


patient **first**

#patientfirst

spring 2015

A photograph of a young boy and a young girl sitting together on a red sofa. Both are wearing blue school sweaters with a circular crest on the left chest. The boy, on the left, has blonde hair and wears glasses. The girl, on the right, has blonde hair tied back. They are both smiling at the camera.

'Every milestone that Alfie achieves is massive and I never take anything for granted. I want Alfie to be the best he can be in life and I am so, so proud of him every day'

Read Debbie Pickett's story about her 6 year old son, Alfie [p8](#)

Top Chinese healthcare professionals visit Tunbridge Wells Hospital [p6](#)

Living with inflammatory arthritis [p12](#)

Welcome to the Spring edition of Patient First!

In this magazine, we have more real-life case studies – we talk to Debbie Pickett about her son, Alfie, who has Down's Syndrome and epilepsy, and the challenges they have faced. You can also read about Susan Christodoulou, who tells us about Sarcoidosis, a rare condition which primarily affects her lungs and skin.

This edition also includes stories about our maternity unit and birth centre, a new cancer support group for young people and there's some charity and fundraising news. You'll find general advice for people coping with arthritis and our Chief Executive, Glenn Douglas, explains the recently published Care Quality Commission reports and what we will be doing in response.

As always, you can test your general knowledge with our quiz, try the delicious recipe from our very own League of Friends cook book, and find practical advice about local services available to you.

Don't forget, we would really like to hear from you – all your feedback and suggestions are gratefully received, so please contact us.

We hope you enjoy this edition of **Patient First** and we look forward to hearing from you.

Best wishes for a happy and healthy spring - we'll see you in summer!

The Patient First team

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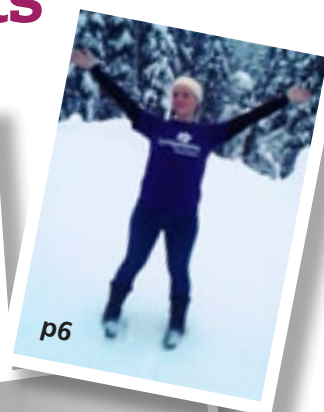
For any general enquiries or advice, please contact our Trust switchboard or visit our website.

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 Women and Children's Services

Throughout 2014 the Friends and Family Test scores have consistently been well above the national average and the team have received some wonderful comments.

For 2015, there are a number of developments planned to enhance the maternity service and improve the experience for women and their families.

The team are about to introduce mobile epidurals for low risk women to enable them to remain as mobile as possible during their labour.

Kangaroo Care continues to be promoted by the maternity team across both sites and it is hoped that it will become standard for all mothers to use Kangaroo Care, with the opportunity to borrow either a kanga wrap or kanga card to assist them with this. The benefits of Kangaroo Care have been recognised internationally and as such, a group from the Chinese Health Department visited Tunbridge Wells Hospital recently to find out more about it and view Kangaroo Care 'in action'.

POSITIVE YEAR FOR MATERNITY SERVICES

Last year was another positive year for maternity services across both hospitals, with a total of 5,625 babies born at Tunbridge Wells Hospital and the Maidstone Birth Centre (421 at the Birth Centre). To put that into context, that's around 187 school classes!

Tunbridge Wells Hospital

2014 was the busiest year ever for the maternity department at Tunbridge Wells Hospital.

The team has continued to work to give the environment a more homely feel and in early 2014 they were successful in obtaining a Department of Health grant to enable them to buy a number of folding beds for partners to use when staying in hospital. Two lounge areas have also been created for women and their partners to relax and to have somewhere to meet others.

The Tunbridge Wells Hospital League of Friends kindly donated funds to purchase some telemetry units so that women needing to be monitored during

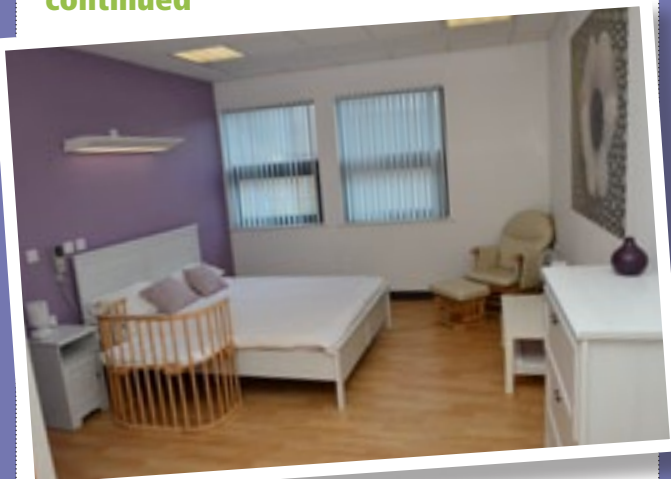
labour can do so without having their movement restricted. The units can also be used in the birth pools, which has helped to offer more choice and has increased the number of women having water births.

For women having their labour induced, the process can often seem long and drawn out and the team wanted to improve the experience. As such, they have introduced the role of Induction Coordinator – this midwife cares for all of the women having an induction and liaises closely with the staff on the delivery suite to ensure safe prioritisation and improved communication to women so they can be kept up to date with what is going on.

The Maidstone Birth Centre

Research has shown that giving birth in a Birth Centre is as safe for women with an uncomplicated pregnancy as it is in hospital, but with the benefits of less medical intervention such as caesarean section, instrumental birth or an episiotomy. As women are now becoming more aware of these benefits, this may have helped lead to an increase in the number of women giving birth at Maidstone Birth Centre in 2014, with a total of 421 births during the year. Most women came from the local area, however there have been several women who have travelled a considerable distance because they have heard of the excellent care and facilities on offer. Whilst located in Maidstone, the Birth Centre is available for anyone under the Trust's care to use (subject to them being deemed suitable).

POSITIVE YEAR FOR MATERNITY SERVICES continued



Since the Birth Centre opened three years ago, more than 1300 babies have been born there. Results from the Friends and Family Test and Maternity Survey, show that these women are extremely happy with the care they receive – scoring a maximum of 5 on the Friends and Family Test and 98% in the Maternity Survey.

During 2014, there have been several developments at the Birth Centre, including a new technique being trialled to help relieve back pain during labour, a research project to investigate the effects of acupressure for inducing labour and also six midwives completed a course enabling them to carry out examinations of newborns (first baby check). So far, around 328 examinations have taken place within the Birth Centre, meaning women do not need to attend other hospital departments for this.

Each month, the team at the Centre also receive around 1000 calls requesting advice and support. This service helps to reduce pressure on other services both within the community and the hospitals.

The team have also been involved in a number of events and opportunities nationally and internationally. They have been able to assist a new Birth Centre in Kathmandu, Nepal through the Global Midwifery Twinning project run by the Royal College of Midwives. This involved a visit by a member of the Birth Centre team (performed in a voluntary capacity) to work in partnership with the Nepalese nurse midwives to develop guidelines, information leaflets and good practice initiatives. We hope to continue this relationship during the year ahead.

NEWS FROM

Freddie's Friends – new young person's cancer support group



Following the recent refurbishment and upgrade of a room on Charles Dickens ward at Maidstone Hospital, named Hayley's Room, in honour of Hayley Martin who raised the money for the work to be carried out, a new support group for young people with cancer has been launched.

Patient, Tom Jenkins, has been working closely with Hayley and Chemotherapy Day Unit Manager, Keli Tomlin, to establish the group, called Freddie's Friends in honour of Hayley's son.

Tom said, "I have recently finished my treatment and was keen to get involved with an initiative to help those fighting cancer. By coincidence I was approached by Keli who asked if I'd be interested in helping to set up the support group, so I jumped at the chance.

"From my own experience, I have rarely come across young people with cancer and so it can feel quite lonely and isolating. I think it's really important that people are able to come together and share experiences and offer support in a friendly, welcoming environment.

"Hopefully the group will be really well received and I know that myself and my family would have made use of it had it been established when I was receiving treatment."

The group, which started on 21st January, meet on the third Wednesday of every month, from 7.00-8.30pm, in Hayley's Room and have recently met for the third time.

If you are interested in finding out more about the group, or if you would like to attend, then please email: freddiesfriendsgroup@gmail.com or alternatively, please call 07703972529.

MYOUR HOSPITALS

Children's A&E drop-in

More than twenty visitors and members of the public provided feedback to a recent drop-in session at Tunbridge Wells Hospital, regarding plans for a new children's A&E department.

Wendy Glazier, Interim Matron for Medical Services, said: "The drop-in session was extremely useful for us as we were able to find out what people's expectations and priorities are in terms of a children's A&E service. Access to refreshments, age appropriate waiting areas and clearly distinguishable (by uniform) paediatric staff were some of the main themes. We want to use this information to work towards setting up a service which is of real benefit and use to those people living in the local area."

If you would like to provide feedback about our plans for a children's A&E in the future, please contact Clare Hughes, Matron for Acute and Emergency Medicine, via the Patient Advice and Liaison Service on 01622 224960 or 01892 632953 or via mtw-tr.palsoffice@nhs.net

Congratulations to Lisa Donlon



Congratulations to Lisa Donlon from Maidstone, the first mum to have three babies born at the Maidstone Birth Centre - daughter Ruby was born on 05/12/11, son Bradley on 02/12/12 and baby Freddie arrived on 14/01/15.

We're delighted that Lisa chose the Birth Centre for the arrival of all her children and we wish them lots of happiness for the future.

Generous donation from League of Friends to benefit rheumatology patients

Patients with rheumatoid arthritis will benefit from quicker diagnosis and more precise treatment thanks to a generous donation from the League of Friends.

The League of Friends at both Maidstone and Tunbridge Wells hospitals have funded the purchase of two new state-of-the-art ultrasound machines, at a cost of around £40,000 each - one for Maidstone Hospital and one for Tunbridge Wells Hospital.

Dr Amit Saha, clinical lead for rheumatology, said: "We are delighted with the new machines and are extremely grateful to the League of Friends for their help.

"These ultrasound machines will allow us to diagnose rheumatoid arthritis earlier and more accurately, which means we can start treatment sooner, giving better outcomes for our patients.

"With rheumatoid arthritis, early diagnosis and treatment is vitally important as this can prevent long term damage and, in some cases, get patients into complete remission."

Rheumatoid arthritis is an autoimmune disease where the immune system attacks the cells that line the

joints, making them swollen, stiff and painful. Over time, this can damage the joint itself, the cartilage and nearby bone.

Rheumatoid arthritis typically affects the joints symmetrically (both sides of the body at the same time) but this is not always the case. The small joints in the hands and feet are often the first to be affected

Dr Saha added: "The ultrasound machines are portable so we can use them in clinic. As a result, patients can now be diagnosed and given a treatment plan at their appointment.

"Being able to see the affected area on screen will also help us administer steroid injections more accurately as we can view precisely where the injection needs to be delivered."

Dr Saha advises patients to see their GP if they are suffering with these symptoms:

- **Joint pain** - usually a throbbing and aching pain, which is often worse in the mornings and after a period of inactivity.
- **Stiffness** - joints can feel stiff. For



example, if your hands are affected, you may not be able to fully bend your fingers or form a fist.

- **Swelling, warmth or redness** - the lining of joints affected by rheumatoid arthritis does become inflamed, which can cause the joints to swell, and become hot and tender to touch.

more

NEWS FROM YOUR HOSPITALS

Vicki Ingleson completes Arctic challenge

Last year, Maidstone and Tunbridge Wells NHS Trust Clinical Trials Officer, Vicki Ingleson, decided to take on a rather unusual charity challenge to raise money for the Lymphoma Association.

At the end of January, Vicki flew to Swedish Lapland, in the Arctic, and took part in a three day dog-sledding adventure in day-time temperatures of -25°C, which has so far raised over £2600.

Now, Vicki is back with her fingers and toes intact – and she's already thinking about what her next challenge might be...!

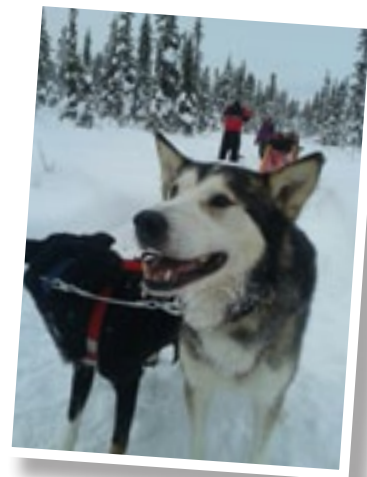
She said: "On the first day of the challenge we got kitted up and were given a ten minute tutorial on how to 'mush' or drive a sled. I quickly learnt how to harness up my own four dogs, attach their lines and pack my sled - then it was time to go! We set off, following the guide, and quickly had to find our feet on the sled. Much of it is about balance and shifting your weight, especially as the terrain you travel across is quite changeable with steep slopes and inclines, and sometimes deep snow. We travelled a total of 27 kilometres

and eventually reached the Wilderness lodge in Väckarjärvi, where we would be staying the night. It was already getting dark by the time we got there and there is no electricity or running water, so feeding 56 dogs and cooking our own dinner was a challenge in itself!

"The second day was a circular route described as a 'difficult trail' with over ten kilometres of the full 37 kilometres through narrow forest trails and eight inches of fresh snow, which had fallen overnight and slowed us down.

"The third day was probably the coldest of them all, when we sledded across a huge frozen lake called Sautosjärvi. The lake took around three hours to cross and we had a constant biting wind in our faces, so it was hard going but the scenery was breath-taking. We headed back to the Musher's lodge for our final night - a celebratory meal and hot showers!

"The following morning, we left the Musher's lodge and were taken, as passengers this time, on a 12 dog sled transfer back to the airport – by far the



best airport transfer I have ever experienced!

"The trip was incredible, and I am already thinking about what kind of unusual charity challenge I could do next!

"My trip to the Arctic was physically hard work, and mentally challenging, but an amazing experience and I would do it again in a heartbeat."

You can still donate to Vicki's cause, the Lymphoma Association, via her Just Giving page: <http://www.justgiving.com/owner-email/pleasesponsor/Victoria-Ingleson>

Alternatively, donations can be made by texting VILA99 followed by the preferred donation amount, eg. £5, to 70070.

Top Chinese healthcare professionals visit Tunbridge Wells Hospital to learn about Kangaroo Care

Tunbridge Wells Hospital welcomed five top Chinese healthcare professionals last week, who wanted to see how we are encouraging new mothers to implement Kangaroo Care (skin to skin contact) with their babies from birth.

The visit was requested by international charity, Save the Children, who were keen to find out more about our research and experience in Kangaroo Care. It is hoped that the visit will have an impact on maternity services in China and could change national policy in the country, now the benefits of Kangaroo Care have been seen first-hand.

The delegates included Ms Bin Cao, Director, Child Health Department, National Health and Family Planning Commission, Mr Tao Xu, Director, Child Health Department, National Centre for Maternal and Child Health, Ms Baohua Gou, Head Midwife, Beijing Friendship Hospital, Ms Danhua Wang, Neonatologist, Peking Union Medical College Hospital and Ms Gengli

Zhao, Obstetrician, Peking University MCH Centre.

During the visit, the delegates were given the opportunity to visit the post-natal ward to speak with new mothers using Kangaroo Care, attend theatre, meet key members of staff within the Trust and go to the neonatal unit where premature babies are cared for.

They were impressed with what they saw.

Gillian Duffey, Head of Midwifery for Maidstone and Tunbridge Wells NHS Trust said: "It's important that we work closely with healthcare specialists from all over the world, and share good practice, as we all have the desire to improve things wherever we can for mums and babies everywhere.

"While they were with us, our visitors were able to speak with mothers on our maternity ward directly, so we very much hope they got a real sense of the benefits of Kangaroo Care."



Jelena Pochin's 250 miles for charity

Trust Complaints Lead, Jelena Pochin, has set herself an incredible fundraising challenge – she aims to complete 250 competitive miles this year, to raise money for the National Autistic Society.

Jelena will cover 250 miles in race style events, which include running, cycling, obstacle course races and a triathlon. Some of the events she will take part in are: Silverstone Half Marathon, Leeds Castle Triathlon, Kent Roadrunner Marathon and the Great North Run.

Jelena chose to raise money for the National Autistic Society as her 12-year-old Godson was recently confirmed as having autism. She hopes that the challenge will not only help to raise funds for the charity, but also raise awareness and understanding about the condition.

If you would like to sponsor Jelena, please visit her Just Giving page: <https://www.justgiving.com/Jel-Aly250miles/>



Dr Tom Blyth, Marathon Runner

Maidstone and Tunbridge Wells NHS Trust Paediatric Consultant, Dr Tom Blyth, will be running the London marathon this year to raise money for the Cystic Fibrosis Trust.

Tom ran his first marathon, at Beachy Head, in October last year, in 5 hours and 15 minutes and raised £1500 for the Cystic Fibrosis Trust.

He said: "I look after children with cystic fibrosis so I was keen to raise money for the Cystic Fibrosis Trust, and I would like to bring in £2000 in sponsorship this year.

"I had only ever done half marathons before last year and I never thought I would actually be able to complete a full marathon but I really enjoyed it. I'm training now for the London Marathon so hopefully, I'll be able to better my time as well as raise more money this year."

You can sponsor Tom at <http://uk.virginmoneygiving.com/TomBlyth>



Patient marries at Tunbridge Wells Hospital

A patient who was being treated on ward 10 married her partner in a special ceremony at the Education Centre at Tunbridge Wells Hospital on Christmas Eve.

Chrissie Murr, who lives in Teston, was diagnosed with cancer in December last year. Her partner, Robin Owens, brought forward their plans to marry and arranged for the ceremony to take place at the hospital.

The team caring for Chrissie played an active role in helping with the wedding arrangements by ensuring the room was beautifully decorated with flowers and seasonal foliage, and assisted in getting her ready for the ceremony. After her marriage Mrs Owens was allowed home for two days before returning to hospital.

In January she was transferred to Kings Hospital London for specialist treatment and has since returned home and is progressing well.



Redevelopment work at Maidstone Hospital continues



Costa Coffee is now open in the main entrance area of Maidstone Hospital.

Work is still ongoing to improve the area as a whole for everyone visiting and working within the hospital. As well as the introduction of Costa Coffee, there is a new reception desk and waiting area.

There will be new bathroom facilities and a larger shop for the Maidstone Hospital League of Friends.

The redevelopment of the main entrance area is part of a wider project to improve facilities and wards at Maidstone Hospital.

Feature



EVERY DAY'S A CHALLENGE, BUT WITH SO MUCH REWARD

The first year of Alfie Pickett's life saw a number of hospital admissions, health problems and even a six day stay in Intensive Care at a leading children's hospital in London. Further down the line, when Alfie was three, came another shock when he was diagnosed with epilepsy.

Here, we talk to Alfie's mum, **Debbie Pickett**, about her amazing little boy, the highs, lows, and day-to-day challenges they face, and why she says she has so much to be grateful for.

When Alfie Pickett was born three and a half weeks early on 27 December 2008, no one knew that he had Down's Syndrome, or that the next year, and beyond, would see his mum Debbie faced with numerous situations most of us can't even imagine having to deal with.

"When Alfie was born, there was no immediate mention of Down's Syndrome," Debbie said, "It wasn't until the next morning that a doctor said he was showing characteristics of Down's Syndrome – for example, a single crease across the middle of the palms of his hands, as opposed to the two that most of us have.

"A consultant I saw the following day said while he was almost sure he was fine, they would run some blood

tests to confirm. Three weeks to the day that he was born, it was confirmed that Alfie did have the most common form of Down's Syndrome – Trisomy 21."

Debbie was immediately put in touch with the National Portage Association, who provide a home-visit and educational service for children and families with additional support needs.

"Portage was fantastic for Alfie," said Debbie, "Through all the good days and bad, the hospital consultants, many doctors, specialist care providers and everyone else we had to deal with, Pam came week in, week out, to provide help and support for me.

"More importantly she treated Alfie as a child, not a patient or someone on her caseload. She always focused on what Alfie could do and built on that, rather than what he could not do. It taught me to take things gradually, and I accept now that the little things will add up to succeeding in a bigger thing later.

"Through Portage I met lots of other families with children with disabilities and some of them are still very good friends who remain a huge support to both myself and Alfie."

At the age of four months, Alfie was admitted to the old Pembury Hospital with serious reflux. At ten months of age, he was admitted again and was so unwell that he spent two weeks in the High Dependency Unit, before being transferred to the Evelina London Children's Hospital. After being transferred, Alfie was taken in to the Intensive Care Unit (ICU) as he needed a ventilator to assist his breathing. While at the Evelina, Alfie was diagnosed with swine flu.

Debbie said, "Alfie not only had swine flu but was also suffering with bilateral pneumonia, encephalitis and tonsillitis and he stayed in ICU for six days before being transferred back to Pembury. He was discharged after a week and allowed to come home."

Between the age of 12 months and three years, Alfie was admitted to hospital around eight or nine times each year.

"I would sometimes find Alfie totally unresponsive in the mornings and would have to call an ambulance. This often happened when Alfie had been suffering with a cold or virus and there was no obvious reason for his unresponsiveness, said Debbie.

When Alfie was two years and four months old, he had his tonsils and adenoids removed and after leaving hospital, he was well for eight months. But then the hospital admissions started again.



At the age of three he was taken to the Evelina London Children's Hospital again with breathing problems, and placed onto a ventilator. It was when he had been transferred onto a ward that Alfie suffered a series of eight seizures in a single day. He was quickly diagnosed with epilepsy.

Debbie said: "After this diagnosis, Alfie's previous bouts of unresponsiveness made a bit more sense. Doctors thought they may have occurred as a result of him having seizures overnight while he slept. Obviously, I wasn't seeing them happen so I just saw the aftermath when I went in to him in the morning.

"He now has regular medication and he has a consultant, Dr Gupta, at Tunbridge Wells Hospital, plus he sees a specialist, Ruth Williams, in London, once a year.

"Since he was diagnosed, he has had a further three or four admissions into ICU and he has stopped breathing twice. However, it became easier to tell if Alfie was likely to have a seizure, as a couple of hours before, I would see warning signs, such as him grinding his teeth or rolling his eyes. What also became apparent was that the seizures only occurred if he had been unwell. No underlying cause has ever been established so it seems that they are always triggered by Alfie having a cold or virus. Doctors believe that they started as a result of him having swine flu as a baby and have carried on since, when he is not in full health."

Last year was a better year and it would appear that Alfie is becoming more stable as he gets older. However, he was admitted to the High Dependency Unit in Hedgehog Ward at Tunbridge Wells Hospital at the end of 2014 after one of his seizures lasted for an hour and ten minutes.

Debbie said, "He may grow out of the seizures and I do think things have got better as time has gone on, but he will need to be fit-free for at least 18 months to two years before his doctors even consider reducing his medication

so we have a way to go.

"When he first started having seizures, and I saw them, it was really scary but like anything, you get used to it, and gradually you become better at dealing with it. There is a lady, Sadie, who lives round the corner from me who is a voluntary ambulance worker and she has helped so much. When she hears that I have called an ambulance, if she is nearby, she often comes straight round to help me, whether she is on or off duty.

"In fact, a lot of people have been hugely supportive. People are quick to complain but actually, I take my hat off to all the nurses and doctors on Hedgehog Ward. They are brilliant with Alfie and very supportive of me."

And in fact, otherwise, Alfie lives a very normal life. He attends a mainstream school – Brenchley and Matfield Primary, with his older cousin, Ellie, 9, who also lives with him and Debbie.

"Alfie loves school," said Debbie, "He has friends there that he has had since nursery and it's great for his social skills. Miss Paget, his class room teacher, Mrs Taylor and

Mrs Holmes, Alfie's one to one support, have worked really hard with Alfie to fully include him in all aspects of school life and help him to progress and achieve, to get him to where he is today. The smile and hug I receive from Alfie at the end of a school day makes me realise that he is where he should be at the moment - he is happy, and that for me is so important.

"He also attends a speech therapy group every Monday morning and he uses Makaton signs and symbols to aid his speech.

"His speech is coming along but at the moment, we are waiting for him to have a procedure to replace his grommets so until then, everything he hears will sound muffled, a bit like it would underwater, which makes it much harder for him to develop

'...I take my hat off to all the doctors and nurses on Hedgehog Ward. They are brilliant with Alfie and very supportive of me.'

Epilepsy

Epilepsy is a condition that affects the brain and causes repeated seizures, which were sometimes previously referred to as "fits". Epilepsy is estimated to affect more than 500,000 people in the UK. This means that almost one in every 100 people has the condition. Epilepsy can start at any age, but it most often begins during childhood.

In over half of epilepsy cases, a cause cannot be found. If there is an identifiable cause, it usually involves the brain being affected by a condition.

There are two main categories of epilepsy:

- **idiopathic (or primary) epilepsy** – where no apparent cause for epilepsy can be found, but there may be a family history, suggesting that the condition is inherited
- **symptomatic (or secondary) epilepsy** – where there is a known cause for a person's epilepsy, such as cerebrovascular disease (problems with the blood vessels that supply the brain), brain tumours, severe head injuries and infections that can damage the brain.

For more information about epilepsy, you can visit the Epilepsy Action website – www.epilepsy.org.uk



his speech. At the moment, his clearest word is 'Ellie'!"

Eliie said, "I like that Alfie is Alfie - if he did not have his disability he would not be Alfie and it would be awful not to have him in my life.

"It can sometimes be difficult, especially when he finds it hard to tell us what he wants. When he is in hospital I get worried and frightened because sometimes he is really really, poorly, and I miss him and Debbie when they have to stay at the hospital.

"Everyone at my school loves Alfie. All my friends want to play with him at break-time. They think he is brilliant."

The reality is that Alfie is like many other 6 year old boys. He loves music more than anything, swimming, trampolining, climbing and dinosaurs, and despite having Down's Syndrome, epilepsy and hypo mobility (which causes him to tire physically a lot sooner than an average child his age), he is still able to do most things that other children can.

"Every milestone that Alfie achieves is massive and I never take anything for granted. I want Alfie to be the best he can be in life and I am so, so proud of him every day.

"That day on 27 December 2008, when Alfie was born, was a step into the unknown for me. And, yes, it has been a roller coaster, but it has been a good ride and we have been lucky. If it wasn't for the hospital staff and Sadie, Alfie wouldn't be here today. The doctors, nurses, outpatients department staff and many others within Tunbridge Wells hospital have been great, they look after Alfie so well when he comes in, and that really helps me too.

"My advice to any parent with a child who has Down's Syndrome, or epilepsy, and to a degree, any challenging condition, is to do your best to treat them like any other child. Make sure you have knowledge and are always prepared, even with practical things such as medication, so you feel better able to cope with anything that crops up day to day.

"It can be hard but we just take one day at a time. There has definitely been progress in the last year or so and I hope that will continue.

"Alfie puts a smile on the face of every person he meets. We have had our bad days and weeks but the good ones are fabulous. He lights up a room when he enters and somehow, without even trying, he always manages to gain everyone's attention.

"Alfie is my pride and joy, and he has made my life complete."



Down's Syndrome

Down's syndrome, also known as Down syndrome, is one of the most common genetic causes of learning disability. Around 750 babies are born with the condition each year in the UK. Down's syndrome affects people of all races, religions and economic backgrounds equally.

The condition is caused by the presence of an extra copy of chromosome 21 in a baby's cells. It occurs by chance at conception and is irreversible. As yet, no one knows what causes the presence of the extra chromosome 21.

As well as some level of learning disability Down's Syndrome also causes a characteristic range of physical features.

Most babies born with Down's syndrome are diagnosed with the condition after birth and are likely to have:

- reduced muscle tone leading to floppiness (hypotonia)
- eyes that slant upwards and outwards
- their palm may have only one crease across it (palmar crease)
- a below average weight and length at birth

People with Down's syndrome also vary in personality and ability. Everyone born with Down's syndrome will have a degree of learning disability. The level of learning disability will be different for each individual.

Screening for Down's syndrome

In some cases, babies with the condition are identified before birth as a result of antenatal screening for Down's syndrome. If screening indicates there is a chance your baby has Down's syndrome, further testing is available to determine how likely it is.

Screening tests don't tell you for definite if your baby has Down's syndrome, but they can tell you how likely it is. The only way to get a definite diagnosis is for a chromosome test to be done using a sample of the baby's blood.

Complications

Many children with Down's syndrome have associated health conditions. Possible complications include:

- heart disorders
- bowel abnormalities
- digestive problems
- hearing and vision impairments
- thyroid dysfunctions
- infections
- cervical spine dislocation
- blood disorders

These conditions vary in severity with each individual. Some children experience none of them, while others experience several.

For more information about Down's syndrome, you can visit the Down's Syndrome Association website – www.downs-syndrome.org.uk

Case study

MONITORING A LONG-TERM CONDITION

Around 10 years ago, Susan Christodoulou, noticed some small granular lumps on her knees. At first she thought nothing of it, but soon after developed a rash on her skin. She visited her GP and, after a series of tests, was diagnosed with Sarcoidosis. We talk to Susan about this rare condition and find out how regular monitoring has helped her keep on top of her illness.

"My GP initially referred me to see a skin specialist at a hospital near Ashford. After undergoing a biopsy on the lumps on my knees I was told I had Sarcoidosis," says Susan, a retired primary school teacher from Headcorn.

"As Sarcoidosis can affect the respiratory system too I was also sent for a CT scan, which revealed the outer

edge of my lungs had small lumps on them.

"Shortly after my diagnosis, I went on holiday with my family in Crete and I soon realised how Sarcoidosis can affect you. I'd been sightseeing and one of the places we wanted to visit was a volcano on the island. It was quite a steep zig-zag path to the top of the volcano and I really struggled to walk up because I was so breathless. I had to stop regularly, which really wasn't normal for me."

On her return Susan was told her condition needed to be monitored regularly, particularly with regards to the functioning of the lungs. "There's no cure for Sarcoidosis and if your symptoms are relatively mild they tend not to provide you with medication. Instead you can manage

the condition yourself through a good diet, and keeping fit and healthy.

"I took a proactive approach to managing my condition and I felt lucky because, other than the breathlessness, my symptoms were not debilitating or life-altering. I knew what would cause me being out of breath, so I was careful to make sure I avoided certain activity – or took it at a slower pace than perhaps I used to!

"Every year I have blood and lung function tests and sometimes a CT scan so my consultant at MTW, Dr Husain, can monitor my symptoms and ensure they don't get any worse."

The respiratory function tests, which comprise spirometry, lung volume measurement and gas transfer tests, are used to see what impact the disease is having on the lungs in terms of whether it is affecting the size of the lungs and how easily oxygen transfers from the lungs to the blood. These measurements allow doctors to clinically assess a patient to determine if further treatment is required, or if treatment is working. Respiratory function tests can be performed every three or six months or annually, depending on the patient's condition.

"Thankfully, my condition has improved and remained stable over the past four years and my Sarcoidosis is now in remission, which is great news!

"The respiratory physiologist team have been so friendly and helpful with my Sarcoidosis and they've made taking the tests so easy for me."



What is Sarcoidosis?

Sarcoidosis is a rare condition that causes small patches of red and swollen tissue, called granulomas, to develop in the organs of the body. It most often affects the lungs and skin. Sarcoidosis is estimated to affect about 1 in every 10,000 people in the UK.

Typical symptoms include tender, red bumps on the skin, shortness of breath and a persistent cough. However, every person is affected differently and symptoms depend on which organs are affected.

There's no cure for sarcoidosis, but the condition often improves without treatment within a few months or years. The symptoms are not usually severe and don't tend to affect everyday life.

It is thought that sarcoidosis happens because the immune system has gone into overdrive, where the body starts to attack its own tissues and organs. The resulting inflammation then causes granulomas to develop in the organs.

A number of different tests may be carried out to diagnose sarcoidosis, depending on which organs are

affected. If your symptoms suggest you have pulmonary sarcoidosis (sarcoidosis affecting the lungs), you may have a chest X-ray or a computerised tomography (CT) scan of your lungs to look for signs of the condition.

Simple lifestyle changes and over-the-counter painkillers (such as paracetamol or ibuprofen) to treat any pain are often all that is needed to control any flare-ups. Doctors will monitor your condition to check if it's getting any better or worse without treatment. This can be done with regular X-rays, breathing tests and blood tests.

Inflammatory Arthritis

It is estimated that around 1 in 5 people in the UK live with some form of arthritis... one of the most common groups of the illness being inflammatory arthritis which causes swelling and stiffness in the joints. Here, we talk to Maidstone and Tunbridge Wells NHS Trust's Lead Nurse for Rheumatology, **Ann-Marie Rae**, about the condition and how to cope with it.



Ann-Marie says:

Inflammatory arthritis is a term used to describe a group of conditions which affect your immune system. This means that your body's defence system starts attacking your own tissues instead of germs, viruses and other foreign substances, which can cause pain, swelling and stiffness in joints.

These conditions can affect people of any age, across the whole body, although for many people the problems tend to occur mainly in the hands and feet. Mainly women are affected – around three women to every man.

There's no cure at the moment, but the outlook for those diagnosed with inflammatory arthritis is significantly better than it was 20–30 years ago. Effective treatment begins much

earlier and new drugs are available, which means less joint damage, less chance of needing surgery and fewer complications.

It's extremely important that people visit their GP at the earliest sign of symptoms. In particular:

- Early morning joint stiffness
- Joint pain or swelling
- Tiredness

Usually, a GP will order routine blood tests and if the results indicate a form of arthritis, the patient is referred to the Early Synovitis Clinic, which runs at both of our hospitals in Maidstone and Tunbridge Wells.

There are things you can do if you suffer from arthritis – these include:

- Exercise – focus on your core strength with activities such as yoga,

pilates, tai chi and swimming

- Make sure you are a healthy weight
- Stop smoking

To cope with specific bouts of pain, you could:

- Ensure you are taking your prescribed pain medication as advised
- Bathe your joints in warm water
- Try some gentle stretching exercises
- Reduce activity until the bout of pain improves

The key issue when dealing with inflammatory arthritis is early diagnosis and treatment. The earlier your condition is identified and treated, the better your outcome.

For further information about inflammatory arthritis, please visit the National Rheumatoid Arthritis Society at www.nras.org.uk

FEEDBACK POSTERS COMING TO TUNBRIDGE WELLS



New feedback posters, like the one pictured, will soon be displayed at Tunbridge Wells Hospital. They are real comments made by our patients and visitors, via social media, email and letter, and the photos are of staff who work within our hospitals.

Feedback posters have been up at Maidstone Hospital for over a year and the reaction from people visiting us and staff has been very positive. We hope this second phase of posters will be well-received at Tunbridge Wells Hospital, and provide people with something eye-catching and interesting to look at.

Recipe Cream of butternut soup

Try this mouth-watering recipe from our very own Maidstone Hospital League of Friends Cook Book...



Method:

Boil the potato until soft, then peel it and reserve the water.

Heat the butter in a heavy based pan and fry the onion until soft and golden.

Add the spices and the sea salt and fry for one minute.

Add the squash, cover and cook until tender, stirring occasionally. Add a little of the potato water if the pan becomes too dry

When the squash is soft, add the potato and water and boil for 20 minutes.

Place the mixture in a blender with the sherry and milk and blend until smooth.

Season to taste.

Ingredients:

- 1 potato (scrubbed)
- 125g/1oz butter
- 1 small onion (chopped)
- 1 pinch ground cinnamon
- 1 pinch nutmeg
- 1 pinch dried marjoram
- 1 pinch sea salt
- 450g/1lb butternut squash (cubed)
- 1 tbsp sherry
- 1 pint of milk

The Maidstone Hospital League of Friends Cook Book is available from The League of Friends Shop near the main entrance of Maidstone Hospital and is priced at £5.

patientfirst WINTER QUIZ

Geography:

Q. Which river separates Cornwall from Devon?

Q. Mauritius is found in which ocean?

History:

Q. Which infamous murderer was arrested on the SS Montrose in 1910?

Q. In which ship did Captain James Cook sail on his first voyage of exploration between 1768 and 1771?

Literature:

Q. Which pottery form takes its name from the Italian for 'baked earth'?

Q. How are the sisters Meg, Jo, Beth and Amy described in the title of an 1868 novel?

Food/dining:

Q. What is wasabi?

Q. What is the traditional topping on a Lancashire Hotpot?

Entertainment:

Q. Played by Hugh Laurie, who is Chief of Diagnostic Medicine at Princeton-Plainsboro Teaching Hospital?

Q. What was Elvis Presley's middle name?

Sport:

Q. In golf, what term is given to completing a hole in two under par?

Q. In which sport is Ben Ainslie a highly successful Olympian?

(Answers to be published in the Summer edition)

Autumn edition QUIZ Answers

GEOGRAPHY • On which river are the Victoria Falls to be found? **Zambezi** • On which Greek island are the cities of Chania and Heraklion? **Crete** **HISTORY** • Founded in 1411, what is Scotland's oldest university? **St Andrews** • What name was given to the women who campaigned to have the vote in the first two decades of the 20th century? **Suffragettes** **LITERATURE** • The Bennet family appear in which Jane Austen novel? **Pride and Prejudice** • What are

the surnames of the title characters in Romeo and Juliet? **Montague and Capulet** **FOOD/DINING** • If you saw canard on a French Menu, what type of meat would be on offer? **Duck** • What forms the base of the Indian dish raita? **Yoghurt** **ENTERTAINMENT** • Who played the Vicar of Dibley? **Dawn French** • Of which television series was Jack Bauer the protagonist? **24** **SPORT** • From which country does Samba dancing come? **Brazil** • In cycling, for what is BMX short? **Bicycle motocross**

Executive Team Update

Glenn Douglas, Chief Executive



As many of you will know, the Care Quality Commission reports on our hospitals were published in February, giving our Trust an overall rating of 'requires improvement'.

We are disappointed not to be rated good on this occasion and we have taken immediate steps to address the actions within this report. However, what is very clear is that our staff are providing kind, compassionate care, are treating patients with respect and dignity, and we do have areas of good and outstanding practice within our hospitals.

I am extremely proud of our staff and the rating of 'good' that this aspect of the services we provide achieved. We will use these strengths as a foundation on which to build upon in other areas which we would like to see improve in coming months.

We have come a long way as a trust, are committed to going a great deal further and see the CQC inspections as an important part of our journey.

Examples of immediate actions the Trust is taking (on both sites unless stated) include:

- Increasing cover at weekends on our critical care units
- We are in the process of setting up an Acute Assessment Unit at Tunbridge Wells to help reduce avoidable admissions
- We are asking for feedback from our patients and visitors about our planned development of a dedicated children's A&E at Tunbridge Wells Hospital
- Water quality checks carried out and passed (Maidstone)
- New leadership programme for clinical and non-clinical managers and executive team leadership development
- Restructuring clinical governance meetings and improving processes for incident reporting and dissemination of lessons

- We have signed up to the 'Sign up to Safety Campaign' led by NHS England and our safety pledges will soon be available on our website
- We are developing a three year safety improvement plan that will run in conjunction with the quality improvement plan, which is being developed following the CQC report
- Appointing a dedicated equality and diversity lead and launching staff awareness courses
- We are continuing to invest in permanent nurses, adding to the 300 we have recruited in the last two years

You can read and comment on the CQC reports on the Trust's website www.mtw.nhs.uk

Your comments will be used to help shape future improvements so please help us if you can.

Glenn

PICTURE OF IMPROVEMENT AS MTW BUCKS NATIONAL TREND

The Trust has paid tribute to its staff after seeing improvements in a key national survey at a time of unprecedented demand for NHS services.

The NHS published the results of its annual National Staff Survey recently – the largest survey of its kind undertaken by any public service. The results were based on comments made by 255,000 NHS employees between November and December 2014 as demand for NHS services was reaching record levels locally and nationally.

MTW achieved one of the highest response rates for staff from any NHS trust in the country.

MTW outperformed the national average in 16 out of 29 key findings, and now has seven areas where its staff

experience places it within the top 20% of best performing trusts in the country.

The picture of overall improvement includes an increase in the number of staff who would recommend the trust as a place to work or receive treatment (above the national average).

The Trust, which employs over 5,000 staff at Maidstone and Tunbridge Wells Hospitals, and is one of Kent's biggest employers, said it was proud of its local workforce.

MTW's latest investment in frontline services is a £750,000 package to recruit additional physiotherapists, pharmacists and radiographers to support seven-day services. It is also recruiting four additional Paediatric Consultants and a new Consultant in Trauma and Orthopaedics specialising in Paediatric Orthopaedics.

you say:

Dear Glenn Douglas,

I would like to say how caring the nurses are on the Gynaecology Ward in Tunbridge Wells Hospital, they have time to listen and talk to patients, answer call bells promptly and attend to any needs. I must also say the hospital food is very good and looks nicely presented, and the domestic staff are very friendly and keep the rooms and ward looking clean.

The Gynaecology doctors are a caring team. I had a hysterectomy and for the first part of the following week I was feeling lousy and did not want to get up or eat anything. But then a miracle happened and I was feeling a lot better, on my food again and up and walking about. It was a surprise for everyone!

Mrs Carolyn Alchin

Choose **well...**

Get the right NHS treatment. If you're not sure what's best, phone before you go.

Self-care

NHS 111

Medical advice 24/7

www.nhs.uk/111

Call 111

Emotional support

Mental Health Matters helpline

Confidential emotional support

0800 107 0160

Stop Smoking Service

For free NHS support to stop smoking contact the Stop Smoking Service on 0300 123 1968.

GP and dentist out of hours

Call 111

Pharmacy

Late night and Sunday pharmacies

Maidstone

Link Pharmacy, 88a King Street, Maidstone – 01622 752990 (opening hours: Mon – Fri 6am – 11pm and Saturday 6am – 9pm)

Morrisons Pharmacy, Sutton Road – 01622 661750

Sainsbury's Pharmacy, Quarry Wood, Aylesford – 01622 790223

Tesco Pharmacy, Lunsford Park, Larkfield – 01622 701449

Sevenoaks

Sainsbury's, Otford Road – 01732 469198

Tonbridge and Tunbridge Wells

Boots, Calverley Road – 01892 526486

Sainsbury's, Linden Park Road – 01892 532569

East Street Pharmacy, 47 East Street, Tonbridge

(opening times, Monday to Saturday 7am to 10pm and Sunday 10am to 8pm) – 01732 770055

Minor injuries units

Edenbridge Hospital

Mill Hill, Edenbridge, TN8 5DA

Tel: 01732 863164

Open 8.30am to 8pm, 365 days a year

X-ray available from Monday to Friday 9am to 2.30pm

Sevenoaks Hospital

Hospital Road, Sevenoaks, TN13 3PG

Tel: 01732 470200

Open 8am to 8pm, 365 days a year

X-ray available from Monday to Friday 9am to 5pm

Crowborough War Memorial Hospital

Southview Road, Crowborough, TN6 1HB

Tel: 01892 603602

Open 8am to 8pm, 365 days a year

Some GP practices also offer a minor injury service. To find out who, visit www.nhs.uk

Emergency Care Centres and Accident and Emergency

For critical or life threatening emergencies, call 999 or go to your nearest Accident and Emergency, open 24 hours a day.

Maidstone Hospital, Hermitage Lane, Maidstone, Kent ME16 9QQ

Tel: 01622 729000

Tunbridge Wells Hospital, Tonbridge Road, Pembury, Tunbridge Wells, Kent TN2 4QJ

Tel: 01892 823535

FIND HEALTH HELP WITH NHS WEB APP

The NHS in Kent has a free web app to help you find the right treatment, especially when you are not sure what to do or who to contact.

Whether you have a baby with a high temperature, a child who is being sick, a teenager who is feeling low or you have sprained your ankle, and for many other health problems, the Health Help Now web app can guide you to the service that will help you best.

Health Help Now lists common symptoms and helps you find the best place for treatment for them in Kent. It shows the nearest services,

whether they are open or closed, and provides a map of their location and directions.

Health Help Now also offers reliable health advice and links to other useful websites. Available at www.healthhelpnow-nhs.net, it works on smartphones, tablets, and computers.

Why not save it to your device now so you have it to hand when you need it?

If you don't have internet access, or if you need medical help fast but it isn't a 999 emergency, dial 111.



Worried someone close to you is losing their memory?

Many people suffer from memory loss as they get older. But if it starts to happen on a regular basis, it could be the early signs of dementia.

Leading the fight
against dementia

**Alzheimer's
Society**

Dementia nhs.uk/dementia
If you're worried, see your doctor