



Palliation
and
the
caring
hospital

**CHARITY
PROFILE**

PATCH

Supporting the improvement of palliative care

Dr Gordon Paterson OBE
FRCPE Chairman



"As PATCH continues to grow as a Scottish charity our emphasis remains on supporting projects which enhance education, training and research into the provision of improved palliative care in hospitals.

"We remain committed to supporting clinical staff and others in creating new initiatives and new models of care which may not otherwise find funding and helping them to deliver far higher levels of palliative care throughout the hospital setting.

"We could not continue to operate and grow the charity without the generosity, enthusiasm and kindness of our supporters and Friends of PATCH. It is they who have helped make this possible, enabling PATCH to show tangible evidence that our initiatives are beginning to make a difference as to how palliative care is being delivered in hospitals in Scotland for the benefit of patients and their families. We are extremely grateful to them all."

Prof Sir Alfred Cuschieri
FRSE FRCS Patron



"It has been my privilege to act as Patron of PATCH since it was founded. Before retirement I was Head of the Department of Surgery and Molecular Oncology at Ninewells Hospital where most of my patients underwent major operations often with pre or postoperative chemotherapy. A sizeable percentage had incurable disease and required palliative surgery and care.

"It is rare for oncological surgeons to talk about their psyche, but rightly or wrongly, they often think they constitute the core treatment of patients presenting with solid cancers. But they do not always cure — not through lack of effort — but because the disease at presentation has reached the incurable stage. But, and this is a big BUT, when it comes to relief of pain and anxiety, not just to the patient, but also to their relatives, the oncological surgeon feels totally helpless. This is why I have always supported PATCH and its originator and Medical Director, Dr Pamela Levack, together with the Board of Directors she has assembled. For the life of me, I cannot imagine a more humane charity than PATCH."



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Registered Scottish Charitable Incorporated
Organisation No: SCO44231

PATCH

The first charity specifically to support 24/7 specialist palliative care for patients in hospital.

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Gandhi

“A patient is the most important person in our hospital. He is not an interruption to our work; he is the purpose of it. He is not an outsider in our hospital; he is part of it. We are not doing him a favour by serving him; he is doing us a favour by giving us the opportunity to do so.”



WHAT IS PALLIATIVE CARE?

PATCH was inspired by the model of care developed in the Acute Palliative Care Unit in Ninewells Hospital, Dundee.

PATCH is the first specialist charity dedicated to providing the stimulus, funding and experience to establish hospital specialist palliative care services and units in Scotland.

Palliative care is effective relief of pain and other distressing symptoms. It includes careful discussions to help patients and

families understand what is happening, what may be medically possible and what matters to the patient, providing a thoughtful plan for patient and family care.

In the UK we traditionally associate palliative care with hospices. However palliative care skills are fundamental to patient care in all settings, but...

Palliative care is not only for patients with cancer. Those with serious non-cancer illnesses such as motor neurone disease, multiple sclerosis, end stage renal failure, or advanced peripheral vascular disease with difficult to control symptoms may also benefit from early referral. Sometimes palliative care is needed over years rather than only the last few weeks of life.



it is not, at present, obligatory for hospitals to have specialist palliative care available on site 24/7.¹

Reports on the quality of hospital care reveal a widespread unmet need for specialist palliative care for patients who are very ill and may be dying.^{2,3}

It is unacceptable not to treat pain or other distressing symptoms, especially as there is now a whole body of specialist palliative care expertise.⁴ Patients and families need to know that relief will be effective and that it will arrive quickly — whatever the time of day or night.

The care and management of symptoms, while invaluable for patients and families, is not the full picture. It is vitally important that there is an opportunity to talk, ask questions and find out in an appropriate and timely way what is, and might be, going to happen.

The chance to share anxieties and worries, think ahead to the future and even practicalities of life and death are all so important. It is a huge part of palliative care to make this available.

¹ Review of palliative care services in Scotland. Audit Scotland. 2008.

² Francis R. Independent inquiry into care provided by Mid-Staffordshire NHS Foundation Trust. 2010.

³ Baroness Julia Neuberger. More care, less pathway. 15 July 2013. <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

⁴ Fallon M et al. Management of cancer pain in adult patients: ESMO clinical practice guidelines, Annals of Oncology 2018; 29 [4]; iv 166 – iv 191



**PATCH is committed
to supporting hospital
specialist palliative care.**

WHY THE FOCUS ON HOSPITALS?

Patients with the most complex needs are usually in hospital. One quarter of all admissions to an acute hospital have some palliative care needs and one third of all hospital beds are occupied by patients in their last year of life. Ten years ago 58% of deaths occurred in hospital⁵, and while the COVID 19 pandemic has shifted this trend somewhat, hospital is still where most people in the UK die.⁷

The hospital environment is a busy one, with different pressures and priorities, but patients should still expect to receive treatment for their underlying illness as well as management of their symptoms.

Many patients in hospital have pain or complex symptoms for which they need, and deserve, access to a palliative care specialist. A number of recent reports found the care of patients in hospital who were very ill or dying, to be wanting.⁶

Only a minority of patients who could benefit from quality palliative care receive it. We are all diminished unless there is urgent improvement.

Hospices fulfil a valuable role in providing specialist care for the seriously ill and dying. However, they do not have enough beds to address the problem nationally and hospital care remains vital.

50% of people die in a hospital

5% of patients die in a hospice⁷

⁵ Review of palliative care services in Scotland. Audit Scotland. 2008.

⁶ Recommendations on palliative and end-of-life care in acute care www.scotland.gov.uk/Resource/Doc/924/0105554

⁷ Finucane AM, Bone AE, Evans CJ et al. The impact of population ageing on end-of-life care in Scotland. *MBC Palliative Care* 2019; 18:112



Skilled palliative care needs to be a core activity of all hospitals. PATCH is dedicated to supporting hospitals to improve palliative care and ensuring patients receive high quality palliative care if needed, when they need it — 24 hours a day, seven days a week.

WHAT CAN PATCH OFFER?

PATCH understands the difficulties of providing quality palliative care in a busy hospital setting.

With the charity's expertise, knowledge and understanding we look to support new initiatives and ideas. We want to help staff, patients and families have a good palliative care experience.

Imagine how much better patient care would be if all patients had skilled, specialist palliative care available 24 hours a day, seven days a week.

That's what we aim to do.

Working with others

We collaborate with others for the benefit of patient and family. PATCH is so far working with:

Universities including Queen Margaret, the Universities of Edinburgh, Dundee and Glasgow.

Charities including the Gannochy, Reekie, Hayward, J Macdonald Menzies Trusts and the Scottish Partnership for Palliative Care.

Hospices and Palliative Care Units including St Columba's Edinburgh, Margaret Kerr Unit Scottish Borders, Cornhill Macmillan Centre Perth, Roxburghe House Dundee, Prince & Princess of Wales Hospice Glasgow.

NHS Boards including Tayside, Fife, Lothian, Lanarkshire, Borders, Greater Glasgow and Clyde, Newcastle upon Tyne, Shrewsbury & Telford and North Tees & Hartlepool.

Royal Colleges including Royal College of Surgeons of Edinburgh.

Businesses including Dragonfly, Rautomead, Hastings Legal, Thorntons Law, Creative Graffix, Shaws of Lauder.

PATCH is the only charity which specifically targets the provision of palliative care in hospitals.

GETTING RESULTS

A case study

A 39 year-old woman in a busy surgical ward was recovering from an operation which revealed extensive cancer. She was in pain, in noisy surroundings, and her family were distraught. The palliative care advisory team were asked to help. They moved her to the dedicated acute palliative care unit under the joint care of her surgeon and a palliative medicine consultant. Her pain and sickness were quickly treated but having four young children, she was desperate to get home.

The unit offered time and space for the family to work out what was important to them. Emotional support, privacy, respect and time talking with staff helped everyone to come to terms with the situation. The patient told staff “When I know I don’t have much time left, I want to be at home.” She didn’t know that time was imminent.

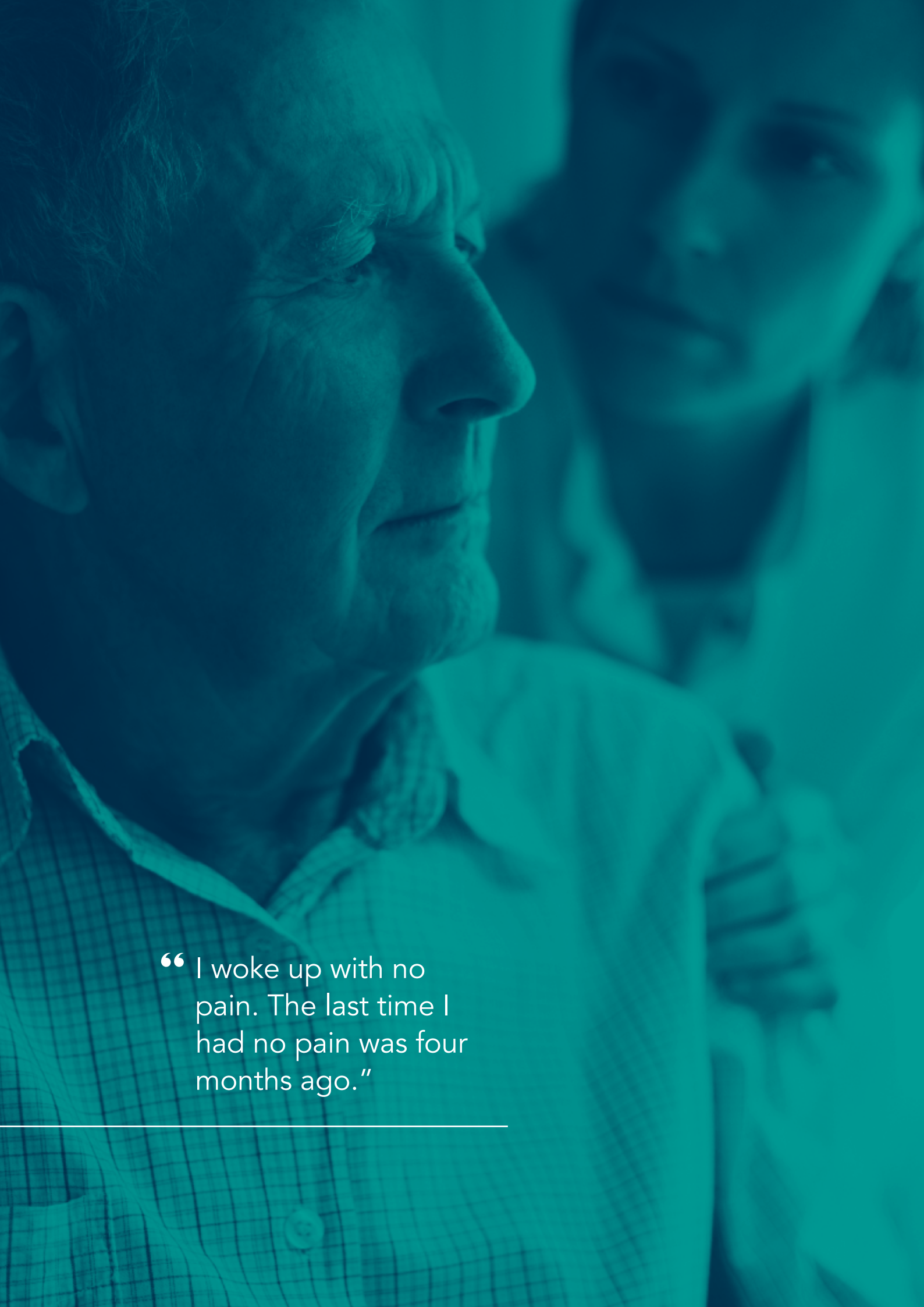
She knew the findings of her operation but not their meaning — and she had not asked. In order to make the right decisions (for her and her family), she needed to know the seriousness of her condition, and the unit staff talked this over with her and her husband. They were then able to communicate their feelings and say what they wanted to happen.

The design of the unit allowed physical and emotional space for talking, listening and comfort (TLC) — difficult on a busy surgical ward. Everyone then focussed on getting her home and as palliative care staff have community experience, she was home within 48 hours with nursing support. The unit was in daily contact with the family. She died at home four days later surrounded by her extended family.

The unit works as a team, taking time to understand and treat the patient.

The unit is a team: palliative care doctors and nurses are skilled in caring for the terminally ill, complementary therapists help patients and families, ministers offer spiritual help, social workers provide information about family benefits and support, anaesthetists help with pain management, physiotherapists help with physical symptoms and pharmacists ensure fast delivery of drugs.

This is the kind of palliative care experience PATCH wants all patients and families to have.



“ I woke up with no pain. The last time I had no pain was four months ago.”

THE PATCH MODEL

PATCH helps staff to develop hospital palliative care services. Applications are encouraged from individuals or teams on the ground who believe they can make a difference.

We understand the pressures faced by those applying to us, and so we work quickly to review, discuss and interview applicants. If successful we identify funding sources promptly, either through our own funds or applications to Trusts we have worked with before, or identify those available in associated regional areas. We want to expedite the process with all the due diligence and financial scrutiny we show each application. The priority is to ensure that care and training are optimised and not held up by an administrative process.



Baroness Neuberger, in her review, 'More Care, Less Pathway', identified the potential for hospital palliative care units to influence care and culture:

“There may be considerable advantages in hospitals designating particular wards or areas for palliative and end-of-life care, even if this entails devising new financial models to enable it. These areas could have two-fold benefit in not only improving end-of-life care but also enabling hospital staff to gain additional expertise and experience in caring for the dying, having difficult conversations and working with bereaved relatives. An adequately resourced specialist palliative care service, which can act as a model of good practice and hub for maintaining competencies within each hospital would do much to raise standards.” — *Neuberger 2013*

PATCH PROJECTS

PATCH was launched in Tayside in 2014. Its focus has been to enhance education opportunities for nursing and other clinical staff, as well as to support innovation and research in palliative care.

Key education projects

Postgraduate nurse education

PATCH funded **128** nurses in Greater Glasgow and Clyde to undergo a week's course of additional palliative care training.

PATCH funded **10** nurses to undertake a postgraduate certificate (one year), diploma (two years) or MSc (three years) in palliative care, run by St Columba's Hospice and Queen Margaret University in Edinburgh and the University of Glasgow.

PATCH funded a new course designed by St Columba's in the Borders. **28** registered nurses studied alongside a PATCH development nurse and other experienced specialist staff, followed by six months of mentoring.

PATCH contributed to an endowment-funded project establishing **16** link nurses in Perth Royal Infirmary, to help make 24/7 palliative care expertise available to more patients, families and staff.

Listening and talking to patients and their families

"More than half of hospital complaints relate to care of a dying patient and most of these are about poor communication.

"In their first year qualified, a doctor sees on average 40 patients who die and the evidence is that they are ill-prepared for talking with families and relatives about this. Over four years PATCH funded a pilot communication skills training course for final year medical students at the University of Dundee. Students practice with simulated patients and families in a safe environment. The course is now mandatory for every one of the 200 per year student intake."
— Dr Fiona McFatter, Consultant

Involving all hospital staff

A PATCH practice development nurse was funded for a two-year period. Janice Logan developed an education programme for the Borders General Hospital and local community hospitals. She took every opportunity to teach by the bedside, by example, before and during COVID.



Scan to find out more on the PATCH podcast.

PATCH PROJECTS

Research & innovation and emergency care

**For people who are ill it can be
frightening to run into problems at
night or over the weekend.**



Coping with Crisis

PATCH funded the publication of 22,000 copies of a 32-page booklet, *Coping with Crisis*.

Difficult decisions often have to be made in the hospital, and there can be doubt about what to do for the best. *Coping with Crisis* explores the difference between doing everything possible and doing what is best. It examines how patients, families, and staff can openly discuss the likely goals of any intervention.

“I think it is brilliant, brilliant, brilliant. There are so many times that I would have found it helpful – with patients and even friends who have been confronted with tough decisions and often ducked them.”

— *General Practitioner*

Personal Treatment plans in case of emergency

PATCH has funded a project in Lothian, which is now being extended to Greater Glasgow and Clyde. The project focuses on exploring the use of personal future care plans. It aims to determine whether these plans, decided upon through careful discussion, can assist patients, staff, and families in reaching a consensus on decisions about treatment in the event of an emergency.⁹

“The NHS is geared towards a one size fits all approach especially in the emergency department. This study aims to break the mould and see if having a personal plan makes a difference in the event of clinical deterioration.”

— *Prof. Robin Taylor*

Robin Taylor, a Professor of Respiratory Medicine, has published extensively on clinical and ethical decision-making.

What help do patients with advanced cancer need out of hours?

A research general practitioner was funded by PATCH to examine why cancer patients in Tayside used out-of-hours care. Every clinical encounter with out-of-hours health staff and all medicines prescribed were recorded with a view to improving the service.

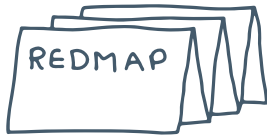
For this work, Dr Sarah Mills⁸ received the University of Dundee Life Sciences Howard Elder prize for the most significant paper in an area related to cancer research.

“PATCH is wonderful because it is so flexible and responsive and it doesn’t take nine months from application to funding.”

— *Dr Sarah Mills*

⁸ A Mills S et al. Death from Cancer; frequent unscheduled care. *BMJ Support & Palliative Care* 2022; 0:1-6

⁹ Taylor DR, et al. Responding to the deteriorating patient: The rationale for treatment escalation plans. *Journal of the Royal College of Physicians of Edinburgh*. 2022;52(2):172-179.



Finding the right words

PATCH funded the production of 3,000 bankcard-sized folded cards, along with a downloadable version, to serve as a quick reference for the REDMAP framework: Ready, Expect, Diagnosis, Matters, Actions, Plan.

These reference cards are invaluable tools for staff, aiding them in finding the appropriate language to navigate challenging conversations. For instance, phrases like *“Can we talk about what is happening with your health and care in case things change in the future?”*

Covering crucial topics like initiating care planning, addressing declining health, discussing end-of-life matters, and navigating conversations about cardiopulmonary resuscitation (CPR), these cards provide essential guidance for effective communication.

“The support from PATCH helped us launch the cards at a time when staff needed advice and support in having meaningful discussions.”

— *Dr Kirsty Boyd, Reader in Palliative Care*

Providing a bed for relative or friend to stay overnight

PATCH has funded the installation of a built-in bed at Kelso Community Hospital for overnight stays and four recliner chairs at Adamson Community Hospital in Cupar. They have proved to be immensely beneficial and is highly appreciated by all the patients and relatives who have utilised them.

“If space allowed, I would introduce more of these beds.”

— *Andrea Johnston, Charge Nurse, Kelso Community Hospital*

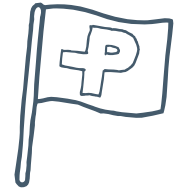


The Dundas Medal was established in memory of Dr C.R. Dundas, a consultant anaesthetist at Aberdeen Royal Infirmary, who died in 2014 of hepatobiliary cancer.

PATCH PROJECTS

The Dundas Medal

This annual award has been a joint initiative between PATCH and the Royal College of Surgeons of Edinburgh since 2017. Highlights include:

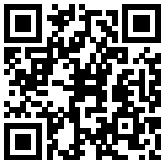


2017: The inaugural award was to The Hospital Specialist Palliative Care Team, Queen Elizabeth University Hospital Glasgow.

They support ward staff caring for patients with life limiting and progressive illnesses irrespective of diagnosis. This includes the management of difficult physical symptoms such as pain and breathlessness and helping to manage psychological and family distress. The team works closely with local hospices and with cancer and non-cancer services.

2018: A joint application by specialist teams in palliative care and heart and lung transplantation at Newcastle's Freeman Hospital were honoured.

The waiting list for heart and/or lung transplants surpasses available procedures. Many patients benefit from palliative care during the wait or if their condition worsens. The award acknowledges the innovative collaboration between the Freeman Specialist palliative care team and the Cardiothoracic transplant service, showcased in their film on Freeman Transplant TV.¹⁰



Scan to view on YouTube.

2020: "Taste for Pleasure" is a video produced by the end-of-life care team at The Shrewsbury and Telford Hospital NHS Trust.

It was inspired by a hospital volunteer who worked with dental hygienists, speech and therapy staff to rethink the commonly held approach to end-of-life care — "nil by mouth" for fear of aspiration.

"Watching my mum eat and drink nothing was awful. This innovation shows humanity and care to the very end."

— PATCH Board member

2022: Dr Roger Flint won with his innovative app SPOT Safer Prescribing of Opioids Tool.

There are more than 4,000 mistakes in the prescribing of opioids in the UK per year. SPOT is an app designed to allow clinicians to double check conversion of one strong morphine-like painkiller to another, safely, quickly and conveniently by the patient's bedside. It is the first such clinical validated support tool available and Dr Flint has won many awards for his innovation. The app has been tested in two Scottish Health Boards and has applied for use nationally.¹¹


2023: The North Tees and Hartlepool NHS Trust palliative care team expanded their service due to COVID, implementing a seven-day service, offering a creative writing course with the Open University for staff welfare, establishing a single point of access telemedicine service, and training end-of-life volunteers for bedside support.

"We have changed from being research naive to research aware"

— Dr Donna Wakefield, Consultant

¹⁰ <http://transplant.tv/portfolio/palliative-care/>

¹¹ Flint R et al, The Safer Prescription of Opioids Tool SPOT. Int J Environ Res Public Health. 2019;16(11)1926.



“Caring for a patient who needs end-of-life care is a real challenge — one seen every day of the week in our busy hospitals. Increasing my knowledge and skills in nursing this important group of patients has enormously improved the level of care I can now provide patients and families.”

— Carol Ann Smith

First nurse to attain a PATCH funded certificate in palliative care. She has since developed the Thistle Programme to care for patients actively dying, throughout Edinburgh major hospitals.

PATCH PEOPLE

Our board members and advisors, who are all volunteers, set the strategy for PATCH and monitor performance to ensure the projects undertaken uphold the core values of the charity as set out in its constitution.



Prof Sir Alfred Cuschieri
FRSE FRCS Patron

Sir Alfred is an internationally recognised pioneer of minimally invasive surgery. He is currently Chief Scientific Advisor at the Institute for Medical Science and Technology in Dundee.



Dr Gordon Paterson OBE
FRCPE Chairman

Gordon worked for 34 years in the NHS, as a GP and latterly as Director of Public Health for NHS Grampian. He contributed to national policy development for cancer services, including palliative care.



Prof Alastair Munro FRCR
FRCS(E) Deputy Chair & Director of Research

Alastair retired as Emeritus Professor of Radiation Oncology at the University of Dundee. He is presently Honorary Professor of Medicine at the University of St Andrews.



Mrs Trudy McLeay MSc
DCRR Director & Secretary

Trudy has 41 years' NHS experience as a radiographer and Macmillan project manager. She was a key fundraiser for the Ninewells' Acute Palliative Care Unit (APCU). She was a non-executive on the NHS Tayside Health Board.



Dr Pamela Levack FRCPE
Medical Director

Pamela retired in 2012 as a consultant in palliative medicine, having established the APCU at Ninewells, Tayside. Her background as a GP with oncology accreditation highlighted the need for palliative care in acute hospitals.



Dr Sarah Mills MRCGP
PhD Director

Sarah, a Lecturer in Academic General Practice, University of St Andrews, has been awarded several prestigious awards for her research into cancer patients' use of out of hours emergency care.



Mr Steven Thompson BSc
Director

Steven is a senior web developer skilled in web development, infrastructure and procurement. He has worked for organisations such as PayPal and the University of Edinburgh Business School.



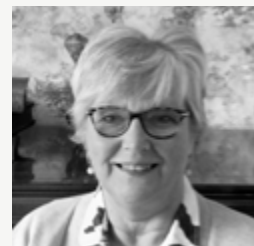
Mrs Kate Forster MA
Director

Kate has been a communications consultant for over 20 years. She originally supported the launch of PATCH in Scotland and now raises awareness of the projects which the charity supports.



Mrs Claire O'Neil
Director

Claire has 30 years' experience in palliative care in hospice, community and hospital. A previous nurse consultant, she is lead nurse and service manager palliative care in Greater Glasgow and Clyde.



Elaine Fair BA
Director & Treasurer

Elaine has been involved with PATCH for six years, handling bookkeeping responsibilities. Recently, she retired from managing her own financial practice.



Mr Paul Corrigan BA
Social Media Advisor

Paul has been overseeing social media accounts since 2014. He currently holds the position of Information Officer at NHS Greater Glasgow and Clyde, where he manages Palliative Care online resources.

HOW YOU CAN SUPPORT PATCH

We are so grateful to all Friends of PATCH and everyone who supports the charity, enabling us to provide funding for 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 PayPal you can choose to donate as a one off or on a regular basis.

You can also leave a gift in your Will that would go to support the work of PATCH to help improve palliative care services for patients and their families in a hospital setting. For more information go to www.patchscotland.com and click on our DONATE section.

**If you would like more information
please get in touch.**

Visit us online

www.patchscotland.com

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THANK YOU

We would like to give a special thanks to everyone who has helped PATCH over the years and those who continue to help us to make this all possible.

Almost all PATCH funds directly support projects to improve palliative care. In contrast to some charities that may spend up to 30% on administration, governance and fundraising we spend only 10% of our income for these purposes.





Palliation and the caring hospital

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