



uclh MAGAZINE

Issue 6 / 2019

05 Sweet dreams – how to cure insomnia

10 UK's largest lung cancer screening – helping to save lives

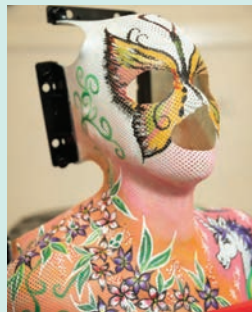
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MEET THE TEAM

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UCLH Magazine is published by UCLH (University College London Hospitals NHS Foundation Trust) for patients, visitors, staff and UCLH members.

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WELCOME



I am delighted to open this edition of our magazine with the news that the Care Quality Commission (CQC) has rated UCLH as “Good” overall for the services we provide to patients.

This is a great achievement and it is thanks to our dedicated staff for the work they do all year round to ensure our patients receive fantastic care.

The CQC’s report is lengthy but there were a few points which really struck a chord with me.

Firstly, what was very clear to inspectors, and also to me when I’m working in my clinic and on the wards, is that our staff treat patients with great compassion, patience and respect. Inspectors spoke to many patients and they were consistently positive about their care.

Secondly, many of our staff told inspectors that they were proud to work at UCLH – a sentiment which I share wholeheartedly. I was particularly pleased with the CQC’s comments about the level of teamwork across the organisation and the sense of common purpose.

Thirdly, inspectors said there was a strong culture of learning, improvement, research and innovation. For me this is

the hallmark of a confident organisation – one that is willing to push the boundaries of medicine and technology to drive improvements for patients and staff alike.

The CQC cited many examples of outstanding practice including our fetal surgery service for spina bifida which is the first of its kind in the UK. You can read about this on pages 8 and 9.

Inspectors also commended the breadth of research and clinical trials at both the National Hospital for Neurology and Neurosurgery, and within our specialist epilepsy service at the Sir William Gowers Centre.

The CQC rated the quality of leadership across the organisation as “Good”. They said leaders at every level were visible and approachable and had a clear vision and strategy.

NHS Improvement rated us as “Good” for how effectively we use our resources which is a reflection of our staff’s commitment to ensuring that

we live within our means.

There were of course some areas where inspectors said we can do better and they rated us as “requires improvement” for safety.

For example, we have been experiencing significant challenges in meeting the standard that 95 per cent of patients should spend less than four hours in our emergency department (ED).

We are taking action as an organisation and with our partners to address inspectors’ feedback.

Overall we are very proud of the CQC’s findings – our staff did a great job of showing what a fantastic place UCLH is to be treated and to work. I would like to thank our people for their continued hard work, professionalism and dedication to our patients.

Marcel Levi
Chief Executive, UCLH

IT HAPPENED TO ME

$$\text{Efficiency} = \frac{\text{Average Time Asleep (h)}}{\text{Average Time in Bed (h)}} \times 100$$

$$\text{Wakeup Time} = \text{Rising Time} - \text{Average Sleep Time}$$

S.E. < 85% ⇒ Move threshold time 15 min later.

S.E. = 85% - 89% ⇒ keep threshold time the same.

S.E. ≥ 90% ⇒ move threshold time 15 min earlier.
(on ↓ medication by 25%)



When SE ≥ 85% ⇒ switch to sleep schedule

SLEEP DIARY

Date	Wakeup Time	Time to Bed	Time Asleep (h)	Time in Bed (h)	Efficiency (%)	Notes
Jan 1	7:30	11:30	10	16	62.5	
Jan 2						
Jan 3						
Jan 4						
Jan 5						
Jan 6						
Jan 7						
Jan 8						
Jan 9						
Jan 10						
Jan 11						
Jan 12						
Jan 13						
Jan 14						
Jan 15						
Jan 16						
Jan 17						
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Jan 21						
Jan 22						
Jan 23						
Jan 24						
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Jan 26						
Jan 27						
Jan 28						
Jan 29						
Jan 30						
Jan 31						

When sleeping becomes a nightmare

Zehavah Handler struggled to sleep for 25 years before completing a five-week course at UCLH's insomnia clinic. Here, she tells us how it changed her life.

Zehavah was just 13 when sleeping started to become a nightmare.

She drew a tiny dot on her bedroom wall and stared at it for hours each night, in the hope of nodding off.

Over the years, Zehavah, who is now 40, tried everything from putting lavender oil on her pillow to over-the-counter pills and hypnotherapy – but sleeping still wasn't easy.

Her GP had little sympathy and her nights and days, revolved around thoughts of sleep.

Zehavah, who has four children, said: "I could never physically or mentally see past when I was going to be able to sleep next.

"I'd get up at seven in the morning and tell myself to make it until midday. Then I'd be so grateful to get into bed until about three in the afternoon. I'd get up when the kids came home and, by 7pm, I was getting into bed."

Sleeping for an average of just two and a half hours of the 12 she was in bed each night, memory loss and irritability became a problem.

Zehavah said: "It was like walking around in a thick fog and there was a tiny light and you are trying to get to it but the fog is distorting it and you can't get there – that's what my mind was like.

"I was always on tenterhooks,

always just trying to get through, rather than living."

Eventually, she was referred to the insomnia service at the Royal London Hospital for Integrated Medicine, part of UCLH.

There she met the clinic's founder, Hugh Selsick (pictured right), a psychiatrist and former insomniac.

Zehavah said: "Seeing him was life-changing. All of a sudden, I wasn't on my own."

“All of a sudden, I wasn't on my own – I feel like I've got my brain back.”

After a night in a sleep unit showed Zehavah's sleep wasn't being disturbed by a medical condition like restless legs syndrome or sleep apnoea, she was enrolled on a five-week group therapy programme.

This used a series of exercises designed to make the brain associate the bedroom with sleep and only sleep.

Laptops, TV and meals in bed were banned and Zehavah was urged to get up and leave the bedroom if she was lying awake for more than 15 minutes.



She said: "That's really hard to do if it's 3am and the whole house is sleeping and the heating is off but it works."

Now, two years later, afternoon naps are a thing of the past. Instead, Zehavah turns in around midnight and regularly clocks up six hours' sleep a night.

There is still the odd sleepless night but, overall, the fog has lifted and her days are much more productive.

In fact, her life has changed so much that she is retraining as a sleep counsellor.

THE A TO ZZZZZ OF INSOMNIA TREATMENT

- Founded 10 years ago, UCLH's insomnia unit is Britain's first dedicated insomnia clinic.
- Patients are first screened for restless legs syndrome, respiratory problems and other conditions.
- A five-week programme of cognitive behavioural therapy involves educating patients about sleep and relaxation, and breaking negative associations to reduce anxiety.
- The clinic sees up to 120 new patients a month. 80 per cent see major improvements and almost half are fully cured.

THE RADIOTHERAPY MASKS IN A LEAGUE OF THEIR OWN

Twelve-year-old Bill Barker has a very special memento of his cancer treatment at UCLH – a customised radiotherapy mask named Jimmy.

Although Bill's treatment for brain cancer is complete and he is back home in Hampshire, Jimmy remains a big part of his life.

He said: "I took him to school to help me explain radiotherapy treatment to my classmates – they thought it was amazing!"

Patients having radiotherapy to their brain, head or neck wear masks that cover their face and shoulders and fasten to the treatment bed. This keeps them still, ensuring the powerful rays target their tumour as precisely as possible, no matter how many radiotherapy sessions they have.

The masks, although essential, can add to what can be a very distressing experience for young patients. But customising them can change that.

Bill's mask features the colours and crests of his favourite football team, Manchester City, and the word "Champions". Bill wanted it painted as if they had already won the Premier League – and during his radiotherapy, they did!

The mask was created by Marina Constantinou, finance manager at the charity Spread a Smile and a talented face painter.

Marina's other masterpieces include Spider-Man, a unicorn and a teddy bear mask, complete with mini mask for the child's own teddy.

"The moment I saw the grey, faceless masks, it was a natural reaction for me as an artist to bring the masks to life by painting them."

She said: "I love the diversity of designs. I have been asked to paint Tom & Jerry, Bob Marley, football and rugby teams and superheroes to name a few. It's very important for me to understand what the child likes – they often tell me exactly what design they want.

"My goal is that the child has a colourful and positive outlook to what can be a very difficult time. Then they can take the mask home like Bill and even give it a name."

Bill's mum, Diana, said: "Your world is turned upside down when your child has cancer.

"But everyone at UCLH made us feel at home and small touches, like a painted mask and a special blanket, make each radiotherapy session that bit more bearable for the children, like Bill, who have to go through this."

“ The moment I saw the grey, faceless masks, it was a natural reaction for me as an artist to bring the masks to life by painting them. ”





THE MEN AND WOMEN BEHIND THE MASKS

UCLH's mould room makes 500 radiotherapy masks a year including around 50 for children.

Each mask starts out as a sheet of mesh plastic that is softened in warm water before placing it over the patient's face. The team then has just five and a half minutes before the plastic hardens to deftly mould it to the patient's features.

Any bushy beards need to be shaved off before the mask is made, to ensure it is as snug a fit as possible. Dental work, such as removing teeth, can alter the shape of the face and

should also be done ahead of the fitting.

David Marsh, mould room manager (pictured above), said: "A patient could have up to 35 radiotherapy sessions and it is vital that they stay still and that their head is in the same position each time. Without the masks this would not be possible."

All the paint used on the children's masks has been thoroughly tested to ensure it doesn't interfere with their radiotherapy treatment.



Just some of the masks created by Marina Constantinou from the charity Spread a Smile

OPERATING INSIDE THE WOMB

Spina bifida, in which the spinal cord doesn't develop properly, is usually treated after birth but studies show that operating earlier can have better results.

Fetal medicine consultant Professor Anna David said: "There are children who can walk, who you wouldn't expect to have been able to walk if they hadn't been operated on in the womb."

During the delicate 90-minute operation, surgeons open up the woman's abdomen to expose her womb.

They then gently manipulate the baby nestled within so that it is lying with its back facing upwards.

A small cut is made in the womb and the damaged spinal cord is painstakingly repaired.

Its spine mended, the unborn child continues to grow in its mother's womb for another two or three months.

Babies born with spina bifida often cannot walk and are often incontinent. They may also need multiple operations to drain fluid that builds up in the brain.

Research from the U.S. found that fetal surgery, while not a cure, almost halves the need for these brain operations and greatly improves the child's chances of walking.

The operation, which is carried out around two-thirds of the way through pregnancy, had only been available abroad until now.

Professor David has co-ordinated a team from UCLH, UCL, Great Ormond Street Hospital (GOSH) and University Hospitals Leuven in Belgium, to offer this surgery for the first time in the UK. She said: "It's fantastic.

"Women now don't have to travel out



of the UK. They can have their family with them. There are fewer expenses. So, all good things!"

The UCLH team spent three years preparing for their first operations and travelled to Belgium to train with Professor Jan Deprest and colleagues, who have done the operation more than 40 times.

Professor Deprest, who also practises at UCLH, was the lead surgeon in the first UK operations and opened up the womb allowing neurosurgeon Dominic Thompson and paediatric surgeon Paolo De Coppi, both from GOSH, to mend the spinal cord.

The team also included fetal medicine specialists, anaesthetists, theatre nurses and scrub nurses.

A £450,000 donation from UCLH

Charity and GOSH Children's Charity and support from the EGA Hospital Charity have enabled UCLH to set up a Centre for Prenatal Therapy with GOSH and fund the first ten operations.

However, it is hoped the NHS will soon routinely pay for the op and that UCLH will become a specialist hub for it.

Professor Donald Peebles, UCLH's clinical director for Women's Health, said: "Research could lead to the operation being done as keyhole surgery, reducing the mother's risk of complications."

Professor Deprest said: "Ten years ago, I would never have guessed that we would be able to do so much to improve the quality of life of babies with spina bifida. It really is a very exciting time and there is more to come."

Frankie – the little girl who loves to dance

In 2014, Gina Lavis from Plymouth was the first UK patient to undergo NHS-funded fetal surgery in Belgium when her unborn baby was 24 weeks old. A routine scan weeks before, showed the baby had spina bifida and was likely to be born paralysed from the waist down. "It felt like a life-changing disability which would impact on every aspect of our lives. We were devastated," said Gina.

The operation in the womb took five hours, a 20 strong surgical team – and great skill. Baby Frankie was born three months later. The consultant surgeon touched the soles of her feet and she responded with movement, a sign that the operation had been a success.

Four years later Frankie is doing well. "She uses a wheelchair but can walk too, is settling into main stream school, loves playing with her baby sister and enjoys dancing. She is a spunky little girl!"



Some of the fetal surgery team



The team carrying out the surgery



UCLH to screen thousands of Londoners in UK's largest lung cancer study

UCLH and UCL are embarking on the biggest ever UK lung cancer screening trial involving 50,000 Londoners to improve early diagnosis and help save lives.

Professor Sam Janes, professor of respiratory medicine at UCL/UCLH and chief investigator said:

"Lung cancer is the biggest cancer killer in the UK because most people only experience symptoms when the cancer is at an advanced stage when it is very difficult to treat.

“This large scale study gives us a unique opportunity to detect lung cancer much earlier...”

"This large-scale study gives us a unique opportunity to detect lung cancer much earlier when treatment is more likely to be successful among those proven to be most at risk – people who smoke or used to smoke, aged between 50 and 77."

People are currently offered screening for breast, bowel and cervical cancer but not lung cancer, despite it being Britain's biggest cancer killer. The SUMMIT Study is designed to show if this ambitious screening programme can be delivered successfully to such a large number of people.

Professor Geoff Bellingan, medical director for cancer and surgery at UCLH and professor of intensive care medicine at UCL, said:

"It provides us with a once-in-a-lifetime opportunity to change how lung cancer is diagnosed – both by paving the way for a national screening programme here in the UK and supporting global efforts to develop a novel blood test for early detection of multiple cancers, including lung cancer."

The study is being undertaken in collaboration with GRAIL, a US healthcare company which specialises in the early detection of cancer. The SUMMIT Study brings together healthcare organisations across north and east London, as part of the UCLH Cancer Collaborative.

Visit www.summitstudy.co.uk for more information.

FACT FILE

- Smokers and ex-smokers will be invited for a lung health check.
- Those who have never smoked will be invited to a group study appointment.
- Blood samples will be analysed to evaluate whether lung and other cancers can be detected through genomic signals in the blood. Participants who are high risk for lung cancer will also be offered a low dose CT scan.
- More than 35,000 lives are lost to the disease every year. It's the most common cause of cancer death.
- Survival rates remain stubbornly low. People are often diagnosed as a late stage when treatment options are limited.
- If diagnosed early 70% of lung cancer patients survive for at least a year, compared to around 14% for people diagnosed with the most advanced stage of the disease.





Professor Sam Janes with the 'Chest Phantom' test tool used in CT scanning to test image quality and radiation doses.



Kirstie Gschmeissner

RADIOGRAPHER

at University College Hospital

“ The thought of being able to easily detect lung cancer early is an amazing thing. ”

Radiographer Kirstie Gschmeissner says it's a real gift to have a job you enjoy so much.

My day starts at...

around 6.30am. I have a shower and breakfast to set myself up for the day. I walk to the tube and listen to music and podcasts on the journey in.

My job involves...

CT scanning. A computerised tomography (CT) scanner is shaped like a Polo mint and uses X-rays to take detailed pictures of the body from lots of different angles. A computer then stitches them together to create a 3D image in shades of grey.

It's beautiful, especially when you see the blood vessels in the lungs. It's like looking at a tree which has lots of little branches with smaller branches growing out of them and even smaller branches growing out of *them*.

On a typical day I...

work on the preparations for the UK's largest lung cancer screening study. Lung cancer is Britain's biggest killer and most cases are symptomless at first and so are only detected at a late stage when they are much harder to treat.

How I become a radiographer...

I knew that I wanted to work in a hospital and a job that combined the medical side of things with the physics behind machines seemed really interesting.

I started at UCLH 18 years ago and have been here in different roles ever since, bar a year working and travelling in Australia.

The best thing about my job is...

In my role as a CT deputy superintendent, every day is different and I learn something new every day. I love being able to talk to patients, reassure them and help them through their recovery.

After work...

I'll go to yoga, the gym or meet friends. I like thrillers and detective programmes and I have a post-graduate certificate in forensic radiography – using scans to identify a body or work out the path of a bullet!

If I could do something else...

I would be a fashion designer. I really love clothes and taking time to think about what I am going to wear. And I like going to Oxford Street for a bit of retail therapy!

To find out more about the lung cancer screening study, see the previous page.



Richard Voges



Our new electronic health record system (EHRS)

Patients are at the heart of everything we do. Here, Richard Voges explains how our new EHRS will help improve safety and allow him and the hundreds of thousands of other patients we see each year to become more involved in their care.

Paper notes and records are being replaced by an electronic system at the end of March – meaning information about a patient’s care will be available at the click of a button to those who need it. Having your information in one place will reduce time spent on admin and help us focus more on caring for you.

At first, when the system is switched on at the end of March there will be disruption as staff get used to new ways of working during the first few weeks.

Richard said: “It will be a challenging time for our staff, so please do bear with us. Delays may occur as staff get used to the system but we will aim to keep disruption to a minimum and we will keep you informed.”

Richard leads a group of UCLH patient representatives who meet regularly with Epic, our EHRS supplier, and UCLH to give their views about the design and features of the patient portal.

Richard explains: “It’s an exciting time for UCLH. The new system will improve safety and save time and money in the long run. It will help staff with the constant challenge of organising appointments, keeping records up-to-date and ensuring clinicians and patients have the correct information at all times.”

The new EHRS includes a patient portal which has been named ‘MyCare UCLH’. Patients can securely log in at home or from their mobile devices to view and

manage information about their care at UCLH. This will include checking appointment times, medications and viewing a library of information that is useful for their care. Patients will also be able to message their care team or receive alerts about rescheduled appointments.

With MyCare UCLH, you don’t have to be technical and it’s as easy as using any other app on a smartphone, tablet or PC.

Choosing to use MyCare UCLH is entirely up to you, and not using it won’t change the direct care or medical treatment you receive. MyCare UCLH allows you to have greater involvement in your care. It won’t replace human contact but we hope it will improve the overall experience of patients.

“The EHRS system will equip UCLH for the future. It’s going to be a massive change, but without doubt the change will be positive, for clinicians, administration staff and also for you.”

If you have any comments please email uclh.ppi@nhs.net.

Our new EHRS, enabled by Epic, will go live on 31 March 2019. Atos, our digital transformation partner, will ensure that all the new computers and technology needed to run Epic are in place before then.

MEET YOUR GOVERNORS



From top left, Maggie Clinton, Allesha Baptiste, Sally Bennett, Jonathan Harper, Andrew Todd-Pokropek, Richard Cohen and Loraine Rogers.

A patient who travels hundreds of miles from her home in Carlisle for treatment at UCLH, a clinical consultant and a patient whose son was born at our hospital – our new governors come from all walks of life and bring with them a variety of skills and experience.

They were among six new governors who were elected last year and took their seat on our Council of Governors on 1 September.

Two governors were also re-elected for a second term (not pictured) and one reserve governor took a seat when an existing governor stood down.

Their views – and those of their fellow governors and partner organisations – will help shape our decisions to ensure we

continue to provide the best possible service and care to our patients.

The Council advises UCLH on issues that are important to patients and the wider community.

Two new governors will also join us in January 2019, following the by-election at the end of last year. Details will be announced on our website.

You can contact your governors via uclh.governors@nhs.net

If you are interested in standing as a governor or becoming more involved with UCLH, please contact the Membership Office for details on 020 3447 9290 or uclh.members@nhs.net.

Research open event

Our annual open day celebrating cutting-edge research at UCLH and UCL takes place on 4 July 2019, from 1pm – 4:30pm.

At this free event, you can talk to doctors and scientists and find out more about how they are working to improve care for patients at UCLH and beyond. There will be interactive stalls, games, prizes and more!

Help us help you stay well this winter



Don't wait until you feel worse

Even if it's just a cough or cold, consult your pharmacist before it gets more serious.

HELP US HELP YOU
STAY WELL THIS WINTER

nhs.uk/staywell

NHS

Prameet Shah, Pharmacist

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If you start to feel unwell, even if it is just a cough or a cold, speak to your pharmacist. Don't wait until you feel worse – the sooner you get advice the better.

Older neighbours, friends and relatives are also more vulnerable at this time of the year. Try to keep in touch, check if they are under the weather and help them stock up on food.

Remember the flu jab is free for members of the public in "at

risk" groups: pregnant women, over-65s and people with serious health conditions.

Your NHS in Camden is working hard to keep you well this winter. We have the free NHS 111 helpline, community pharmacies and GP hubs which offer evening and weekend appointments.

Follow the expert advice of NHS staff and visit nhs.uk/staywell.

ARCHIVE

1930

In the Middlesex Hospital in the 1930s, trainee nurses practised their first aid on a dummy patient said to be suffering from shock after an accident. A stoneware hot water bottle keeps the pig-tailed manikin warm while her pulse is taken.



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