PATCH
care when it's needed

Issue No. 04, August 2020

*Sir Michael Nairn*

## IN THIS ISSUE



# WELCOME FROM THE CHAIRMAN

Welcome to the fourth issue in a series of occasional newsletters.

With the support during the past year of charitable trusts and generous donations by individuals and corporate donors, PATCH has been able to fund specialist training in palliative care in the acute hospital setting in Ninewells Hospital Dundee, Queen Elizabeth University Hospital Glasgow, Borders General Hospital Melrose, University Hospital Wishaw and has funded a Diploma in palliative care in Greater Glasgow.

None of us could have believed when PATCH was formed in 2013 that the need in hospitals for improved standards of palliative care would come into such sharp focus as it has done this year. The heroic stories in this newsletter make humbling reading and provide just a snapshot of the dedication and bravery of those who have been on the frontline in hospitals over the past few months.

While this emergency has lasted, it has been unrealistic to expect qualified nursing staff and young doctors to have time for specialist training, though the directors take comfort from the skills that have been gained through past PATCH-funded training and are being applied in often really difficult circumstances. A special case has been at The Borders General Hospital where the first PATCH nurse, in post since September last year, has been able to provide on-the-ward training to other nursing staff throughout the current crisis.

Once the current pandemic has passed, I have no doubt that Covid-19 will have changed society in ways which will be far-reaching, but are still hard to define. Though the circumstances have not been those which any of us would have wished for, public awareness and respect for high standards of palliative care in hospitals will surely be one of those changes.

As a small but growing charity, PATCH remains hugely grateful to all those who believe in our mission and have supported us. May I thank you all.

With most sincere thanks,
Sir Michael Nairn Bt
*Chairman, PATCH*

# PATCH & COVID-19

The core purpose of PATCH is to provide support and funding for projects and initiatives which will enable 24/7 specialist palliative care for patients in hospital.

*Dr Roger Flint*


## The most unreal period of my medical career

*Dr Roger Flint, Founder of SPOT*

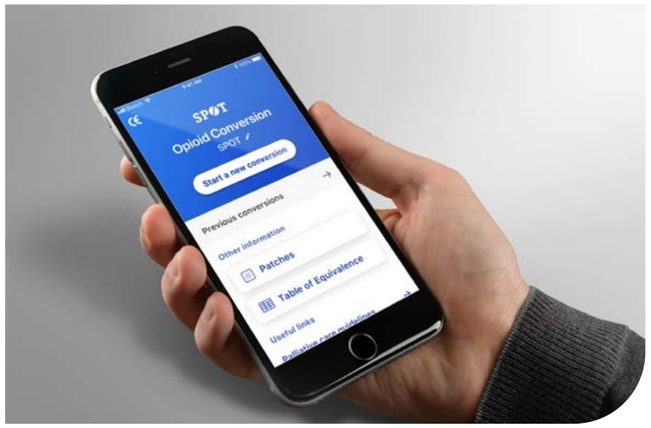
**Dr Flint invented SPOT, the Safer Prescribing of Opioids Tool, a novel smartphone application in 2016. It is the first clinically validated opioid converter in clinical practice, and its purpose is to reduce errors in prescribing of strong morphine-like painkillers. PATCH is proud to have provided initial funding for the prototypes of the tool.**

"Working in Medicine for the Elderly and rotating between 'red' and 'green' wards in the Edinburgh Royal Infirmary, I have directly witnessed the effects of Covid-19. Nothing prepared me for its effects.

Over the past few months I have been astounded by the selflessness, commitment and bravery of my NHS colleagues, providing close personal care to patients suffering from Covid-19. Despite considerable staff sickness, everyone worked together and there was a camaraderie — like that in the military.

With the increased demands on palliative care physicians and limited ability to review patients in person, colleagues took on new roles in unfamiliar clinical areas: new doctors graduated early to join the NHS front-line alongside recently retired health professionals.

One of the cruellest consequences has been the difficulties of family and friends visiting dying patients. Nursing teams have been providing comfort to those in their final hours."






## Planning ahead when ill

*Professor Robin Taylor, Consultant in Respiratory Medicine, NHS Lanarkshire.*

**Robin has a long-standing interest in providing good end of life care, especially for patients admitted to hospitals at the end of life.**

**PATCH is providing funding for a current clinical research project of Anticipatory Care Plans for patients with blood cancers.**

"It is the best of times for Anticipatory Care Planning (ACP) — many patients and their families are receptive to having a conversation.

It is also the worst of times. The Covid emergency has generated unprecedented levels of anxiety and the anxiety is understandably directed at the threat of death. The offer of a conversation about ACP is, especially in family members, perceived to intensify the threat.

In early April I had a conversation with Elsie aged 90. She was concerned for herself and her frail husband Jim. She asked, 'Dr Taylor, if I get pneumonia, should I agree to be put on a ventilator?'. I asked her what she knew about mechanical ventilation – not a lot. I then explained that, based on current evidence, about 60% of Covid patients do not survive mechanical ventilation. She asked what dying on a ventilator might be like – and I told her about the inability to communicate, the physical discomforts, and the need for sedation. What was really shocking to Elsie was that there is a 30–40% chance that she would have a permanent loss of cognitive function similar to mild dementia. In a 90-year-old, this would mean losing her independence and her ability to look after Jim.

'Well, that's me decided' she said: 'I don't want it'. I didn't have to talk about the new triage guidelines for ICU admission, introduced because of Covid. I didn't need to. She was given the facts and she made up her own mind. We proceeded to complete her ACP (including all the other important elements). The conversation was meaningful and even satisfying — at the end Elsie expressed her sincere appreciation.

I wish that the post-Covid world might be full of Elsies. I wish that providing balanced explanations about the harms as well as the benefits of major medical interventions were commonplace, dispassionate, and free of fear. I wish that hospital medicine might be relieved of the pressures and the burdens of 'doing everything possible'. Perhaps applying the good lessons learned during the Covid emergency – including that triage is based on outcome statistics and not prejudice — will help to grant me my three wishes."


*Robin is also the author of the booklet 'Coping with Crisis', a practical and down to earth guide for decision making at turbulent times. PATCH is supporting its distribution throughout Scotland. copingwithcrisis.org*

# PATCH & COVID-19

## Planning for the unknown

*Claire O'Neill, Macmillan Lead Nurse and Clinical Services Manager for palliative care, Greater Glasgow and Clyde.*

**PATCH has funded four PATCH training courses for Band 5 nurses — with more in the pipeline.**

"There was so much information from Spain and Italy yet so many unanswered questions. Every day felt like two days; staff were juggling concerns for their families, their own health, childcare and the sense of 'what was coming?'. There was an eerie period with empty hospital beds — waiting for the 'worst'.

I have great admiration for the courage shown by the ward teams and acute palliative care teams I work with.

One of the hardest things about caring for patients has been the challenge faced around visitor restrictions. Not a day goes past without hospital palliative care teams feeling the devastating impact of this separation for patients and families.

Members of the public knitted and crocheted hearts and stitched syringe pump bags and these acts of kindness have been the pots of gold at the end of our rainbows."

*Palliative care team members.*

## Where are our usual patients?

*Jenni Henderson, Clinical Nurse specialist at the Glasgow Royal Infirmary, Glasgow.*

**PATCH funded Jenni's certificate in palliative care and her postgraduate diploma.**

"It has been difficult trying to do the best you can at work, while managing fears and worries about your own health and that of your friends and family. Every day started with a feeling of unknown; daily hospital briefings, forever changing guidance of what PPE to wear and which hospital wards were now Covid-19 wards.

Throughout the months, I've wondered, 'where are our usual patients?' There was, quite rightly, a focus on Covid-19, but there were a huge number of patients at home not accessing acute hospital care. Sadly we are now starting to see these patients attending hospital with advanced disease, and you do wonder if things could have been different for them.

The most difficult issue they had to deal with was the visiting restrictions. The heart breaking moments when family members are saying goodbye to their dying relatives over Facetime or families having to pick one relative to visit and sit at the bedside.

Not a day goes past without hospital palliative care teams feeling the devastating impact of this separation for patients and families."



## Will the crisis reset end of life care in hospital?

*Jules Lewis, Facilitator and Lead Nurse, for End of Life Care Service at Shrewsbury and Telford Hospital, is a member of the team that was awarded the PATCH/ RCS Edinburgh Dundas Medal in 2019. Steve Hams is Director of Quality and Chief Nurse at Gloucestershire Hospitals NHS Foundation Trust.*

In a recent webinar Jules and Steve both agreed there was much that they would never want to change, for example policies went through in hours instead of months or more; experienced senior nursing and medical staff worked clinically alongside everyone; there was recognition it was okay not to be 'okay' and 'wobble rooms' were available.

The fundamentals of end of life care haven't changed including the belief that no-one should die alone. Neither Trust stopped families visiting, namely next of kin plus one.


*Jules Lewis and Steve Hams.*

> *"The effort to plan for COVID-19 was huge. We turned our hospital upside down and inside out in four weeks to respond to the challenge."*
> *Steve Hams*

Teamwork became enjoyable and although there were some things which were very difficult, such as the unpredictability of death even for experienced staff, there were things to make one smile, like the 90 year old using an iPad to see her great grandchild.

Palliative care services, which both Trusts already had in place, were strengthened: namely The Swan Scheme[1] in Shrewsbury and Telford and the 'Every Name is a Person'[2] initiative in Gloucestershire. As Steve outlined in the initiative "Every name is a person, every person is a life lived and every life has a story behind it."

**The full webinar can be viewed here: www.facebook.com/medicalrealities/ videos/166929538083233**

[1] https://www.sath.nhs.uk/patients-visitors/ advice-support/end-of-life-care/

[2] https://www.onegloucestershire. net/every-name-a-person/

# PATCH & COVID-19

In each edition we share stories and updates on some of the latest PATCH activities and highlight some special people who have been associated with PATCH.

## We all gave the best care we could

*Carol-Ann Smith, the first nurse PATCH funded to do a certificate in palliative care.*

**Carol-Ann Smith is now education co-ordinator in the Surgical Directorate, Royal Infirmary of Edinburgh. Her passion is end of life care 'it means the world to me – I'm like a dog with a bone!'**

"I love education and believe knowledge is the foundation of excellent patient care. So when Covid-19 hit I worked alongside ward nurses — wherever I was needed.

All my new nurses were thrown in at the deep end. Staff were demobilised from theatres and were really nervous about coming out and having to deal with patients who were dying. Student nurses also stepped up and I spent a lot of time supporting staff.

ITU and HDU were tested to the limit. There were many who fought very hard but sadly did not make it, including one of our nurses in the emergency department. That was very hard.

The hospital set up telephone and online support groups plus a first class lounge, as part of 'Project Wingman' run by aviation staff, to give NHS staff some respite — a gesture which was very much appreciated."

Carol-Ann has also been developing the Thistle Programme for end of life care and bereavement in the Royal Infirmary of Edinburgh.

*The use of the thistle symbol on the door of a patient indicates that the patient is dying and that staff are committed to ensuring end of life care is of good quality.*



## The Olden Days: Pre-March 2020

*Dr Kim Steel, Consultant in Palliative Medicine, Victoria Hospital, Kirkcaldy.*

*Palliative care team members.*

"I remember calling all the patients that I had known for a long time and who attended our hospice day services to say that it would be shut. No-one was surprised. We all knew that 'it' was coming.

The senior clinical leadership in the organisation communicated well — 'perfect will be the enemy of good'. We could not wait for the perfect plan, we just had to do a good enough job. It was time to build as much resilience into the system as possible, and at speed.

Colleagues from all areas of the NHS — clinical, procurement, physics, domestics, IT, pharmacy set the pace. It was fast. We were accountable for our area and to make sure we linked with everyone else. The relationships we had established over the years allowed us to mobilise fast.

Patients with palliative care needs, who may have been previously admitted to hospital or hospice, adamantly did not wish to come if families could not visit- they wanted to remain in the community. Although we still had patients with palliative care needs in the hospital there were many more in the community so we weighed our resources there.

There is something about a medicalised environment that makes people in normal times feel less vulnerable with people that 'know what they are doing' when people are symptomatic or dying. With advanced care planning many patients had decided that if things were hard they would not want to be at home. But there was a huge mind shift and people made brave choices to choose home and family, although they had always prepared themselves for something else.

Fear permeated. I work in palliative care but I live with a respiratory doctor and our young children have spent the last three months in a childcare hub. I feared for my family. We had a Covid-19 outbreak in our team and I spent my days believing that one of our team would die. We still live with fear — what does the winter hold?

However, my biggest source of hope has come through watching our doctors in training. Warm, friendly, supportive, compassionate and driven to do the right thing. Some of them have been thrown into the pandemic within a year of qualifying and others thrown in months before they were supposed to start work.

It has been a hard and horrible time but there is much to be proud of."

# HOW YOU CAN SUPPORT PATCH

As ever, if you are interested in receiving this newsletter, have a story to tell or would like to support the charity or have questions please visit **www.patchscotland.com/connect** or send an email to **contactus@patchscotland.com**

**We are very grateful to all our Friends of PATCH who support the charity and enable us to provide funding for key palliative care projects across Scotland.**

There are many ways to become a Friend of PATCH – you could organise, support or attend a PATCH event; select PATCH as your company's charity of the year or for a single donation; or through virginmoneygiving.com you can choose to donate as a one off or on regular basis.

For more information go to http://uk.virginmoneygiving.com/charity-web/charity/finalCharityHomepage.action?charityId=1009152

## And from our patron

"At a time when the minds of all of us are so focused on Covid-19, let us also remember that compassionate end-of-life care is an enduring need in society everywhere.

PATCH is there to make a difference."

Prof Sir Alfred Cuschieri,
*University of Dundee*

## GET IN TOUCH
## www.patchscotland.com

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