

New care project can save NHS millions

Rhona McLeod on how to solve the problem of bed blocking



Delayed discharges from hospital cost the NHS in Scotland £114 million in 2013-14. According to the latest statistics, more than three quarters of delayed discharge cases are for health and social care reasons. These can include the lack of a suitable place in a community setting, the patient having to wait in hospital to have their social care needs assessed or delays in putting appropriate care arrangements in place.

The practical effect of these delays on the NHS is a significant drain on resources and a shortage of beds. For the individual, it means remaining stuck in hospital for days or weeks longer than necessary.

Trust Housing Association has been exploring potential solutions. In particular, we have a growing number of Housing with Care (HwC) developments which enable elderly tenants to continue living independently while receiving anything from under five hours to more than 25 hours of personal care each week.

The HwC model could offer an affordable solution to long-term delayed discharges from Scottish hospitals. Over a three-year period, a study found more than 50 tenant admissions to acute hospitals that would have been required had the tenant been living in mainstream housing were avoided as a result of living in an HwC development.

HwC could be a cheaper solution than residential care for local authorities, particularly for older people on lower incomes in receipt of substantial levels of personal care on a weekly basis.

Innovative solutions such as HwC have a role to play in improving the integration of health and social care while delivering improved outcomes for the individual and big savings for the NHS. Rhona McLeod, Chief Executive Trust Housing Association

Trust
your home
& more

Trudy is part of our happy and fulfilling family

When I learned of the new Non-Invasive Prenatal test (NIPT), I had already given birth to our daughter, Trudy, one of the 750 babies born each year with Down's Syndrome in the UK.

My initial reaction was that this test was good because it was non-invasive. Parents would be at a much lower risk of miscarriage if they wanted to know for certain whether their child would be born with a serious chromosomal condition.

However, the more I considered the implications of this test, the more I realised that, with nine out of 10 people terminating a baby with Down's Syndrome, this was not necessarily screening for, but screening out.

The NIPT is based on a maternal blood test. It analyses genetic fragments of the foetus present in maternal blood during pregnancy and it can be carried out from 10 weeks of pregnancy.

At present, the NIPT is not available on the NHS in Scotland but is available privately. However, it is already possible to read statements such as: "It is now possible to use NIPT to detect Down Syndrome" and that "NIPT detects more than 98 out of 100 babies with Down syndrome" (NHS Rapid Project 2016).

I know that the majority in Scotland believes in choice, that every parent has a right to choose whether they continue a pregnancy before 24 weeks but I am not sure that people are aware they can choose to terminate up until birth if there is a substantial risk that the child would suffer from serious physical or mental abnormalities.

A child with a genetic disorder such as Down's Syndrome could be terminated right up until birth.

The most important thing to consider here is the notion of 'choice', and I question what those choices are based on, with so much negative



Bringing up a child with Down's Syndrome, one must consider the notion of 'choice', says Lauren Elliott Lockhart

information coming our way. When Trudy's diagnosis was confirmed, we were given a manual of all the associated health risks, of which there are many.

I never received this for our son who does not have a genetic disorder but is at risk of disease, impairment or mental health conditions just because these are the risks we all live with.

I think that if I had been given such a manual with an antenatal diagnosis of Down's Syndrome, I would have been very fearful of the future. It seems that too much information can sometimes be a bad thing and that we need to be very careful about how this information is being presented.

I am glad that science is advancing and, without this progress, Trudy would not have survived the first week. There is very little that can make you appreciate life, regardless of how it manifests itself, than the prospect of losing it. But science



COMMENT

"I am glad that science is advancing and, without this progress, Trudy would not have survived the first week"

LAUREN ELLIOTT LOCKHART

seems to believe that they are alleviating the 'burden of disability', that they are making humankind better by giving us the option to eradicate the abnormalities. People cannot be cured of genetic disorders, so why not screen them out?

At the risk of extrapolating, we could be eradicating any condition that we can now prenatally screen for, such as leukaemia which is a form of blood cancer. This may not be the explicit objective of this project but I cannot help but wonder whether the implications have been properly considered.

Who is making the decisions about screening for Down's Syndrome? Are they in a position to judge the quality of life for a person or a family of a person with a genetic disorder? The evidence, qualitative and anecdotal, seems to suggest that families live happy and fulfilling lives. We certainly do.

Trudy has an extra 21st chromosome in every cell, but that is all we know. Like so many people with disabilities, she cannot be reduced to her condition or negative assumptions about what she can and cannot do. She likes, she dislikes, she wants, she rejects.

We have been told from numerous reports that she has global development delay and low muscle tone, but you should see her splashing in the water! She gets tired, but she never tires of talking! I fear that the objective of this project is not to better equip parents for the future but to give them the option of avoiding it, and all at the expense of a potentially wonderful and inspiring life. These lives are one of the threads



of human diversity and are precious, regardless of how they process the world.

More needs to be done about the impact of this test on families living with Down's Syndrome and other genetic disorders, and of the future

of this small population who bring so much joy to people's lives.

Mrs Lauren Elliott Lockhart is a languages teacher working with children with disabilities and a guest writer for the Scottish Council on Human Bioethics.

↑ Trudy Elliott Lockhart was born with Down's Syndrome but likes to talk, likes to make a splash in water and gives her family joy



Marathon men and women help to run hospice

Amateur athletes care about raising money, writes Jon Heggie

The Edinburgh Marathon Festival is almost here and people across the city will be getting their outfits ready, fuelling up and making their last-minute preparations, whether they are taking on the full marathon, the half marathon, 10k, 5k or the marathon relay. Taking part in these events is special for the runners, as well as the city and the spectators – being there as people take those first steps at the start of the event, along the route around our beautiful city, and finally across the finish line accompanied by the cheers of their loved ones.

People take part in the Edinburgh Marathon Festival because they want to take on a challenge, because they love running or because they want to do something amazing to

support a cause close to their hearts – for some people it's all three.

At St Columba's Hospice we are always honoured when people choose to run for us. Whether someone is running their first 5k, their first full marathon or they are a seasoned marathon runner – every step and every penny raised is hard-earned and we are incredibly grateful for their support.

This year, 19 friends from Lochend Boxing Club have put themselves into teams to take part in the marathon relay. The friends chose to support us because many of them have loved ones who have been supported by the hospice. When the hospice cares for a person with a terminal illness, we also support that person's friends and family too. Dawn, who is taking part in the

marathon relay with her friends from the boxing club, said: "I hadn't realised how much St Columba's Hospice does for people. I recently found out that it is great for sorting out pain medication. A close family friend has terminal cancer and he couldn't get his medication right, was sick and in a lot of pain. He was admitted to the hospice for a few days and they took him off everything and then started it from scratch again – he was a changed man! I know he will not get better but to look at him, you would never know he is terminally ill."

"I am in awe of the counselling that is offered and understand that counselling can help people close to the patient, not only to understand the treatment better, but also what may happen in the future.

Part of the challenge with events like the marathon relay is fitting training runs into your everyday life, but doing it with friends can make that easier. Dawn said: "I am so chuffed to be running with my gym buddies to support the hospice. We all have different levels of abilities, from being able to do half marathons to being brand new to running. Everyone is up for it and looking forward to getting involved."

"It can sometimes be difficult to fit in the training for a race, so as well as going to Lochend Boxing Club's fitness classes we are running before the fitness classes, before work, or squeezing it into our weekends. No one wants to let each other, or St Columba's Hospice, down."

One of Dawn's gym buddies is

Dianne, who will also be running in a team in the marathon relay. The team's spirit has brought people together and will carry each person over the finish line. "Lochend Boxing Club is a small club with a team of huge hearts, everyone who attends the club is more than happy to get involved in events that involve great causes like supporting the hospice. St Columba's Hospice is a great cause and it reaches so many hearts, everyone has a story to tell of a family member or friend who has spent weeks or days in the hospice and been truly looked after. That is what reaches the hearts of their family and friends and inspires them to run in the marathon relay."

As people take to the streets with just their feet and minds to get them to the finish line we encourage

you to get out there, support them, give them a cheer, make a donation to their cause, and help to make this the best ever Edinburgh Marathon Festival for the runners, the city and the many charities being supported. Jon Heggie, Director Fundraising, St Columba's Hospice



JOIN THE DEBATE
www.scotsman.com

THE SCOTSMAN
Scotland on Sunday

Subscribe to The Scotsman,
and enjoy your quality daily
read at 50%* OFF



6 day = £4.72 per week 7 day = £5.57 per week

We send you vouchers to use instead of cash when you buy the paper.

Subscription also includes free access to the tablet edition worth £7.99 per month, meaning you can still enjoy your copy of The Scotsman wherever you are.

To take up this offer visit www.localsubplus.co.uk/six and use the code **330PA-SIX** for The Scotsman or include **Scotland on Sunday** for seven days of news by visiting www.localsubplus.co.uk/sco and using the code **330PA-SCO**

or call **0330 123 5950** and quote your chosen code above

Offer available to new subscribers only when paying by Direct Debit. * 50% discount available for the first three months, then 20% discount applies thereafter. Calls will be charged at your standard network rate.

HOW TO BECOME A FRIEND

On these pages we present articles written by our Friends, with them setting their own agenda, using their own words. Being a Friend of The Scotsman is open to institutions, trade associations, professional bodies, societies, interest groups, charities and others. Individuals are not eligible nor, generally, are individual companies or political parties. The Friends of The Scotsman pages are a forum for discussion and debate and for the transfer of information rather than a marketplace. In return, the Friends sign up to a subscription package that ensures a supply of The Scotsman at a discount rate to the people in the organisation who require it. For more information, e-mail euan.mcgrory@scotsman.com or visit www.scotsman.com