



**Palliation
and
the
caring
hospital**

**CHARITY
PROFILE**

2018

PATCH

Supporting the improvement of palliative care



Sir Michael Nairn Bt
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."

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PATCH People

PATCH Patron:

Professor Sir Alfred Cuschieri
FRSE FRCS

Board of Directors (2018):

Sir Michael Nairn Bt
Chairman

Dr Pamela Levack FRCP
Medical Director

Mrs Trudy McLeay MSc
DCRR Director

Dr Gordon Paterson OBE
FRCP Director

Mr Steven Thompson BSc
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Mrs Kate Forster MA
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Mr John Light MA
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Advisors:

Professor Alastair Munro
FRCR FRCP Research Advisor

Ms Mary Mackenzie BSc
RGN Nursing Advisor

Registered Scottish Charitable Incorporated
Organisation No: SCO44231

PATCH

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



“
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.”



PATCH AND PALLIATIVE CARE

PATCH was inspired by the model of care developed in the Acute Palliative Care Unit in Ninewells Hospital, Dundee which was started by a charitable donation and is now funded by the NHS.

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

Palliative care is state of the art 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...

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.

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.

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

² Francis R. Independent enquiry 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 O'Brien T, Kane C. Pain services and palliative medicine. Br J Pain 2014; 8(4):163-171



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

THE SIZE OF THE PROBLEM

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.⁵

Many patients in hospital have pain or complex symptoms for which they need, and deserve, access to a palliative care specialist.⁶

The role of hospices

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; approximately 55% of people die in hospital, compared with 5% in a hospice.

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.

When so many treatments are available, it can be difficult to be certain when treatment is no longer helping. It may then be too late or the patient may be too unwell to transfer to a hospice. Some patients and staff who have been looked after by hospital staff for a long time may choose to stay in hospital.

55% 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 Julie Ramsay, National Records of Scotland; Katharine Sharpe Information Statistics Division (2009-2012 data). Personal communications 2014.



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 7 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.

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

Working with others

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

Universities, such as Queen Margaret University, University of Edinburgh, the University of Dundee and Glasgow Caledonian University.

Charities, including the Gannochy, Reekie, Hayward Sanderson and J Macdonald Menzies Trusts.

Hospices and palliative care units, including St Columba's Edinburgh, Margaret Kerr Unit Scottish Borders, Cornhill Macmillan Centre Perth and Victoria Hospice Kirkcaldy.

NHS Boards, including Tayside, Fife, Borders and Greater Glasgow & Clyde.

Medical Royal Colleges, including Royal College of Surgeons of Edinburgh.

THE PATCH MODEL

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



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 will support:

Palliative Care Teams	Ward Nursing Staff	Medical Staff
<p>Most hospitals have an advisory team which offers advice to the patient’s consultant and ward staff. PATCH can help support teams with ideas to improve their services.</p> <p>A typical team is small, consisting of one to four palliative care nurses and one or two senior doctors for hospitals with up to 800 beds. Such specialist palliative care staff may be attached to a local hospice and visit on request. Services are generally available Monday to Friday 9am–5pm.</p>	<p>PATCH will fund the development of enhanced palliative and end-of-life care skills for ward nurses.</p> <p>As a result of such support there are now more nurses with these enhanced skills in Perth Royal Infirmary and a number of hospitals in the Scottish Borders who are equipped to provide palliative care and support to patients and families with funding support from PATCH.</p>	<p>Many of the complaints in relation to end-of-life care are about poor communication — patients and families not knowing what is happening or what might happen.</p> <p>PATCH funds communication skills training for medical students and recently qualified doctors.</p>

PATCH can contribute to the funding of palliative care beds in hospitals.

A few hospitals in Scotland already have palliative care beds which are neither hospice wards nor hospital wards. They are something in-between encouraging the teaching and practice of palliative care in an acute setting.

For example, Ninewells Hospital, a cancer centre in Tayside, has a short-stay three-bedded acute palliative care unit — the inspiration for PATCH. Patients are transferred to the care of specialist palliative care staff who work alongside a team of other skilled staff. Such an approach can improve the patient’s chances of getting home.

Three district general hospitals also have dedicated beds which are providing much needed palliative care to patients. Dumfries Royal Infirmary — the eight-bedded Alexandra Unit; Queen Margaret Hospital, Dunfermline — a specialist palliative care ward; and Royal Alexandra Hospital, Paisley — a surgical palliative care ward with specialist palliative care input.

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.

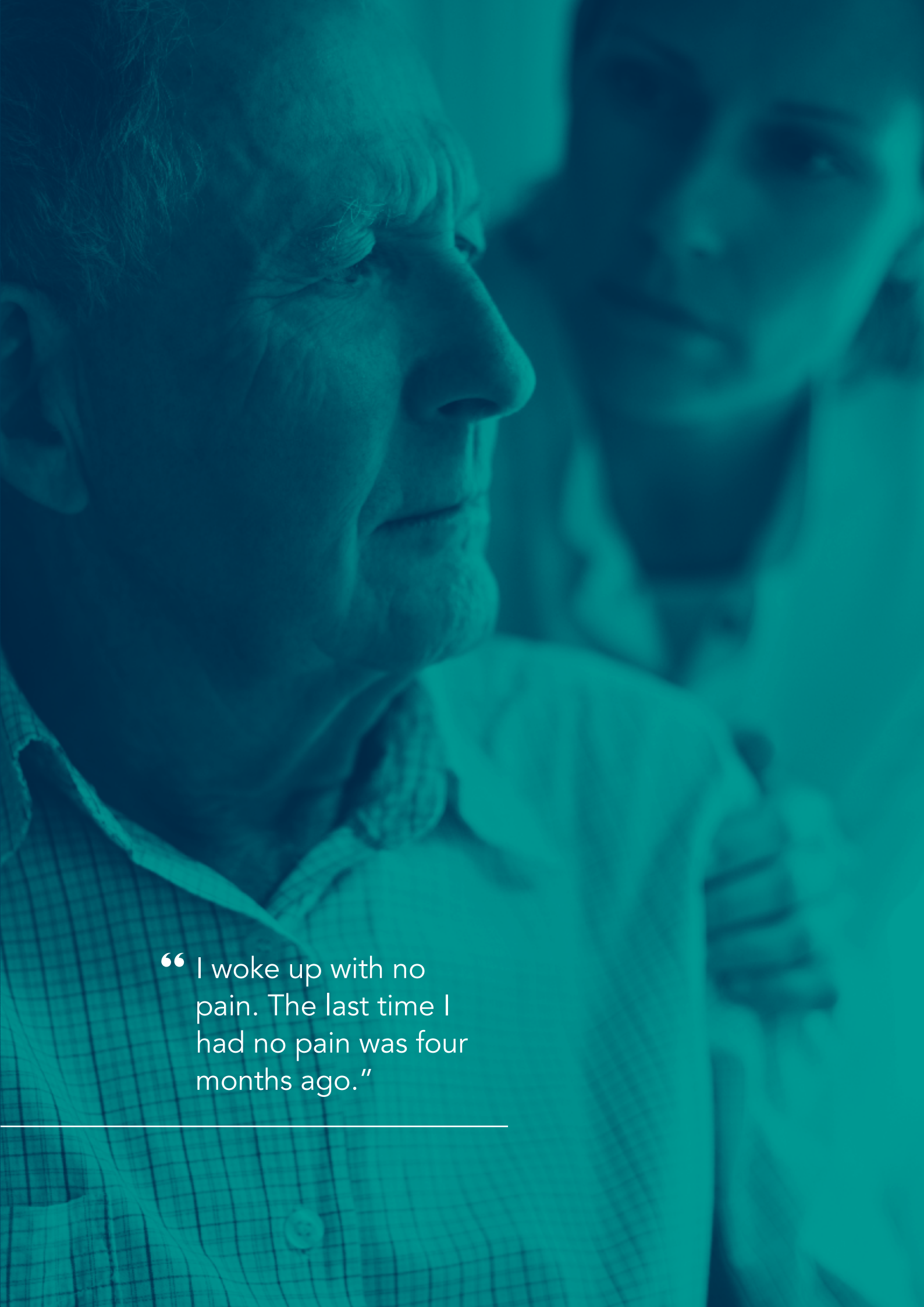
She knew the findings of her operation but not their meaning — and she had not asked. In order to make the right decisions (for her and her family), she needed to know the seriousness of her condition, and the unit staff talked this over with her and her husband. They were then able to communicate their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

CHARITY ACHIEVEMENTS

Our vision is that patients in hospital who need specialist and skilled palliative care will receive it when they need it, and that it is available 24 hours a day, 7 days a week.

PATCH was launched in Tayside in 2014 and launched nationally as a Scottish charity in 2015.

Since it was established the charity's key areas of focus have been to enhance the education opportunities for nursing and other clinical staff; support innovation in care; and fund relevant research in the area of palliative care.

Education

PATCH has funded nurses to undertake the postgraduate certificate and the MSc in palliative care, run by St Columba's Hospice in Edinburgh and Queen Margaret University.

PATCH has funded a new course in the Borders designed by St Columba's. Registered nurses study alongside and shadow specialist palliative care staff for one week, followed by six months of mentoring. By late 2018, 28 nurses will have completed this course.

PATCH has contributed to an endowment funded project to establish 36 link nurses in Perth Royal Infirmary. Link nurses throughout the hospital make 24/7 palliative care expertise available to more patients, families and staff.

PATCH is funding 15 ward staff in Queen Elizabeth University Hospital Glasgow to undergo additional palliative care training.

Innovation

PATCH funded the prototype stage of SPOT (Safer Prescription of Opioids Tool) — a novel application that can be used on a range of mobile devices including laptops, tablets and smartphones to calculate painkiller dosages.

"Two weeks after starting work as a doctor I was asked to switch painkillers for a patient who was very ill and towards the end of their life. It took me a long time to calculate the correct dosage. There was no way to double check my calculation, and I felt unable to prescribe the pain relief. It was a sobering lesson and I was determined that no other junior doctor or patient should be put in the same position." *Dr Roger Flint*

Research

For people who are ill it can be frightening to run into problems at night or over the weekend. A research general practitioner was funded by PATCH to examine why patients in Tayside with cancer 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.

Dr Mills has recently been awarded a Chief Scientist Office Fellowship to develop her work for a PhD.

"PATCH is wonderful because it is so flexible and responsive and it doesn't take nine months from application to funding." *Dr Sarah Mills*



PATCH PROJECTS

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.

We have shared below an update on some more of the projects we have supported from across Scotland since the charity began in 2014.

The Dundas Medal

The Hospital Specialist Palliative Care Team at the Queen Elizabeth University Hospital Glasgow (QEUH) was the first team to be awarded the Dundas Medal. This annual award is a joint initiative between PATCH and the Royal College of Surgeons of Edinburgh.

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

PATCH ensures that almost all of its 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.

Palliative care in Acute Medical Admissions ward

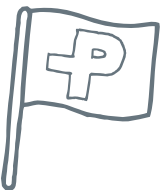
Many people approaching the end-of-life are caught in a revolving door of repeat emergency visits to hospital. PATCH, together with NHS Fife is funding a project to provide palliative care assessment for patients as soon as possible after admission.

A specialist palliative care nurse and palliative care occupational therapist will work with the palliative care team at the Royal Victoria Hospital Kirkcaldy to involve palliative care during patients' hospital stay or organise support for patients who want to be at home.

Listening and talking to patients and their families

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

In their first year after qualification, doctors care, on average, for 40 patients who die and the evidence is that they are ill-prepared for talking with families and relatives about this.⁸ PATCH is funding extra communication training for final year medical students at the University of Dundee.



⁸ Whyte R et al. Medical students experience of personal loss. Incidence and implications. BMC Medical Education. 2013; 13:36.

“Caring for a patient who needs end-of-life care while in a busy hospital ward is a very real challenge — one seen every day of the week in the acute surgical and medical wards. Being enabled to increase my knowledge and skills in nursing this important group of patients has enormously improved the level of care I can now provide.”

Carol Ann Smith
Respiratory ward nurse
(Undertook a postgraduate certificate in palliative care funded by PATCH)



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.



Sir Michael Nairn Bt
Chairman

Sir Michael is founder and chairman of Rautomead, an engineering business based in Dundee. His company has been an active supporter of the Palliative Care Unit at Ninewells Hospital.



Dr Pamela Levack FRCP
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.



Mrs Trudy McLeay MSc
DCRR Director

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. She is a non-executive on the NHS Tayside Health board.



Dr Gordon Paterson
OBE FRCP Director

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.



Mr Steven Thompson BSc
Director

Steven has been developing and designing websites since 2007. He is currently a web developer for both Zaza Shelley and the University of Edinburgh Business School.



Mrs Kate Forster MA
Director

Kate has been a communications consultant for over 15 years. She originally supported the launch of PATCH in Scotland and now raises awareness for the projects which the charity supports.



Mr John Light MA
Director

Now retired and living in Perthshire, John worked as a Headteacher in the UK, Jordan and the Netherlands. He serves as trustee on several charitable boards in Scotland and England.



Prof. Alastair Munro FRCP
FRCP Research Advisor

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.



Ms Mary Mackenzie BSc
RGN Nursing Advisor

Mary is a founding member of PATCH, retired after nursing for 42 years, and was a theatre sister, ward sister and specialist nurse in the palliative care team in Ninewells Hospital, Dundee.

HOW YOU CAN SUPPORT PATCH

We are so grateful to all Friends of PATCH who support the charity and enable 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 virginmoneygiving.com 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 or to receive our bi-annual newsletter please get in touch.

Visit us online
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Write to
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THANK YOU
We would like to give a special thanks to everyone who has helped PATCH over the past few years and those who continue to help us to make this all possible.





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BP-07-18-v2

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