

Our year 2017



Royal Hospital for Neuro-disability



Welcome to the Royal Hospital for Neuro-disability

Founded in 1854, we are a charity hospital and research centre providing services for adults with complex brain injuries.

Based in Putney, we offer specialist care, innovative technologies and therapies to meet the needs of people with the most profound disabilities. Life-altering disabilities that can be, for example, the result of an accident, a fall, stroke, heart or asthma attack. Our specialist therapies and assistive technologies help to maximise what is possible for our patients and residents, while improving their overall quality of life.

What really sets the RHN apart from other hospitals are the extra services that our charity fundraising allows us to provide. These include specialist communication devices, bespoke wheelchairs and nurse escorts for patient outings, to name just a few.

We believe in providing the best possible quality of life for every person entrusted to our care, and while the level of ability is different from person to person, we ensure that our patients and residents are at the centre of all the decisions we make.

In some cases that will mean helping them to enjoy the activities they did before coming to the RHN, and in others we'll help them to try new things.

The life-enhancing extras that we provide are only possible thanks to the kind and generous donations of the people who support the hospital.

A word from our Chief Executive and Chairman



Des Benjamin Chairman

We are very pleased to report on another successful year at the RHN, with many highlights and achievements. In particular, our rating of ‘Good’ following a comprehensive inspection by the Care Quality Commission (CQC) in March 2017, was a great result.

As part of the ‘Plan for the Future’ which we published in 2016, it was a pleasure to open our newly refurbished restaurant, aptly named Reed’s Restaurant after our founder, Andrew Reed. This is a great space for everyone in the RHN community to meet, eat and relax. It is one of many steps in our ambitious capital programme, which will see Drapers ward refurbished early in spring 2018, followed by our new Therapy Hub and a five year rolling ward refurbishment programme thereafter.

This year we launched our first ever RHN Festival. You can read more about this on **page 6**. Bringing staff together, and giving patients, residents and their families the opportunity to take part, is all part of shaping the RHN culture and building on our strong community spirit. The week ended with a fantastic Bake Off competition, which was a joy to judge.

We recognise that in order to continue investing and delivering high quality care, we must be financially stable. For the second year in a row, we are operating at a surplus, but we cannot afford to be complacent so continue to focus our efforts on controlling our costs.

There is a national shortage of nurses, which is challenging, but we continue to work hard to retain and recruit the best staff across all areas. We have also continued to invest in our leaders with various development programmes.

Our Putney Nurse programme, a qualification in Neuro-rehabilitation nursing, was launched – with Royal College of Nursing support – and will be developed further in 2018 with Masters level university accreditation. We are also looking to develop a similar programme for healthcare assistants.

It has been a challenging year for our fundraising department with donations falling short of the overall target, but we continue to be creative in terms of new events and how we engage with our supporters. Income from donations stands at 10% of our overall income and allows us to provide many extra services and activities.

Amongst many high points, the highlight of the year in Research was our hosting of the End of Life in Disorders of Consciousness Conference here at the hospital. Congratulations are also due to Dr Agnieska Kempny and Dr Sonja Soeterik who were awarded their PhDs in 2017.

Thanks to all our staff and volunteers for their continued commitment to serving our patients, residents and their families.



Paul Allen Chief Executive

Our year in numbers

Our patients and residents come from all over the UK and we are one of the largest providers of specialist neuro-rehabilitation services for people with complex disabilities. We have residents who have been with us for many years and for them, the RHN is home. Rehab patients can be with us for a few weeks to several months.



160

people admitted to the RHN



217

people treated in the hospital at any one time*



134

patients treated in the Brain Injury Service



17.1

how many weeks patients spent in our Brain Injury Service*

Beds occupied across the hospital*

50 out of 55

Specialist Services
(91%)

46 out of 52

Brain Injury Service
(88%)

121 out of 122

Specialist Nursing Home
(99%)

How you helped us in 2017

In 2017 we had a challenging fundraising target of £3.1 million, which we fell just short of. This was partly due to a significant drop in legacy income, but also the result of operating in a tough fundraising environment. Last year your donations help us to fund:



Aquability pool sessions



Computer therapy and specialist communication aids



Leisure and Family Services (including disability sports)



Music therapy



Nurse escorts and transport for patient trips



Occupational therapy art



Onsite multi-faith chapel services



Our programme of research



Physiotherapy equipment and hoists



Specially adapted wheelchairs

As part of our overall target we continue to raise money for the refurbishment of one of our Brain Injury Service wards and the creation of a Therapy Hub – a purpose built, state of the art rehabilitation facility. We are now a third of the way to our £3 million target. The hub will be an uplifting space that boosts morale and promotes healing and wellbeing, with zoned areas to provide privacy for patients.

*on average

Meet one of our patients

Ian's story

After blood clots on his brain caused him severe brain damage, Ian started an intensive program of rehabilitation on the RHN's Drapers ward.

His condition began to noticeably improve, and one day when his fiancée Doreen came to visit, using his Eye Gaze system (a tablet that uses an eye controlled mouse) to communicate, Ian surprised her with a message: "I want to get married asap, and I want to do it here."

Doreen said 'yes' to Ian for a second time, agreeing it was a great idea and wanting to mark the occasion with all of the people who'd helped Ian the most. As Doreen put it: "The team have been great, and the technology here is amazing. The RHN gave Ian's life back to him."

With the end of Ian's rehab looming, his therapy team went into overdrive to help him organise the wedding and adapted his goals to turn his sessions into 'wedding therapy'.

Psychology sessions helped Ian and Doreen to plan the day, while speech and language therapy turned to work on Ian's vows. Occupational therapists worked on Ian putting the ring on Doreen's finger, and physiotherapy started him on trials with a powered chair – so he could surprise Doreen by making his own way down the aisle.

On a sunny Friday in October, Ian and Doreen's wedding blessing ceremony went ahead at the RHN. With a crowd of family, friends and RHN staff looking on, Ian and Doreen said their vows and exchanged rings.

With a wedding blessing from the hospital's chaplain, a surprise performance by the RHN choir and a cheeky best man's speech, it was a very special day. "Everyone was brilliant," says Ian. He's positive about their future: "I'm going to get better."

The happy couple were originally quite nervous to come to the RHN. Things feel different this time around – united, they're more confident now. In Doreen's words, "This time we feel like the move, wherever it's to, we'll cope with it together."



RHN Festival



In 2017, for the first time, RHN staff were treated to an onsite 'festival'.

An alternative to a traditional staff conference, the RHN Festival was a packed four days of team talks, information sharing and activities.

Staff had the opportunity to meet, have tea with our trustees, and take part in workshops and wellbeing sessions.

There was also a bake off, an epic rounders game, a highly competitive quiz and a mini sports day!

The aim of the festival was to spend time with colleagues in other teams, bring staff together to learn more about different areas of the hospital, share ideas and have fun along the way.





Founder's Day

Every June, we celebrate our Founder's Day – which this year coincided with the RHN festival.

The event gives the hospital community the chance to come together for an afternoon of fun!

The afternoon was kicked off by our chaplain Geoff Coyne and followed by a welcome from Chief Executive Paul Allen.

Wandsworth's then-Mayor, the late Cllr Jim Maddan, also shared his thoughts about the work we do and his memories of the RHN as a young man living in the area.

The weather let us down, but as always, there was a great atmosphere across the hospital thanks to live entertainment, lots of activities and stalls onsite.



Enjoying some ice-cream!



Soul Jacks' performance



Staff on Founder's Day

1854

The Reverend Dr Andrew Reed, a prolific philanthropist, decides there is a need 'to give permanent relief to such persons as are hopelessly disqualified for the duties of life, by disease, accident or deformity' – and establishes the Hospital for Incurables in Carshalton, Surrey.

1861

Florence Nightingale provides advice on the design of the hospital.

1863

After demand for the hospital increases, and years of fundraising from 'celebrities' of the day including Charles Dickens, the hospital moves to its permanent home on West Hill, then called Melrose Hall.

1880

Edward, Prince of Wales becomes the first of several royal patrons.

our timeline

RHN heritage

The long history of the RHN is another of the things that makes us so very special. The hospital's archives were formally established in 2012, and then in 2013 the archive collection was assessed by the National Archives and judged to be 'of national significance'.

In the last year the project to develop and protect our treasured archives has gained momentum thanks to our fundraising and research teams.

A scoping study funded by the Wellcome Trust has helped us develop plans to secure our archive and all of its materials for the foreseeable future. We have recruited a permanent RHN archivist who will help ensure that our history is preserved and can be shared with our local community, the wider public, and academics all over the world.

At the start of the project we launched an online survey to get feedback and opinions from our local community and history enthusiasts.

The results of this survey confirmed that people outside of the hospital are just as interested in our history and its continued preservation as we are. This is such an exciting project for us and there is a lot to be done. Our plans include:

- Cataloguing and digitising our archive materials so they can be accessed publicly online
- Renovating our Grade II listed reception area to incorporate an archive display
- Reinstating the stained glass windows in our Assembly Room that were destroyed in WWII
- Creating a visitors centre to allow visitors to see for themselves what life was like for chronically ill Victorians, and how it's changed over the years
- Offering workshops to schools, businesses and community groups

For more information about our stained glass restoration project, visit www.rhn.org.uk/support-us or search 'Victorian restoration project' on our site.



If you'd like to find out more, or support any part of the archives project, please contact RHN Archivist Chris Olver on **020 8780 4500** or at colver@rhn.org.uk

1919

The hospital receives its Royal Charter.

1993

The country's first 'transitional rehabilitation' service opens here.

2003

The Institute of Complex Neuro-disability (now the Institute of Neuropalliative Rehabilitation) launches to advance research in the science of care for people with neuro-disabilities.

2011

The nationally recognised Sensory Modality Assessment and Rehabilitation Technique (SMART) that accurately diagnoses disorders of consciousness is developed here.

Reed's restaurant opens

In October, after significant building works our new hospital restaurant opened. Previously on the lower ground/basement floor, the new bigger and brighter restaurant now located on the ground floor of the hospital opened its doors for the first time.

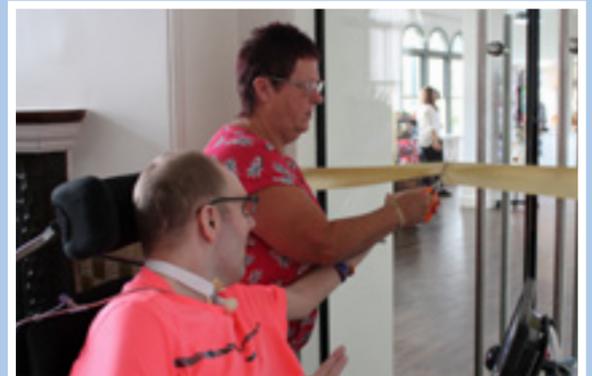
At the opening ceremony – attended by patients, residents, relatives and staff – the name of the new space was also revealed. As a tribute to our founder Dr Andrew Reed, it has been named Reed's.

Our Chief Executive Paul Allen unveiled the name, and the crowd also heard from resident Mark Howe.

Using his communication aid and showing off his famous sense of humour, Mark formally declared the space open and cut the ribbon with his mum Ilsa.

The new restaurant, which was created from our old café, the Morris room, and the Andrew Day room next door, has kept much of its previous charm in the dining area, with classic-style tiles and fireplaces, while the serving area is contemporary with a brand new hot service and café zone.

The aim was to make a comfortable and attractive space for the whole RHN community to use, and this has been definitely achieved thanks to students from the KLC School of Design who designed Reed's.



Five different KLC student teams worked on potential schemes for the restaurant. The winning team, whose scheme is now a reality, also went on to win an 'Architects for Health' student design award!

Your incredible fundraising

Donations from our supporters are vital in order to fund life-enhancing services for our patients and residents.

Each year our incredible fundraisers work with our events team and take on a host of challenges, hold events and raise awareness of our work, and 2017 was no exception.

London Committee

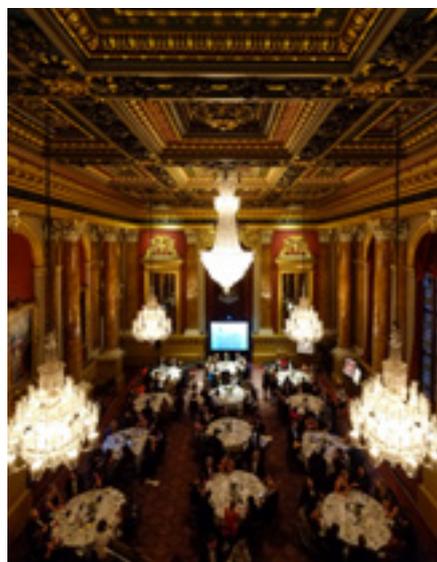
March

Thank you to the London Committee for hosting their long-standing annual bridge event in March, which raised just shy of £4,000.

Virgin Money London Marathon

April

15 incredible runners took on the mighty London marathon for the RHN, joining 39,000 people to take on the famous 26 miles. Together the team raised a staggering £41,200.



Goldsmiths Gala Dinner

May

This year's Gala Dinner was held at the breathtaking Goldsmiths Hall in the City of London. The evening was a wonderful success raising £80,000 towards our Therapy Hub renovation project. We also say a very special thank you to both the Gala Dinner Committee and our event sponsor Healthcare and Locum Recruitment.



Scottish Ball

June

We were happy to again welcome the wonderful dancers to the Summer Scottish Ball for an evening of dance, entertainment and fine food. The 18th annual event raised a fabulous £12,400.



Prudential RideLondon - Surrey 100

July

This year's Team RHN was formed of 10 very brave cyclists who took on the huge challenge of cycling 100 miles from Canary Wharf through London and Surrey, finishing at London's iconic Mall. Collectively they raised an incredible £11,575.

South Coast Challenge

August

Our chaplain Geoff Coyne, and his team who volunteer at the hospital, walked the 50km that makes up one of the South Coast Challenges. Perla Perlini took on the entire 100km challenge and collectively they raised just over £5,000.

Christmas Carol Concert

December

Our annual carol concert was a wonderful way to see out the year raising £8,250. We were delighted to welcome Angela Rippon CBE and TV presenter Naomi Wilkinson who gave festive readings, alongside stunning performances from The London Chorus, Putney High and the Royal Harmonics.





Putney nurses

The past year has seen the RHN develop a specialist training programme to help our nurses provide the very best of care to our patients and residents – the majority of whom have highly complex needs.

Carole Beighton, a registered nurse and teacher, was employed to design a postgraduate course in caring for patients with complex neurological disorders.

Generously supported by the Burdett Trust for Nursing and accredited by the Royal College of Nursing, the 'Putney Nurse' programme has had a successful start. The first cohort to take the course started in February 2017, and the nurses are soon to complete the 12-month course.

The first class had monthly teaching sessions – each focusing on a different theme relevant to patients who have a complex neurological disorder, and delivered by a specialist team of nurses, therapists, doctors, allied health professionals and even the hospital chaplain.

Due to popular demand, a second cohort has already started on the course – and the pace has picked up, with weekly study days rather than monthly ones. The course is being constantly evaluated and as a result is also continually evolving.

With the success of the programme for registered nurses, we are also now planning to develop a specialist course (the 'Putney HCA') for our healthcare assistants, who spend the most time in direct contact with our patients and residents.

Our long-term goal with the course is to contribute to improving patient outcomes nationally. We're working with the School of Health Sciences at Surrey University to develop the current programme into a level 6 (degree) university module. This will still be delivered by our specialist team at the RHN, and we're aiming to launch the course to external candidates in October 2018.

Carole has now moved on from the RHN, but we're pleased to announce her successor, Julie Scholes, a qualified nurse and professor of nursing at the School of Health Sciences at the University of Brighton who has taken over as project lead. Julie has a lot of experience in healthcare education and so will prove invaluable to how the Putney Nurse programme progresses.

Staff Nurse Wendy, who recently completed the Putney Nurse course, tells us how she found it



“The Putney Nurse course has been empowering. It's been great for my career here and I can see how I'd transfer the skills I've learned to other areas of nursing.”



Research

Our research department is an important part of the hospital and works to advance the science of treatment and care for people living with neurological disabilities.

This is carried out through targeted research, developing assistive technologies to improve quality of life and by sharing expertise.

2017 was an exceptionally busy year for the team.

Our annual conference

'End of Life in Disorders of Consciousness (DoC)' was held at the hospital in March 2017 and was another successful event.

This conference, led by consultant in neurorehabilitation Dr Andrew Hanrahan, brought together professionals and carers from a range of specialities to discuss clinical, ethical and legal issues relating to end of life decision-making and care for people in DoC.

This fascinating day highlighted the complex and often emotional issues in this area, and also the commitment of professionals from a range of clinical, legal and related backgrounds.

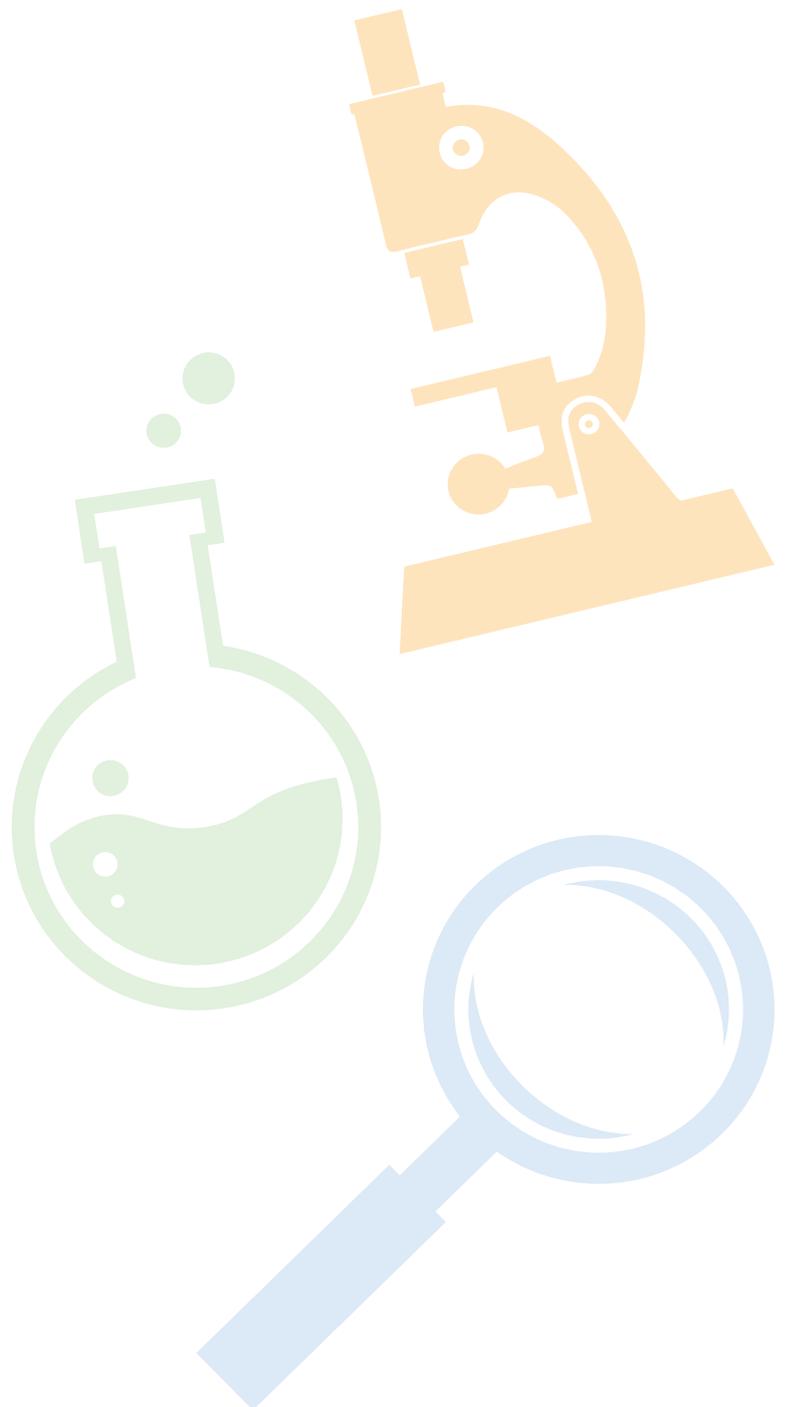
Living well to the very end

The RHN was selected as one of the Patient and Family Centred Care (PFCC), 'Living Well to the Very End' programme sites.

The programme, a collaboration between The Point of Care Foundation, Bee Wee, National Clinical Director for End of Life Care (NHS England) and Nigel Acheson, Regional Medical Director, NHS South is funded by The Health Foundation.

The 'Living Well to the Very End' programme uses an evidence-based and radical approach, drawing on the collaborative methodology of the Institute for Healthcare Improvement. The programme is jointly led by clinicians and quality improvement experts from the Point of Care Foundation and NHS England.

The RHN project will be concentrating on improving the end of life care for patients with disorder of consciousness.





Publications

Research colleagues were also responsible for a number of publications in 2017.

These included:

‘The psychological impact of prolonged disorders of consciousness on caregivers: a systematic review of quantitative studies’

SM Soeterik, S Connolly, ED Playford, S Duport and A Riazi

Clinical Rehabilitation - October 2017

‘The role of the SMART and WHIM in behavioural assessment of disorders of consciousness: clinical utility and scope for a symbiotic relationship’

AM Morrissey, H Gill-Thwaites, B Wilson, R Leonard, L McLellan, A Pundole and A Shiel

Neuropsychological Rehabilitation - August 2017

‘Late recovery of awareness in prolonged disorders of consciousness - a cross-sectional cohort study’

K Yelden, S Duport, LM James, A Kempny, SF Farmer, AP Leff and ED Playford

Disability and Rehabilitation – June 2017

‘The assessment of language and the emergence from disorders of consciousness’

A Pundole and S Crawford

Neuropsychological Rehabilitation – April 2017

For a full list of recent and past publications, visit our website www.rhn.org.uk/professionals/research



New projects

Preserving the incurables for the incurably curious

After receiving funding from the Wellcome Trust for an archives scoping project led by Sinéad Moriarty and Dr Sophie Duport, an archivist and a conservator connected to the Trust visited the RHN to assess our collection and to provide recommendations for the future of the archive.

Based on this scoping report an archives development project is now in place and we are actively seeking funding to ensure that the archives material can be preserved so we can share our unique history with researchers and the wider public. (You can read more about the project on page 8).



Award

Dr Kudret Yelden, consultant in rehabilitation medicine, was awarded the ‘best young investigator abstract award of acquired brain injury’ at the international Brain Injury Association conference in New Orleans, for her paper on ‘optimisation of circadian rhythms in patient in disorders of consciousness’.



PhDs awarded

Dr Agnieszka Kempny, speciality doctor, presented her thesis on ‘Characterising brain function in vegetative and minimally conscious states patients’ at University College London.

Dr Kempny pioneered the use of near infrared spectroscopy (NIRS), a non-invasive technique which measures changes in brain tissue oxygenation, to detect residual cognitive functions in patients with prolonged disorders of consciousness using a motor imagery task.

PhD awarded in October 2017.

Dr Sonja Soeterik, consultant clinical psychologist, completed her thesis, ‘Neither a wife nor a widow’: disorders of consciousness and the experience of families and professionals who care for them’ with Royal Holloway University.

This research has been important in understanding what health care professionals can do to support families of people with a disorder of consciousness. Turn over to page 14 to read more about the study.

PhD awarded in December 2017.

Neither a wife nor a widow: disorders of consciousness and the experience of families and professionals who care for them

Disorders of consciousness (DoC) are relatively rare medical conditions following a severe brain injury that create sudden changes to a person's awareness and consciousness. This means that a person may show periods of time where they are awake and asleep but have no or limited awareness of themselves and the world around them.

These severe injuries are psychologically distressing for the whole family, but little has been known about what the families of people with DoC experience.

Dr Soeterik has been leading a research project investigating what DoC is like for families and how healthcare professionals can best support the whole family.

In-depth interviews found that the female family members of people with a DoC described four common themes.



Loss without a name

“who I know is gone, but there's a body there”

Families shared that they were faced with a unique and strange sense of loss, their family member was still alive, but had also disappeared. This loss was not a death to grieve, but in some ways was experienced as worse than a death. Families found it hard to describe their loss and it was deeply painful.



Relationship without a title

“neither a wife nor a widow”

The DoC created changes to their relationships that were difficult to make sense of. The DoC means the injured person doesn't have awareness of who is visiting, and this means the family has a strange unreciprocated relationship with them.



Symbiotic relating

“I won't rest until I've done everything I possibly can”

Families felt strongly they had to be the injured persons voice and fight to get them the best services they could. By becoming so involved in the care and rehabilitation they experienced a sense of entwining with the injured person such that fluctuations in the person's medical status had dramatic effects on their own psychological wellbeing.



Frozen futures

“this is how she is”

Families shared that they found it too painful to look back on their old lives, and too hard to imagine an uncertain future when they have no idea what will happen next. They became trapped in a day to day system.

From these findings, Dr Soeterik developed a model of understanding the family experience and a psychological intervention to support families to cope with caring for someone with DoC.

This intervention was created with input from expert colleagues across the RHN – the chaplain, a social worker, a neuropsychologist, a rehabilitation consultant, a nurse and a family member with lived experience of DoC. This was approved by the NHS Ethics Committee.

Two families agreed to take part in the pilot of this new intervention and went through the full process with Dr Soeterik. At the end, both families agreed that it was useful and would have been very helpful for other people coping with a DoC in their family. The next step is to see how this intervention can be put into practice with more families.



Meet one of our patients

Trudi's story

Trudi was at a work party at King's College Hospital in London when she experienced a large subarachnoid haemorrhage.

Fortunately, Trudi was surrounded by nurses and neurosurgeons, who very quickly got her into the CT scanner in the emergency department next door for a diagnosis.

Shortly after that, Trudi had a fit, and had to be ventilated in the neuro intensive therapy unit. The next day, the aneurysms in her brain that had caused the haemorrhage were coiled (filled with hair-like coils of platinum to block them up) but Trudi remained unconscious.

It wasn't until she'd been transferred to St George's hospital, and had another procedure to reduce the fluid in her brain, that Trudi began to regain consciousness.

She was soon transferred to the RHN, and began a timetable of intensive rehabilitation.

Initially confined to a wheelchair, Trudi had rehabilitation every weekday. She made incredible progress, and after a few months was able to walk independently.

By that point, Trudi was going out regularly with family and friends, including spending weekends at home. When the time came, she finally walked out of the hospital under her own steam. Trudi has stayed in contact with us, joining the volunteer programme to stay connected with the hospital.

Every Tuesday she helps out with the 'making music' session for patients and residents. Trudi also helped out the hospital by presenting her story to the CQC when they came to inspect in 2017.

Trudi now plays a key role at the RHN and was appointed by the Board to the Patient, Safety and Quality committee, with effect from October 2016.

If you're interested in volunteering at the RHN, you can find more information and contact details on our website at www.rhn.org.uk/support-us/volunteering



The volunteer programme at the RHN is very well organised, and forms some of the lifeblood of this very special place. – Trudi



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