RHNSupporter NEWS



Royal Hospital for Neuro-disability

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NEWS FOR SUPPORTERS OF THE ROYAL HOSPITAL FOR NEURO-DISABILITY

AUTUMN 2021

THE PEOPLE ON THE PLAQUES



The RHN's grounds contain several memorials dedicated to patients, staff and friends of the hospital. Many names feature on our Lavender Plaques located in our peaceful gardens and some on our new 'Tree of Celebration' which sits in our hospital chapel. Two of the people whose names appear on these memorials are Tom and David.

Tom McClure was cared for at the RHN whilst suffering from an extremely rare condition called Familial Alzheimer's - indeed, his was one of only three cases worldwide. The last year was particularly hard for our patients when they were unable to have visitors in person. Tom; with his trademark smile and happy demeanour, was very quickly embraced into the RHN family as our ward staff focussed more than ever, on creating a homely and caring environment for everyone.



Sadly, Tom's condition deteriorated rapidly and in December 2020; at the age of 35, he died peacefully, with his family by his side. In recognition of the fantastic care Tom received, his family and friends raised a staggering £26,000 for the RHN. These funds have gone towards our 'Patients without Relatives Fund' for those who do not have family around to support them.



David Perry was known to many as a deeply caring and generous man. At 50, David suffered a devastating brainstem stroke which left him 'locked-in,' meaning he was only able to communicate by moving his eyes up or down. It was a very distressing time for David and Kerim; his fiancé, as in the hospital he had been admitted to, there was no specialist equipment available to help David communicate. Kerim and David were fortunately (though in sad circumstances) able to marry on the hospital ward just shortly before David died.



Kerim collected £12,000 in David's memory from family, friends and colleagues. Having researched eye track software, Kerim decided to donate the funds to the RHN, specifically for those reliant on eye gaze devices. With the money, we have purchased two new eye gaze machines. These machines not only help our patients communicate with the

outside world but also help our therapists diagnose new patients coming in.

David, Tom and their families have left a truly wonderful legacy for future patients of the RHN and we are very grateful.



Focus On Music Therapy:

An interview with former RHN patient, Trudi Kemp by Senior Music Therapist, Michael Jenkins.



Living with serious brain injury can be very challenging. Accidents and illnesses that affect the brain can cause complex disabilities that affect communication, cognition, mental and physical health. The RHN provides a range of intensive therapies to help patients recover some of the fundamental skills needed for daily life and independent living. One of those therapies is Music Therapy. **Senior Music Therapist, Michael Jenkins** recently interviewed **Trudi Kemp**, a past RHN patient who is now a member of the hospital's reception team on her experiences of Music Therapy.

MJ: You completed a music therapy program with me during your rehabilitation at the RHN in 2016. I'd like to ask you some questions about your experience of music therapy. First of all, was music a big part of your life before you brain injury?

TK: It was a very big part of my life when I was growing up. I played the clarinet. I started at the age of nine and I played in the city of Leeds Youth Orchestra all the way through my school life.

MJ: So would you say that music was an important part of your life?

TK: It was hugely important yes.

MJ: Would you say that it helped you to form some of your social connections?

TK: Yes. I'm married to someone who's very involved in sport and I didn't do team sports. I think music was my team sport because I was working together with people to make music.

MJ: The primary aims of your music therapy with me were to strengthen your breath support, your voice skills, and your attention. We did this by singing some of your favourite songs. Do you feel that music therapy helped you with those aims?

TK: Yes, it did. When I was in hospital, I tired easily and I had not much concentration. When I had my tracheostomy out my voice was a problem, so speaking and singing were a really important part of my rehabilitation and I think the stuff we did in music therapy was hugely important with helping with that. I had visitors an awful lot so therefore my voice and talking was really important. Music was a really interesting way of doing that rather than formal speech therapy which I also did.

MJ: Do you think that the music therapy sessions had any additional benefits besides those aims?

TK: I think a huge part of what happens after a brain injury is that you are mourning a life that you used to have. You didn't appreciate what you had until you don't have it anymore and the thing about music is that it allows you to go back to the person you used to be and the life that you used to have, and for me that was an incredibly important part of my recovery. I had to kind of work out that I still existed and that I could exist in a way that was fun and comforting and I think that music therapy is a really important part of that.

MJ: Would you say that music therapy helped you to adjust to your new abilities?

TK: Yes, exactly right.

MJ: In addition to your individual music therapy sessions, you attended a weekly music therapy group with other patients on the same ward. This group involved choosing songs to listen to and sing with other group members. This group also offered opportunities to play musical instruments as an alternative way of expressing emotions. Can you describe some of the benefits of these group sessions?

TK: For a lot of people there, a lot of the songs that were played were very emotional. Both I and other patients had moments where a song played and we started to cry, and I think that goes back to what I was saying before. You're going back into the person that you used to be and the life that you used to have, but now maybe you don't have in quite the same way anymore.

MJ: So it offered an opportunity to express emotions related to adjusting?

TK: Yes, and there was a togetherness there as well. Everybody was in the same

MJ: Yes, and you're all doing something together. There were patients in that group of diverse ages, abilities, and cultural backgrounds

and despite that, everyone was able to find something in the music that connected to them.

TK: I think that's absolutely right. I remember vividly that one time we played "Loch Lomond" and the lady sitting next to me started to cry. She was Scottish. So that touched something really important in her, and I can remember the song that I started to cry to. It was Bette Midler, "The Wind Beneath My Wings". You can just play that and I do cartoon crying.

MJ: Isn't it fascinating that a song can hold a memory? You can forget the memory, the memory can go, but when you hear the song again the memory comes with it.

TK: Yes, and that is a song that does exactly that for me, and everybody has at least one song that does that.

MJ: It sounds like music can be extremely powerful for not just the functional aspects of rehabilitation but also the emotional.

TK: Yes, and I think that what happens to people when they have a brain injury is that their emotional responses change, so things are not the same for them. I know that I cry more easily than I ever used to. I also laugh more easily than I ever used to. So after your brain injury you're not quite the same as you were in many ways.

MJ: How have you incorporated music into your life since your discharge from the RHN?

TK: I was always part of a choir. One of the things that we did in music therapy at the RHN was listen to and sing pieces from "The Messiah". One of the first things I did when I was discharged was I re-joined the choir. I was discharged in September and I sang "The Messiah" at the Royal Albert Hall in November. I knew from having done that that I could still read the music. I thought "what I should do is go and get my old clarinet out and see if I can still play it". I left school in 1981, shoved my clarinet under a bed, and left it there for 30 years. I thought that playing clarinet would be good for coordination because you've got to read the music, process the music, and make your fingers move at exactly the right time. So, I took my ancient clarinet

to a lovely man in London who mends clarinets and he transformed it into something that was playable. I found an agency that matched music teachers with pupils and I said "I'm 50-blah years old and I just spent a year in hospital following a big brain haemorrhage and I'd really like to have some clarinet lessons. I want a teacher who will be patient and kind and will happily come to my house" and that's what I found. I started that at the end of 2017, about a year after I came out of hospital, and I'm still doing it.

MJ: Did having music therapy sessions at the RHN influence this inclusion of music into your life afterwards?

TK: Completely, totally, and utterly, yes. When you've had a brain injury one of the things that you're worried about is what will happen to your brain as you get older, so you need to keep it active. I'm now in my late 50s. I do three things; I do Duolingo with French, I do my music lessons, and I listen to Intelligence Squared stuff because I'm determined that I've got to keep using my brain. Music for me now is incredibly important in a way that it hasn't been for 30 years.

MJ: It's interesting that you joined a choir straight after you were discharged from RHN. Perhaps you thought the benefits that you derived from group music therapy at the RHN could be continued in a choir after discharge. The music therapy group offered social bonding and a shared experience and you found something after discharge where you could also experience that.

TK: Yes, and also doing something reasonably skilful that I used to be able to do, and connecting back to my ability to do those things has been really important.

MJ: Yes, and it doesn't take skill to benefit from music. I think music is a really wonderful thing because even if your engagement in music is small you still derive all of the benefits. Music never loses integrity, regardless of how big or how small it is, so everyone can engage and everyone can benefit.

TK: Yes, and it doesn't matter how you do it I don't think. What I needed was something that I could do, rather than something that I couldn't do.

MJ: Would you recommend for people who are discharged from rehabilitation to find some way to be involved in music such as join a choir?

TK: Yes, I absolutely would, especially for the social side. I'm such an extroverted person so social interaction with other people was is really important for me.

MJ: It seems like the music therapy that you received at the RHN was beneficial at the time and also afterwards.

TK: Yes, absolutely, and still today.



The Music Therapy Team are always busy. They will hold nearly 1000 group and individual Music Therapy sessions every quarter. They assist brain injured patients in recovering a huge variety of skills and abilities, from speaking and walking to fingertip control and hand eye coordination.

The Music Therapy Team also help patients who are coming to terms with being disabled. Music composition and song writing are just two ways in which patients can express the feelings of frustration and grief that so often accompany brain injury.

They do all of this without any NHS funding. The vital work of our Music Therapy Team is entirely funded by our supporters, who help us raise £200,000 every year to ensure every patient who would benefit from Music Therapy can do so. The funds cover everything from simple musical instruments to the cost of one-to-one support from a qualified Music Therapist.

If you would like to support the work of the Music Therapy team, please turn to the back page for more details on how to donate to our Music Therapy appeal.

International Nurses Day

with RHN Archivist Chris Olver

On the 12 May 2021, the RHN celebrated International Nurses Day, an annual event to celebrate Florence Nightingale's birth and to mark the achievements of the nursing profession and the contributions nurses make to society.



As part of the festivities, the RHN Archivist, Chris Olver, created a temporary exhibit of documents, photographs, bound volumes, pamphlets and digitised films celebrating the vital role of nurses throughout the hospital's long history. The event was put on exclusively for our nursing staff, who visited at regular timed intervals throughout the afternoon (ensuring the hospital's social distancing measures were followed).



Items on display including our first casebook from 1854, which lists the earliest patients who were treated at the hospital.

Each group of nurses were guided through a display of historical material dating from the hospital's creation in 1854 to the present. They were then encouraged to put on gloves, both for infection control and conservation reasons, and explore the archive material themselves.

Some of the highlights included our very own set of letters written by Florence Nightingale (1820-1910), an early supporter of the hospital. The archives holds a set of eight letters written by 'The Lady of the Lamp' between 1861 and 1881, on subjects ranging from hospital design to recruiting a Matron. The latter story is particularly interesting as the Matron who was appointed, Miss Linike, was effectively poached from a Dublin Hospital on Nightingale's recommendation and the letter includes a very frank appraisal of her character – she was 'self-satisfied' but in a good way!



The exhibit featured some of other treasures from our collection, including the original Royal Charter from 1919 and photographs and artefacts taken from our previous Royal visits, including Queen Elizabeth's visit to open the Chatsworth Ward in 1976, and Princess Diana's two visits in 1991. Some of these items have been recently catalogued and digitised thanks to our National Lottery Heritage Fund which has funded these activities.

Also on display were some of the early rules for patients and staff at the hospital. A 1944 staff rule book was striking as to how strictly the hospital controlled the behaviour of their nurses. Nurses were banned from bringing any alcoholic liquors on to the premise, gambling, loitering in sitting rooms and conversing with male staff, except for actual work purposes!



The strictness and lack of creature comforts for the nursing staff in the past was also seen from a complaint made by a group of nurses about living conditions on site to the House Committee in 1926. The nurses asked to have central heating in their rooms, more hot water for bathing and breakfast available for off-duty nurses. The Matron, Lucy Begg, was unsympathetic to the complaints, noting that the 'extravagant use' of hot water was the reason behind the water shortages, and branding the off-duty nurses as 'lazy' in not getting up for breakfast.

By the late 1970s, things had moved on to some extent judging by the teaching material of the residential nursing course at the hospital. The course providing guidance on feeding a patient, caring for unconscious patients and even a class for care for the dying. However, it is interesting that the qualities of a nurse listed in the nursing ethics lecture remained largely the same as from Florence Nightingale's time with an emphasis on kindness, tact, obedience, control of feelings and sympathy. There was also still a clear emphasis on cleanliness and orderliness as seen by these example of model trays for various procedures.



While the theme of 2021 International Nursing Day was looking forward to the future, there is still much that can learnt from our shared history. The hospital has changed beyond recognition from its early days but the importance of 'care for the patient' and being a 'home' and not just a 'hospital' remains. The RHN nursing staff underpin the central ethos of the charity and will continue to do for years to come.

Support the RHN with Amazon Smile

If you like to shop on Amazon, you can now support the RHN by signing up to **Amazon Smile.** Just go to http://smile.amazon.co.uk and search for the Royal Hospital for Neuro-disability in their list of supported charities. Once you've signed up, remember to access Amazon via the Smile page, and for every purchase you make a small donation will wing its way to the hospital.



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Lavender Remembrance Fund

Below are the names of past patients, volunteers and staff at the RHN, whose loved ones have chosen to set up a tribute fund and plant a lavender bush in their memory. The tribute lavender beds can be found in the RHN gardens. Please feel free to visit the hospital and take a look.

Adeh Murray Sellar Anne Prosser Antony Olley Avis June Smith Barbara Garnham Barbara Kelly Catherine Ann Fitzgerald Christopher Bedford David Driver David John Fincham David John Gillett David Richard Perry Diana Merrick Edith Kitty Roper Eileen Dorothy Barrett Eileen McKay France-Raoul Chateau Gabrielle Orchard Ghulam Sarwar Graham Boiling

Graham Phillips Henry John Old Hugh Munro James Pirie Jean Ann Stowe Johnathan Panaguiton Kamaljit Toor Lesley Jean Hyams Lucy Jane Denniston Margaret Deller Mark Goodfellow Marvin Couson Mand Riley Maureen Lesley O'Brien Megan Paton Megan Walters Michael Brocklehurst Michael Lindsay Neale Gordon-Wilson Omar Hayat Shaikh

Patricia Burston Paul Loft Peggy Stannard Peter Gow Peter John Davies Peter Newton Roger Smith Rosemary Ann Shurrock Sean Hamilton Shirley Gill Sirima Suansiri Stephen John Mitchell Stuart-Copping Taranjit Kaur Chadha Ted & Gladys Black Tom McClure Trevor George Kingham Ved & Helena Aggarwal Winifred Warwick-Mayo

Lavender Funds are a way of celebrating the life of a loved one while helping others in need of our specialist care and support. After setting up a fund you will also have the opportunity to plant a special memorial lavender in our peaceful garden.

For more information please contact Isabel Barrett in Fundraising on 020 8780 4557 or ibarrett@rhn.org.uk

Chaplain's Corner



RHN Chaplaincy Assitant, Asi Munisi

This month's Chaplain's Corner is written by Chaplaincy Assistant, Asi Munisi.

Wow, what a year and a bit now that we have had to live in uncertainty, never knowing what will change or when. I like my routine, so for me this past 18 months has been very unsettling. I am a planner at heart, so not being able to plan, not really knowing anything about how to plan in these circumstances, has put me into a bit of panic.

Unlike the change of seasons, which are expected, the weather has also been unpredictable this year, and I found myself affected by that too, even though living in the UK I should be used to it being sunny one moment and raining the next. So how did I become so sensitive to all these constant changes and unpredictability? I was unable to answer that question, but what I did find in my search, was the wealth of resources available to all who seek to maintain a positive mind-set.

One practice that I learnt was building my own sanctuary in my mind, which I can go and visit anytime I want or need to. My favourite image is sitting by the shore of a lake. This is where I breathe deeply and practice being still, especially at times when I feel frantic. Like a lake, even if there are storms going on around me, I can remain still beneath the surface, and it is amazing the effect that stillness has on those in my presence.

So I would like to encourage you and invite you to practice being still, if only for a few minutes, and notice the impact that stillness has on your body and your mood. Put your worries and fears aside for the moment, and be kind to yourself.

RHN Staff Take On The London to Brighton Challenge



On May 29 two members of staff, Craig Lloyd and Catherine Hewitt, took on the London 2 Brighton Challenge and walked 100km to raise money for the RHN.

"We knew how hard the hospital's fundraising had been hit due to COVID-19, so we wanted to do something challenging after seeing how hard our colleagues worked during the pandemic," said Catherine.



The pair left Richmond at 8.30am on Saturday 29 May. The start of the walk took them through Richmond, Teddington, Kingston and New Malden, before continuing through Sutton. The walk was spread out over a two day period, meaning walkers had to complete 56km on the first day and 44km on the second. Rest points were set up along the route, roughly every 12.5km.

"Our second to last checkpoint on the first day was around the 40km mark. By this point we were very tired. Our feet were sore and bleeding and our ankles were quite swollen, but we pushed on," said Craig.

They reached the last checkpoint around 11pm, meaning the duo had walked for over 12 hours.

"I was documenting the whole thing with live updates on the RHN's Instagram page, and you can definitely see us looking more and more tired with every post!" said Craig.

After something to eat at the rest stop, they arrived at their accommodation at midnight. They started the next day early and were back on the trails again at 6.30am.

"At the start of the second day we were pretty broken. We'd been to the first aid tent first thing to get our feet bandaged up. There was lots of cuts, blisters, bruises and we were pretty tired from a rough's night sleep. We tried to keep positive and push through," said Catherine.

The first check point of the second day was around the 70km mark, but Catherine had sustained injuries to her feet, leaving her with swollen ankles and large blood blisters.

"I really wanted to continue with the walk, but after all the first aid I just had to stop. I was in a lot of pain and knew I'd probably reached as far as I could go," said Catherine.

The pair agreed that Catherine would get the shuttle bus to Brighton and Craig would continue on his own. A few hours later, Craig made it to the 82km check point where he needed first aid for blisters, swollen ankles and knee pains.

"I was told by the first aiders that I probably shouldn't keep walking. They recommended I take a shuttle to the end because the checkpoint was closing but I found myself begging them not to. They bandaged my feet and agreed to let me continue."

Craig continued the challenge from Plumpton with only 12km to go until he reached Brighton.

"I was in contact with Cath the whole time and I don't think I could have got through it without her cheering me it was only 12km to go but the hills were massive and it was hard work. The challenge ended at the race track in Brighton, but we had to walk a quarter of the way around the race track

quarter of the way around the race track to reach it. Not ashamed to say I was crying because of the pain at that point!" said Craig.

Catherine was waiting in Brighton to meet Craig at the end and cheered him on until he passed the finish line where he was handed a medal and celebratory glass of prosecco.



"I was so glad to see Cath, it genuinely felt like a few days had passed since I last saw her. All I remember is having a glass of prosecco and immediately heading towards the first aid tent where they were doing sports massages!"

At the time of writing Craig and Catherine have raised £1000 plus Gift Aid for the RHN.

"It was physically and mentally demanding, and a lot harder than both of us expected, but for two people who didn't even think we'd make it past the first day we definitely did ourselves proud. We were very grateful for our friends, colleagues and family who sent us messages of support along the way and donated to us – thank you!" said Catherine.

Dates for your diary

Summer Stroll

18 September

Take a summer stroll with us and walk five miles through Wimbledon Common with a treasure hunt quiz, starting and finishing at the RHN. A great event for all - even your pet pooch will enjoy this one!





Superhero in the City

30 September

This is your chance to walk, run or jog 5km past some of London's most iconic locations, in a Superhero outfit! You will receive a free mask, cape and a finisher medal. There is a registration fee of £25 and a fundraising target of £100. Under 16's go free!

If you'd like to take part in Superhero In The City, but are unable to make it to London this year, you can still get involved.

Royal Parks Half Marathon

10 October

Set yourself a fantastic autumn challenge and grab your guaranteed place in this stunning central London run taking in world famous landmarks on closed roads and four of London's royal parks.





Christmas with the RHN

December

Tis the season to be jolly! For all of your gift and stocking filler needs, visit our on-site Christmas Fair on Wednesday 1 December with a festive performance from Merlin School's choir at 1.45pm.

Join us for an evening of musical performances, cheerful carols and indulge in delicious complementary mince pies and mulled wine for our Christmas Concert on Thursday 9 December. It'll be sure to put you in the festive spirit!

For further information and event updates please visit www.rhn.org.uk or contact the events team by email events@rhn.org.uk or call us on 020 8780 4560.

Please click here if you'd like to support

The Royal Hospital for Neuro-disability's Music Therapy Service.

- £30 will provide a range of new musical instruments for patients to play such as xylophones and drums.
- £50 will provide for the maintenance and upgrade of more complex instruments such as pianos, guitars and electronic keyboards.
- £100 will cover the cost of a one to one intensive session of music therapy with a qualified Music Therapist.
- my preferred amount today.



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Donate online: www.rhn.org.uk/online-donation / Or call: 020 8780 4568



Thank you for your support!

You can also donate by post, sending your gift to: Royal Hospital for Neuro-disability, FREEPOST, London SW15 3SW. Using a stamp will save RHN money. When sending a donation by post, we would appreciate it if you could include your address and email details so that we can continue to keep you updated on our work.

You can change the way we contact you or stop our communication to you by calling 020 8780 4568 or emailing fundraising@rhn.org.uk