environment, it would only cost £8,500 a year. This would not only save money but would actually help to engage with these men on a regular basis. Over 12 months, it could significantly improve diabetes control, reduce hospital admissions, and potentially reduce the risk of long-term complications.

When I suggested this to the local commissioning group and the prison, they were more than happy to change. This meant I would create a new kind of community clinic – one in their community setting, where they would be seen regularly. There would be no more excuses made to rationalise why they couldn't make their appointments, as the clinic would be on site. I was also able to start to educate the prison health care staff and those men with diabetes in order to help improve their diabetes management.

Within the first twelve months of the clinic being moved to the healthcare centre on the prison site, there were no emergency hospital admissions for hypoglycaemia or DKA (Diabetes Ketoacidosis). Everyone attended their clinic appointments. If a prisoner didn't attend the clinic, I would visit them in their prison cell at the end of the session.

This model has been used in the prison now for more than four years. Satisfaction rates have improved, and staff knowledge around diabetes has increased. Engagement with this group has improved and acute and longer-term complications reduced. Overall, those men with diabetes have improved their long-term outcomes through their improvement of glucose control – reducing their risk of complications by more than 30%.

I could have managed that first gentleman in the emergency department and let him go back to prison, only to re-attend as he had done many times before. I would have continued treating the symptoms without actually dealing with the cause. I strongly believe that changing practice to fit local needs has improved the health and care of this challenging group of men whilst at the same time increasing the knowledge of other health care professionals and saving the NHS money. As far as I can tell, the only downside is that 'Arthur' can no longer expect an annual birthday reprieve in hospital.

15. A Day with a District Nurse

Suzanne Gordon

Liz Alderton's working day is a complex choreography of motion. A District Nurse at a health centre in outer London, she leads a team of 18 nurses and four healthcare assistants. She also teaches students, supervises trainees, and works closely with ten to twelve GP practices in the borough where she works. She also coordinates with pharmacists, hospice and care home staff and carers who go into patients' homes in the community as well in care homes. Add to that the unavoidable management duties, staff roster and supervisions for a team of 22 staff – all together a very challenging role.

Then there are the patients - on any one day, her team will see between 100 and 130 of them – whose acute and chronic conditions she helps manage. Many of these patients have, among other conditions, cancer, asthma, diabetes, chronic obstructive pulmonary disease, leg ulcers - and mental health problems. One of her main jobs is to make sure their last days of life are lived in comfort and with dignity and that they die in their preferred place – which is, most often, their own homes.

Liz Alderton is a Queen's Nurse – a title given by the Queen's Nursing Institute, a charity established in 1887 to train district nurses. In 2018, she also received the Queen Mother's Award for Outstanding Service. After spending 32 years practicing in the community, she still feels that, "This is the best job in the world. Don't let anyone tell you any different." Unfortunately, for her patients and the thousands of district nurses across England, NHS planners don't seem to agree.

The QNI and Royal College of Nursing have warned that District Nurses, the hidden heroes of the NHS, are under total siege, with numbers in the profession having fallen by half since 2010. As an American healthcare journalist, I am fascinated by what the district nursing model could offer to the US healthcare system, which lacks such care management and coordination in the community. While I can only marvel at the money nurses like Liz Alderton save the British healthcare system, and the alleviation of pain and suffering they bring to their patients, I am shocked to learn that the district nursing service is still under relentless pressure. On the same day I accompanied her on her rounds, Alderton received a letter advising her that she had been 'identified for redeployment,' and that NHS was going to reduce the number of District Nurse team leaders in the borough from six to three – with further cuts possible. Following Alderton for only one day, I begin to see what this decision will cost patients and the NHS.

Alderton begins her day checking her computer for any new referrals that have come in overnight and then allocating them to the rest of the staff. Other junior nurses visit patients who have more routine needs – routine as in chronic and post-operative wounds, those who have infected leg ulcers, who are too immobilized by arthritis or other debilitating conditions to manage their own insulin shots or antibiotic therapies, and patients who have concurrent mental health problems. Alderton herself will go out and visit patients with more complex needs – wounds that refuse to heal, pain that is refractory or mysterious in origin, patients who need intricate end of life care, or co-ordination with social and mental health services.

She also advises other nurses, like the one who asks her counsel about a patient who has short-term memory loss due to an aneurism and nasty pressure sores. He won't let the nurse have a look at the sore on his bottom. What should be done? The nurse asks Alderton and the two confer about the best course of action. As they talk, she is interrupted by a call from one of the GPs located in the health centre. He wants to consult with her about yet another complicated case, so she excuses herself and runs down the corridor and a flight of stairs to his office.

The pleasant, grey-haired physician – an 'old fashioned GP' she tells me – has just received a complaint from the son of an 87-year-old gentleman who's had a stroke, is paralyzed on one side, and has an indwelling urinary catheter that requires routine nursing care, but which causes him and his family much anxiety. His 80-year-old wife has pancreatic cancer that had abated after treatment and has now come back in its full fury. The son has complained that the couple has not received enough attention. Alderton and the GP discuss the couple's care and she says she is planning to visit them later in the day. The GP thanks her and says that, pending her report, he will also visit the family.

Alderton sprints back to her office and calls the pharmacy to make sure they have the medication she needs for her first patient. After stopping to collect it, she visits Bruce, who has an aggressive disfiguring cancer and has become a recluse. "It's been quite a journey to build up trust with him so he will let me visit him; he was so self-conscious about his looks and anxious about medical professionals," she tells me. He and his wife are struggling with their grief and anger, which they express to Alderton as they sit in their cramped but tidy living room.

Bruce, who has experienced a great deal of pain after multiple surgeries, is difficult to treat because he appears intolerant to most pain remedies. Today, Alderton is contending with another pain whose origin is difficult to assess and diagnose. She gives him an injection of oxycodone – synthetic morphine – in the hope that he will tolerate the medication and that it will relieve his symptoms. She explains all this to Bruce and his wife. As she gives him the injection, he flinches and his wife jests that, "you've become a proper wuss."

Alderton tells them to call her if his pain does not abate in an hour. She also warns Bruce's wife that he may be groggy and sleep a lot and that if he needs another injection in the middle of the night, they shouldn't hesitate to call for a nurse to come out and give it. As we leave, she explains that Bruce will go to a hospice for a short stay, for control of his complex symptoms. "We have to find out what's important to Bruce," she explains. "Does he want me visiting him every week? Does he prefer to see me less?" Whatever his wishes, Alderton tells me as we leave the small house, she and her colleagues will be available to him and his wife until he dies.

Alderton's next stop is in a nearby block of flats. Her patient, Colleen, has had a radical mastectomy on one breast; Alderton and her team are treating a large wound that has taken its time to heal and which required a vacuum assisted closure pump for some weeks. Because the patient had blood clots in the lung, she gets daily injections to thin her blood. Alderton examines the wound and declares, "It's looking much better." However, she checks under the arm and notices a red area, which suggests an infection that will require antibiotics. Then she gives her patient an injection in her stomach. Colleen tells her about upcoming tests – a heart scan and a CT scan on her abdomen. Alderton reassures the visibly anxious woman that things are going well.

As we leave the house, Alderton stops turns to me and says, "Colleen is a terribly worried person and I wanted to make her feel that her needs are important and that she feels reassured by my visit. One of the key skills in this job, she adds, "is to work at speed while making patients think that you are giving them a lot of time." It's clear to me that she can do that because she has more than 30 years' experience and has built trusting relationships with the GPs, pharmacists, hospice and residential care staff and so many others with whom she works. This is evident again when she visits the family that has complained to the GP about their father, Albert, not getting sufficient attention.

We are greeted at the door of their pleasant semi-detached house by one of the couple's children, Alice, who lives nearby. Inside, we're joined by Albert's wife Susan and son Peter and all three usher us into the living room. Albert sits in a wheelchair and a high hospital table covers his lap. A hospital bed with sliding arms is placed in front of the window. While Alice and Peter stand sentinel, Susan plops down wearily onto the couch.

Alderton asks how Albert is doing. Alice talks about his bowels and the fact that he is getting constipated and then – when that is episodically addressed - having very messy accidents. Alderton prescribes a different regimen of medication that will prevent this and says she will give the prescription to the pharmacy herself.

Then she sits on the arm of the couch and addresses Susan. "Are you feeling less well?" she asks, to which Susan nods her assent. Susan says that they operated on her pancreatic cancer three years ago; they got most of it but clearly not all. She's now experiencing dizzy spells and floaters past her eyes.

"Do you have pain?" Alderton asks.

Susan seems so exhausted by her own illness and caring for her husband that she can barely respond. "Yes," she says in a whisper," a lot of wind in my back."

"Do you have pain every day?" the nurse asks.

She tells Alderton that she does and that she occasionally takes pain tablets, which don't work very well.

Alderton suggests Susan takes paracetamol three times a day and, as she looks at Alice, she explains that taking pain tablets now and again won't help. "We can't do anything about the cancer but we can try to make the experience as easy as possible."

Susan says that she is resigned to what will happen and does not want any further treatment. She does, however, want whatever happens to happen quickly.

Alderton asks about other fears or concerns. "Are you worried about what will happen to Albert?" she asks.

Tearfully, Susan nods. Across the room, Alice begins to weep.

Alderton sits calmly in the middle of this scene of grief and reckoning and says that she and her colleagues will help them get through it.

Alderton is worried about how Susan will fare, as her family will be going on holiday in the next few weeks. She can fast track nursing care in a residential facility if Susan meets the criteria of rapid deterioration in her condition. So Alderton asks another series of questions. Is Susan less mobile? Is she more fatigued and sleeping more? Has she lost weight? Lost her appetite? The boxes all ticked, she says she will make necessary arrangements. Meanwhile, she worries that lack of mobility will lead to pressure sores and says she will order a special cushion for Susan to sit on.

As Alderton and the family talk about Susan's condition, the son who complained to the GP enters the room. While his sister stands by alternately silent, abashed, and tearful, he seems all jutting elbows and pointed questions. Why doesn't Mum eat more? Shouldn't she be having smaller meals more frequently during the day?

Alderton responds without a hint of defensiveness, explaining calmly that it won't help to force a dying woman to eat if she's lost her appetite. She reiterates the instructions about pain management. Finally, she asks the family to start thinking about what will happen if Susan gets less and less well. Where would she like to be cared for? "We need to bear in mind that we need to start thinking about all this even though it's very painful," she says gently, adding that that conversation can wait until the following week, to give them time to come to terms with the situation.

Over the following week, Susan becomes even less well and shows signs of raised intercranial pressure, which suggests metastases to the brain. Alderton prescribes low-dose steroids to reduce pressure in her brain, which may also improve her appetite and low mood. Susan still has pain despite regular doses of paracetamol, so Alderton commences her on slow-release morphine as an additional analgesia.

After I leave Alderton, she visits another family. The wife has terminal cancer, a diagnosis which the husband adamantly refuses to accept. He is in constant denial and very aggressive. She also visits a younger woman dying of cancer to give her a morphine injection. She's on a morphine pump that the nurses refill every day, but she needs an injection to prevent break-through pain.

Her work and that of the other nurses whom she leads saves the NHS billions of pounds a year. In just one morning, she's saved thousands of pounds by preventing hospital stays, pressure sores and infections, not to mention pain and suffering to her patients. Her reward? A letter inviting her to reapply for her job and, if she fails to get it, an offer of redeployment, who knows where – all to save a few thousand pounds.

"It's really sad," Alderton tells me as she reads the letter once again. "I'm absolutely, passionately committed to the NHS. I feel I provide a really good service, as do the thousands of other qualified district nurses around the country. We have senior practitioners with a really high level of expertise and experience. You need experts like us at the coal face. You have excellent nurses doing the work. You need more of us, not fewer."

A version of this story was published in the Independent in June 2019 https://inews.co.uk/news/long-reads/district-nurses-hidden-heroes-of-the-nhs-funding-cuts-302651

16. Enabling People to be Cared for at Home

Mandy Kazmierski

I am a Community Matron and work with patients who have complex medical conditions. My focus is to improve their quality of life, helping them to manage their own healthcare problems and ultimately avoid hospital admissions. I am often referred patients who are admitted into hospital frequently. In the last 15 or 16 years I have, in fact, seen a huge rise in the complexity of the patients I care for. One of the main reasons is the rise in patients developing dementia as they age. People who were managing quite well suddenly start to decline. They struggle to manage their conditions and end up with a multitude of problems and increasing admissions.

Previously I worked as a District Nurse and remain passionate about palliative care. Many of the patients I see have conditions that are not getting better. Many are on optimal medical treatment and slowly deteriorating. As I developed in the role, I realized nobody was talking to these patients about their wishes. No one was asking them what they wanted to happen or if they wanted to continue being admitted to hospital. No one was exploring how they felt as their condition deteriorated. In fact, when I conducted my own research for my Masters degree, some matrons told me they had difficulty getting these patients onto the Gold Standard palliative care register.

I know things are improving but there is still a long way to go to ensure their voices are heard. My job is to help patients take back control and support them and their families, so they know there is not a medical solution when death is approaching.

I have been working with a gentleman over the past two years who is a perfect example of this work. For many of the people involved in his care, the focus was on managing his angina – see, treat and pull out. But as a community matron or 'Miss Marple' as we sometimes call ourselves, we go a little deeper, unravelling, unpicking that knotted ball of string.

This gentleman was 89 and suffered from severe, unstable angina. He'd also had two subarachnoid haemorrhages that had left him with chronic headaches. When I was first involved with him, I learned that his wife had died at home and he had tried unsuccessfully to resuscitate her. What upset him most was the haunting feeling that he felt he had failed her. I did a lot of work to help him understand that on the day his wife died there was nothing he could have done to save her. She was 89 and had suffered a major heart attack. Our discussion helped to relieve his anxiety and reduce some of the angina attacks.

He had been going into the hospital twice a week with severe angina. Admittedly some of these episodes were anxiety, but the paramedics would always take him in just to be sure. Their attitude was 'you can't mess around with chest pain.' I connected with cardiology and neurology and as a result he was on optimal medical treatment. I explained that we could try to avoid those hospital admissions by managing his angina at home. We worked on relaxation therapies, which helped a little. Nonetheless, he was still going into hospital regularly.

I kept broaching advance care planning with him and a 'do not resuscitate' order was put in place. I also explored discussions around an advance decision if he no longer wanted to be admitted. After several months of working together, he finally told me that he did not want to die in hospital. I told him frankly, but kindly, that the chances of that happening were very high because one of these angina attacks could be fatal and he would be in A&E or on the ward when that happened.

He asked me what we could do. I told him we could manage this at home and have some just in case medication on hand. I also said that we would need this to be written in an advance decision, so that the medical profession would be clear what his wishes were if he was unable to communicate with them. I knew that he often became a little confused during an attack and would call 999. The paramedics would come and would be so focused on treating his condition that he would be taken to hospital.

He was clear that even though his life was at risk, he wanted to stay at home and manage his condition. He was fed up of going into hospital and more importantly he wanted to die at home. An advance decision was put in place. I also got him engaged with hospice care. He now goes to daycare once a week, which has really helped with his anxiety around his chest pain. Last year he only had one admission to hospital and that was for a suspected stroke. He's now in control of his chest pain. When he gets an attack, he takes a dose of oxycodone and puts himself to bed and he just rests.

Advance care planning can sometimes be quite a quick thing to do, but often with our complex patients it can take time. You must slowly navigate difficult and stressful conversations and help them understand their options. He wasn't ready to do this when I first met him. My ability to work slowly with patients is what is so unique about the Community Matron role. As with this patient, my role is not only to assess clinically, making sure he's on optimal medication and that he understands his meds and the conditions he is coping with. My role is also to unpick what is going on. To do this, you must build a rapport and they need to trust you.

This gentleman is now able to manage his angina, whereas before it was controlling him. Because of this he feels so much better and his family are also relieved not to be getting several calls a week and having regular trips to the hospital. The value to the Trust? I know I have earnt my year's wage by reducing just one patient's admission, which averaged seven or eight times a month. He had only one admission last year!

It's interesting, but sometimes when we get these things in place, people tend to live a little longer because they're not in and out of hospital. They don't have to deal with the trauma of being in A&E for several hours being poked and prodded. More importantly, hopefully, they get to die peacefully at home or in a place of their choosing and not in the back of an ambulance or A&E surrounded by strangers.

I am semi-retired and am very grateful to be able to continue to work two days a week as a Community Matron. I have just done a two-year diploma course to become an end-of-life doula. I do that on a volunteer basis one day a week at my local hospital. Medicine has its place, but I feel strongly that we need to encourage open and honest conversations to enable our patients to take back control. We've got to de-medicalise death.

Here are just a couple of quotes that as a medical professional I always bear in mind:
'Do not leave death to the experts. Remember that death is a social event with a medical component, not a medical event with a social component. The larger part of dying happens outside of the institution and professional care.'
Professor Allan Kellehear

'We all want to be the authors of our own stories, and in stories endings matter.' Atul Gawande - Being Mortal

17. Building Confidence in a New Mother

Maria Mockett, Queen's Nurse

I have been a nurse for 40 years, working as a critical care specialist in acute care settings. For the last 20 years I have been working as a public health nurse, as a Health Visitor in the community. My primary focus is health promotion, early identification and intervention of health needs that supports children from zero to five years of age. My job is also to support their parents.

Research shows that if children are to develop to their full physical, social, emotional and psychological potential, they must have the best possible start in life. As soon as a child is born, parents and new babies have to learn to get to know one another. Not all parents find it easy to transition into their new role. That's why Health Visitors – nurses who are skilled and knowledgeable in supporting parents and their babies from birth to five years of age – play such a critical role.

That role begins with the first contact – the new birth visit. For parents, this first meeting provides an opportunity for them to understand what the health visiting service provides. For the Health Visitor, it is an opportunity to meet new parents and their baby and begin building a trusting relationship so that we are able to work with the parents as they and their new baby move to become a family unit.

Sometimes the unexpected can happen when a visit that should be routine isn't and working with the family can have unexpected challenges. Health Visitors like myself must have the skill, ability and agility to quickly think, assess, interpret and strategise as a guest in someone else's home.

On one routine new birth visit I had gathered all the information I could, before contacting the new mother and arriving at the home visit. There was very little antenatal information available for me to review before I met with the mother on day 11 post-delivery of her baby daughter.

During the visit I noted that the mother was giving me very superficial information while I was completing the family health needs assessment. The mother appeared to me to be answering my questions without providing any real insight into how she was feeling about her new baby. When I asked an important question about how her baby was feeding, she became very defensive. I carried on with some more questions and probed further into her feelings for her baby. Without being judgmental or confrontational, I tried to ascertain why she was defensive when asked about feeding. The new mother looked anxious and upset but continued to talk with me.

As the home visit continued the mother revealed that she had previously had an eating disorder and mental health issues. She was concerned that if she revealed these problems, she would be judged to be ‘abnormal’. She desperately wanted to feel ‘normal’ but was afraid she would relapse. I knew I had to be careful in probing what could be a minefield of complex issues.

One of the most invaluable tools a Health Visitor brings to a visit is the ability to communicate. The art of conversation and having a non-judgemental approach, not labelling or stereotyping this new mother was essential. Coming to an agreement with her and gaining her cooperation in the supportive relationship was key to engagement. By mobilizing the knowledge and expertise I had gained over decades, I was able to gain the mother’s trust, and carry on a conversation, probing without being intrusive. It was essential for me to understand and build a picture to be able to safely support the mother, her baby and their relationship. Over the next few months, the mother did face challenges, but with the right support and time to understand her feelings and behaviours she worked to bond with her baby. Sometimes she was hypercritical of herself, but always met the needs of her baby with warmth and love. My role was to support and have a consistent relationship, seeing her either at home or at the clinic to meet the needs of mother, baby and family in the transition to parenting. Over time, contact and the need for on-going support decreased and the family were just seen for routine appointments.

Three years later I did another new birth visit to meet her second child. The difference in this visit and my first with this woman was astonishing. Instead of meeting a woman who was frightened and defensive, I reconnected with a mother who was confident, open and in charge of asking for what support she wanted or needed.

18. Parkinson’s Disease and Complexity of Care in the Community

Anonymous

I was a District Nurse for 6 years and have now been a Parkinson’s Nurse in the community for the last nine years. After years of experience, I know that community nursing is so valuable because we, as nurses, are able to move far beyond what appears to be a single problem as we address the many complex problems that patients so often have.

Let me give you an example of how a visit to deal with what appeared to be a single problem - a patient’s failure to attend for medical outpatient clinic – unearthed a host of other issues that were successfully resolved.

In this case, I went to visit a patient who had Parkinson’s disease and had missed several medical outpatient appointments. There may be many reasons why patients do not attend reviews. I believe that it is not my role to challenge that: it is to help the patient access the right care at the right time.

To do this, I always entered this couple’s house as a guest. I was offered – and accepted – a cup of tea and then said I’d come to have a chat and see how Mr. and Mrs. White were doing. It worked. The couple relaxed. Then I asked Mr. White about his Parkinson’s and how he was doing with his medication. Whilst I was there, his wife had cut her leg on the edge of a table and wrapped a tea towel around the wound.

The couple began to confide in me. Mrs. White allowed me to check her leg wound. I encouraged her to make a call to the GP surgery to arrange for the laceration to be treated. Then I asked about Mr. White’s medication and suggested I could take a look at the tablets to make sure they were the right ones. Had someone asked this question in an outpatient visit, Mr. White might have said he was taking all his medication on time and even rattled off the appropriate information about when he was supposed to take his tablets. What I learned when the couple allowed me into their home and showed me the medication bottles, was that Mr. White had taken himself off all his medication. He was only on his Parkinson’s medication but had stopped his blood pressure medicine, and other medications.

I saw a collection of medicine bottles part used and others not used. He had filled his prescriptions but not taken the tablets as directed. I suggested that I could take the unused medicine back to the surgery and he agreed. I discovered that Mrs. White not only had a bad cut on her leg but had trouble with angina and hadn’t been to see a GP because her husband became very anxious and paranoid if she was out of the house, other than shopping with their son. Even going to the washing line was an issue at times. His untreated mental health issues – agoraphobia, or fear of crowds and other people - had led to increasing paranoia. Mr. White worried that his wife would leave him for someone else even if she went out to hang the washing on the line.

That day, with their consent, I returned the excess medication - approximately £1500 of unused medication - to the surgery. I initiated a GP visit for a general medication review and a district nurse visit to care for Mrs. White's wound. This led not only to the prevention of an unmet need and possible infection but also enabled optimal management her angina.

Over the course of several months, the couple began to improve. Mr. White can now tolerate his wife leaving the house. He is taking his Parkinson's medication and has improved his concordance with medication in general.

All this was possible because, when we go into a patient's home, we see things we would never see in a GP surgery or outpatient clinic setting. Patients go to the doctor often well-presented and putting the best face on what may be serious problem. Or, like Mr. and Mrs. White, they may not go to see a GP at all. In a patient's home you can see what the reality is. Then, as a skilled nurse, you can ask the right question at the right time.

Had I not gone into the couple's home, his condition would have continued to deteriorate. His wife's health would have suffered. Her heart problems would have been exacerbated and her leg wound may have become more complex in nature. A simple visit turned into a journey of discovery that helped the couple stay healthy and potentially saved further intervention. Chronic long term care prevention, offered at the right time, can save costs and reduce unscheduled care and treatments. My qualifications as a District Nurse and Specialist Clinical Nurse give me the skills to help patients with complex needs.

19. Co-ordinating Palliative Care for a Man at Home

Parveen Akhtar, Queen's Nurse

In the 1990s, my final school report stated, 'Parveen has a keen interest in the welfare of others'. What it didn't mention was that I exhibited this interest by chattering, being inquisitive, and a general busybody. All of this has served me well as I have devoted the past ten years of my life to helping others as an End-of-Life Community Nurse lead. As a Palliative and End-of-Life Care Nurse, my work area has expanded from serving a small local GP practice to working in two large boroughs of south east London.

South east London has a dense and highly diverse population. As well as being a mishmash of different cultures, its population suffers from high degrees of poverty and deprivation. Most of the low-income population, many of whom receive benefits, live in cramped local authority homes. My job involves far more than treating the symptoms of a patients' disease. It involves dealing with the poverty, social isolation, lack of social support and transportation, poor housing, as well as the many other variables that impact the way patients and their families navigate the last days of life. Things like damp and mould due to inadequate construction and heating – even poor lighting – can affect mental and physical wellbeing.

A gentleman I will call Mr. M is a perfect example of the issues nurses like myself confront. Mr. M was a 42-year-old Rastafarian man who lived with his wife and three young children. He had been diagnosed with metastatic colon cancer and both he and his family wanted him to die at home. Before even meeting Mr M, I had coordinated with staff on his hospital ward and ordered home delivery of a hospital bed and air mattress that would prevent pressure sores. This assured that his discharge would not be delayed and his family would be able to welcome him.

As is typical of such patients, Mr. M had complex nursing needs. He was in acute bowel obstruction. Without nursing help, he would be in extreme pain and at great risk. To help relieve the symptoms a nasogastric tube had been inserted through his nose and stomach to suck out air and fluid and to relieve abdominal swelling.

Mr M also had two syringe pumps – the needle placed under his skin. Both were small infusion pumps to administer medications that would keep him pain free and comfortable. He also had a PICC line (Peripherally Inserted Central Catheter), which would deliver intravenous antibiotics, nutrition, medication, and make drawing his blood less painful. Another tube was inserted directly into his small bowel so he could be fed directly. Community nurses working for Mr. M with me would closely monitor these tubes and lines.

My job was to coordinate and supervise his care and make sure he and his family were comfortable and understood what was happening. When I came for my first visit, Mr. M's wife greeted me and led me into a cramped bedroom which Mr. M was sharing with his teenage son, who slept on a bunk bed so that he could be near his father. Mr. M's wife told me that her son had nursed his father during the night, which was why he was sleeping when I arrived.

Speaking softly, I explained that we needed to make sure that Mr. M didn't develop any pressure ulcers, which are a huge risk for bedbound patient's in their last weeks or days of life. Because pressure ulcers are painful to the patient and costly to the system, it is critical to prevent them with devices like air mattresses and frequent patient turning. Once a pressure sore develops, patients are at high risk for infection and even premature death. The cost of managing pressure sores in the UK has been estimated at between £1.4bn and £2.1bn, or 4% of total NHS expenditure. More than 90% of the cost of treatment is the nursing time required to care for pressure ulcers.

Thankfully, Mr M did not have any pressure sores. However, I wrote a pressure area prevention plan of care for the community nurses and the carers so that his pressure area care was managed and monitored.

Mr. M had been sleeping most of the night but opened his eyes and acknowledged my presence when I introduced myself. I asked Mr M if he was experiencing any pain. No, he mumbled, struggling for breath. I held his hand and offered reassurance. His wife asked me if it was possible to get Mr. M a urinary catheter. I explained that insertion of a catheter carried the risk of urethral trauma and infection and suggested that using incontinence pads would be a better option. Mrs. M agreed and I gave her some pads that I carried in my kit bag.

After two hours, the Community Nurse arrived. I gave her an update of my assessment and we both agreed to share and collaborate closely while caring for Mr. M. This kind of collaboration always assures better patient outcomes. I took charge of renewing his medication in the syringe pump whilst the Community Nurse attended to Mr M's jejunal feed, his abdominal wound, and taught his wife how to troubleshoot the feed pump if it started bleeping, should the line become occluded or stop functioning.

Whilst setting up to renew the syringes for the pump I noticed that Mr M had been discharged without one of his medications. Nor had the correct dose been prescribed on his syringe pump charts. As a nurse prescriber I was able to prescribe the medications and amend the medication chart. This helped avoid having to contact a busy GP who is often difficult to reach. It also avoided the need to contact the specialist palliative hospice to visit and amend the charts. My ability to prescribe and chart meant the patient would quickly get the correct pain relief medication, which would both reduce his pain and relieve his family's anxiety.

As I wrote out the prescription, I realised that I would have to collect the medication myself from the local pharmacy, which was over three miles away. Mr. M's wife had no means of transport. A trip to the pharmacy would require two bus rides and take over an hour and a half – precious time she needed to spend with her dying husband. My colleague, the Community Nurse, was happy to stay and care for the patient while I made a quick trip to the pharmacy in my car.

When I returned, the Community Nurse and I were able to set the syringe drivers, provide more necessary nursing care and spend time supporting the family. I also made sure to refer Mr. M to the evening palliative care team so that he and his family were supported at night.

Throughout that day and the next, as I cared for the family, I made sure to involve Mrs. M in my decision making, giving her the opportunity to ask questions and make suggestions. I also encouraged her to express her grief and distress as well as her wishes about her husband's care.

Mr M sadly died few days later. I continued to support his wife through bereavement care, encouraging her to talk about her feelings, fears for the future, or memories of her husband. This kind of care can help people cope with their grief and learn how to live without a loved one. Those people who struggle to grieve may find that difficulty expressing their feelings has an impact on their health in later years. Unresolved grief can be exhausting and may weaken the immune system and make people prone to colds and illness.

Mr M's wife expressed her gratitude for our care. She told me she felt well supported during Mr M's last few days. She was grateful that he was able to have a peaceful, pain free death at home, as he had wished.

There is nothing more important to families than helping their loved ones die in peace and with dignity. I always emphasise this when I'm teaching end-of-life care in the community. We cannot prevent death from a terminal illness. But we can help construct the kind of good death whose memory lives on in those who have cared for a friend or loved one during their last days of life.

20. Building Trust in Sexual Health

Sue Capstick, Queen’s Nurse

Sexual Health Nurses, who are on the frontline of a vitally important NHS service, share the most intimate part of their clients’ lives. Because we often see people only once, and for a very short time, we have to mobilise our skill and expertise to examine, diagnose and treat people with a variety of problems. To do this, communication is arguably the most critical skill we must master. This story explains why.

It was a usual Tuesday morning open access clinic, and the waiting room was full of dozens of people – of mixed ages, gender, ethnicity, and sexuality – waiting for unscheduled visits. The next person on my list was John, whom I called into the consultation room. I introduced myself and asked why he had come to the clinic today.

John said he had come for a check-up after he’d had casual sex with a number of people over the past six weeks. He hadn’t used a condom with his different partners. I explained that what he told me would be held in confidence and that I would be asking a number of questions that could be embarrassing for him. I told him I hoped that he would feel able to answer these questions honestly.

John was 29 years-of-age and worked as a bouncer at the weekends and a lorry driver during the week. He also worked out at the gym three or four times a week. John had never been to our clinic before but told me he had attended other clinics in the past in other towns.

Initially John was abrupt and slightly defensive. This is quite common because people are usually embarrassed by being in the clinic. It is important to quickly develop a relationship which enables people to speak honestly about their reason for attending and help them feel in control of the appointment.

John initially refused an examination. As he had no symptoms the check-up could be done by collecting a sample of urine and a blood sample. I did not push or encourage him to have an examination. While I took the blood sample we chatted, and he seemed to relax a little. I explained how he would get the results of his tests, and encouraged him to protect himself by using condoms when he had further sexual encounters.

As he stood up to leave, John suddenly said, ‘Can I ask you something?’

‘Of course,’ I said.

John then told me he had had a lump on his left testicle that he first became aware of when he was 9 years old. He said had never told anyone about it.

I asked him questions about the lump to ascertain if it was of concern or part of his unique anatomy. He allowed me to examine the lump. I told him, it was indeed part of his anatomy and was nothing to worry about.

John burst into tears. He had worried about the lump for years. Because of it, he had always felt inadequate, even breaking off relationships because he was worried he was 'abnormal.' As a look of relief flooded his face, he told me he had always wanted to ask about the lump but was too frightened and ashamed to ask a GP about it.

After John left my office, I reflected on the encounter. It lasted less than 30 minutes. Nonetheless, in just a brief time, I was able to mobilise my skill and compassion to help this young man unburden himself of worries that had troubled him for much of his life. He clearly had a lot of work to do to restore his self-confidence and rebuild his relationships. But his journey was now beginning.

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