

# Primary Palliative Care Research Group

Usher Institute of Population Health Sciences & Informatics, The University of Edinburgh



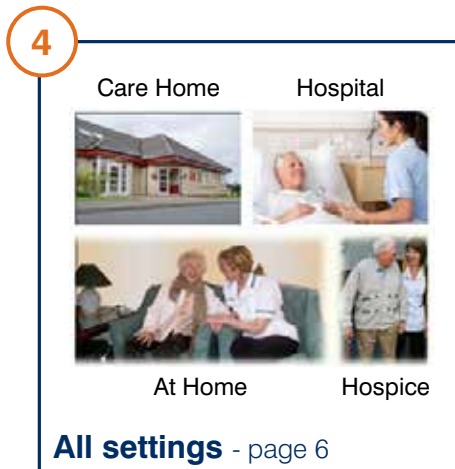
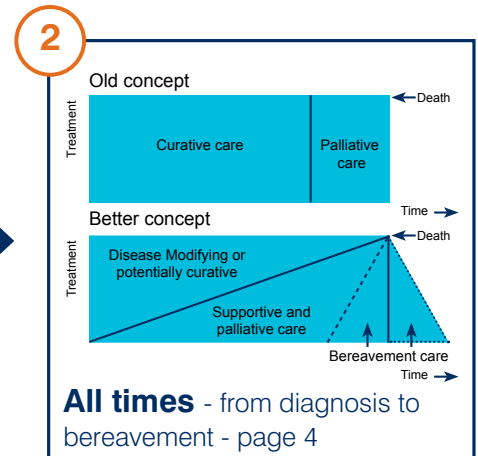
THE UNIVERSITY of EDINBURGH



**Palliative care is becoming an urgent priority in Scotland, UK and beyond. How governments respond to this challenge will be a test of the country's development as a civilised nation.**



**Five key palliative care challenges drive our research**



## Recent successes of the Primary Palliative Care Research Group

- Advising WHO on how to best integrate palliative care in primary care internationally
- Published a Toolkit on how to introduce palliative care in primary care nationally [www.eapcnet.eu/LinkClick.aspx?fileticket=QDeFwspXKkA%3D](http://www.eapcnet.eu/LinkClick.aspx?fileticket=QDeFwspXKkA%3D)
- SPICT™ is being widely downloaded from our website and used internationally to identify people for palliative care. The Supportive & Palliative Care Indicators Tool <http://www.spict.org.uk/>

## International Primary Palliative Care Network

Scott Murray chairs the International primary palliative care network to encourage research in the community in both the economically developed and poorer countries.

See: [www.ippcn.org/](http://www.ippcn.org/)



Prof. Scott Murray MBE





## Chronic Obstructive Pulmonary Disease

### What can be done to help and support people living and dying with COPD?

**Funder:** Dunhill Trust

**Research team:** Hilary Pinnock, **Marilyn Kendall**, Susan Buckingham, Ulugbek Nurmatov, Cristina Matthews, Susie Ferguson



People with severe COPD live with disabling symptoms. This project aimed to provide people who had just had a hospital admission with an assessment of their physical, psychological, social and spiritual care needs and to plan actions that might help them cope.

The study is now complete and the first paper published in the *npj Primary Care Respiratory Medicine*. People appreciated the holistic assessment, though the intervention generated fewer actions than we had expected. This was partly because our intervention overlapped with routine discharge planning, but also because the people with severe COPD had adapted their lifestyles and preferred not to be seen as needing help.

<http://spcare.bmj.com/content/early/2015/08/26/bmjspcare-2015-000904.full.pdf>

## Heart Disease

### A randomised controlled trial of care planning for patients with advanced heart disease (FLAME trial)

**Funder:** Marie Curie Cancer Care



**Research team:** **Gill Hight**, Martin Denvir, Sarah Cudmore, Shirley Robertson, Lisa Donald, Christopher Weir, Kirsty Boyd, Scott Murray

Patients with cancer have better developed palliative care services than people with heart disease. To address this we evaluated a care planning intervention with patients and families. This combined a holistic needs assessment by a cardiologist and cardiology nurse with the creation of a shared future care plan and nurse led care in the community, following a recent unscheduled hospital admission with acute coronary syndrome (ACS) or heart failure (HF). We explored whether such a complex intervention is acceptable to patients, their carers and health professionals, and if it is practical, deliverable and feasible.

The primary outcome measure was quality of life of patients and carers. Patients with a 12 month estimated mortality risk of 20% or greater were randomised to either early (upon discharge) or delayed (after 12 weeks) intervention. 50 patients were enrolled into the study (22% ACS, 68% HF, 10% valvular heart disease). Findings demonstrated that the intervention and outcome measures were acceptable, feasible and deliverable. A multi-centred clinical trial is being planned.

<http://heart.bmj.com/content/early/2015/04/21/heartjnl-2014-306724.full.pdf+html>

## Multimorbidity

### Living with advanced multimorbidity

**Funder:** National Institute for Health Research

**Research Team:** **Bruce Mason**, Kirsty Boyd, Anne Donaldson, Marilyn Kendall, Allison Worth, Scott Murray

In a recent study of patients in Edinburgh, London and Warwick we discovered that most people during their last year of life had multiple needs requiring a range of health and social services. However such patients and their family carers reported these services to be inflexible, unresponsive and poorly coordinated. Family carers played a significant role in managing the care of patients with multimorbidity and often bridged the gaps in professional care coordination. Patients wanted to retain a sense of autonomy and self-control often through limiting their interactions with the health service. Identifying such patients is crucial so that they can receive equitable care appropriate to their multiple needs. Multimorbid patients receive much less palliative care than cancer patients with an equivalent burden of need. <http://spcare.bmj.com/content/early/2014/05/28/bmjspcare-2013-000639.full.pdf+html>



### 3 All Dimensions of need

#### Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family caregivers of patients with lung cancer

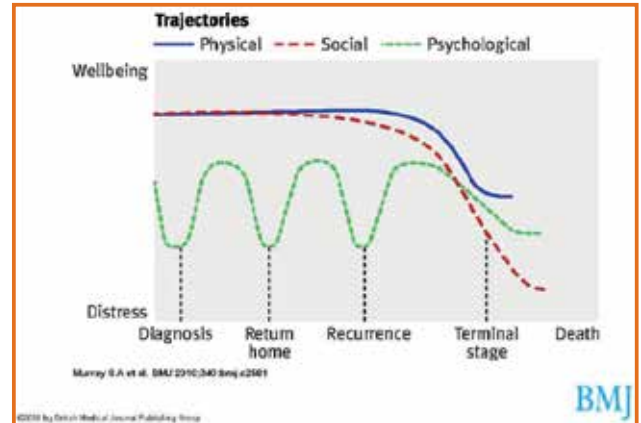
**Funder:** Chief Scientist Office

**Research team:** Scott Murray, Marilyn Kendall, Kirsty Boyd, Liz Grant, Gill Highet, Aziz Sheikh

We explored if family caregivers of patients with lung cancer experience the patterns of social, psychological, and spiritual wellbeing and distress typical of the patient, from diagnosis to death. Secondary analysis of serial qualitative interviews was carried out every three months for up to a year or to bereavement. The findings revealed that carers followed clear patterns of social, psychological, and spiritual wellbeing and distress that mirrored the experiences of those for whom they were caring, with some carers also experiencing deterioration in physical health that impacted on their ability to care.

Certain key time points in the illness tended to be particularly problematic for both carers and patients: at diagnosis, at home after initial treatment, at recurrence, and during the terminal stage.

The multidimensional experience of distress suffered by patients with lung cancer was reflected in the suffering of their carers. Carers need support from diagnosis and not just in the last weeks.

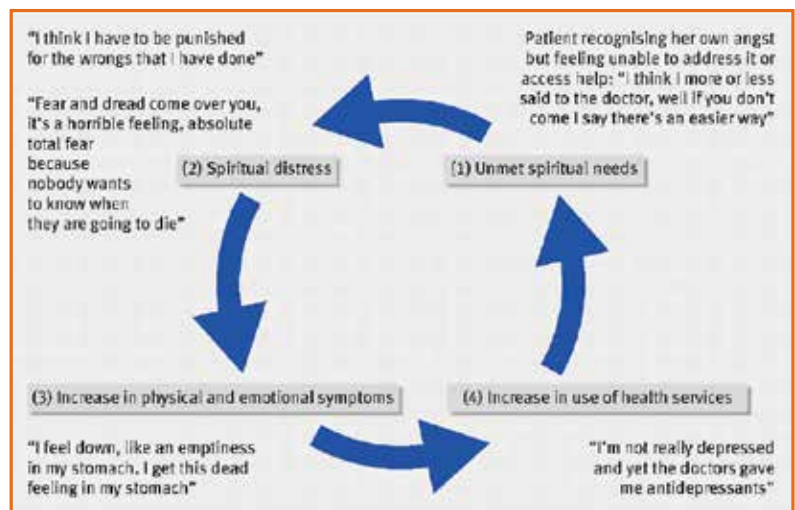


#### Spiritual dimensions of dying in pluralist societies

**Funder:** Chief Scientist Office

**Research Team:** Liz Grant, Scott Murray, Aziz Sheikh, Marilyn Kendall

We mapped spiritual distress across different disease trajectories, identifying triggers of spiritual need in order to understand better the spiritual issues that patients experienced and the times in patients' illness journeys when spiritual care could be of most value. These are at *diagnosis*, at *returning home*, at *disease progression*, and in *the last days*. Many patients identified feelings of emptiness, and loss, a sense of worthlessness and a fear of dying exacerbated by a longing to connect with others including, for many, the sacred. They expressed a desire to be at peace and to make amends and a number looked for religious and social rituals that would help them gain and retain meaning in life, when disease became the predominant concern of the health professionals. For patients spiritual support was often deeply intertwined with empathy and the valuing of the individual.



#### Influencing empathy: A qualitative longitudinal study of medical students' views and experiences



**Funder:** Self-funded

**PhD candidate:** David Jeffrey. **Supervisors:** Marilyn Kendall, Marie Fallon, Michael Ross

This qualitative study uses interpretative phenomenological analysis (IPA) to gain a deeper understanding of the influences on students' empathy as they progress through their training.

## 4 All Settings

### To scope the feasibility of establishing a Care Home Centre of excellence, innovation, training and research (CHC)



**Funder:** Burdett Trust for Nursing

**Research team:** Jo Hockley, Scott Murray

Care homes are the largest provider for the 24-hour care of frail older people in the UK. There are currently 18,000 care homes supporting 400,000 older people - three times the number of NHS beds. People over the age of 80yrs old now represent the fastest growing group within the UK population. However, care homes have suffered from an over-exaggerated bad press often being seen as 'places of last resort'. The project will collate the international literature on the development of teaching nursing homes in the USA, Canada and Australia, and visit specific sites in Norway and The Netherlands. This knowledge will be shared with clinicians and academic partners across Lothian while undertaking a feasibility study to establish a CHC in Edinburgh. A CHC would not only be homely and a place of excellence for frail older people requiring 24-hour nursing care, but also challenge the perceptions of the care of frail older people and encourage a new generation of professional carers through training and research alongside empowering staff in local care homes.

### Improving palliative care in care homes: A community palliative care clinical nurse specialist led model of support



**Funder:** Marie Curie and the Robertson Trust

**Research team:** Anne Finucane, Emma Carduff, Barbara Stevenson, Libby Milton, Scott Murray

National and international policies call for care homes to provide reliably good end-of-life care. Building on previous research conducted by Dr Jo Hockley, this study aims to improve the delivery of palliative care in 29 nursing homes in the Edinburgh area. The intervention is being delivered by the Community Nursing team at Marie Curie Hospice Edinburgh. It consists of: support from a dedicated Community Palliative Care Nurse Specialist; identification of one palliative care lead in each care home; targeted training in response to individual needs; multidisciplinary palliative care review meetings, and support to use tools to help identify residents who may be approaching end of life. Key outcomes such as the proportion of residents who die in the care home and the proportion who die with an anticipatory care plan in place are being assessed. This type of approach allows palliative care specialists to help improve the quality of care for people with frailty and dementia.

The research group works closely with the Marie Curie Hospice, Edinburgh. We have a strong history of collaborative work and the supervision of medical students. We have worked on a number of joint publications.

### Caring with Integrity: Developing the conceptual underpinning of relationship-centred palliative dementia care in care homes



**Funder:** ESRC PhD studentship

**PhD candidate:** Julie Watson. **Supervisors:** Heather Wilkinson, Marilyn Kendall

People with advanced dementia struggle to maintain relationships and can ultimately experience social death before their physical death. Understandings of, and assumptions about, the effect of dementia on personhood directly affect the way people with dementia are perceived by others, the quality of their relationships, the quality of their care and the quality of their life. This ethnographic study examined care-giving/care-receiving relationships in a specialist dementia care home. Findings show that people with advanced dementia continue to experience and respond to the world, and those around them, until they die, particularly in embodied ways. These findings are used to develop thinking on relationship-centred palliative dementia care. Ethic of Care theory is used to argue why a broad understanding of personhood is vital, not only at the frontline, but also in dementia and palliative care policy, if care is to have integrity.



# Carers

## A feasibility study of early identification, assessment and support for informal carers in primary care



**Funder:** Marie Curie and Dimbleby Cancer Care

**Research Team:** Emma Carduff, Scott Murray, Marilyn Kendall, Alison Jarvis, Anne Finucane, Gill Highet, Nadine Harrison, Jane Greenacre

Approximately 17% of the Scottish population provide unpaid care for a relative, friend or neighbour. Those supporting someone with terminal illness often cope until the situation becomes overwhelming. Earlier identification could enable more timely support.

We modelled and piloted a systematic approach to identify, assess and support carers in primary care. We found that general practices need to proactively identify carers using existing opportunities, resources and computer systems, and also adopt a public approach to raise carer awareness and perceived support within their communities. This work informed the Scottish Carer Bill which was passed in the Scottish Parliament in February 2016. Emma has now moved to lead research at Marie Curie Hospice in Glasgow and maintains close links with the group. <http://bmcfampract.biomedcentral.com/articles/10.1186/s12875-016-0414-2>

## Health Promoting Palliative Care

### Advancing education and support around death, dying and bereavement: hospices, schools and health promoting palliative care



**Funder:** Strathcarron Hospice  
**Dr Sally Paul**

Children are often excluded from conversation about dying and bereavement and this can result in negative experiences. Adopting the principles of health promotion to palliative care can address this. Such approaches have gained recognition internationally. This study used action research to explore, implement and evaluate interventions where hospices and schools can work together to advance education and support around death, dying and bereavement. Several practice innovations were taken forward. Hospices can develop community capacity in end-of-life and bereavement care with school communities. Sally is currently a lecturer in Social Work at the University of Strathclyde and is building on this work whilst being an active member of this research group. <http://bjsw.oxfordjournals.org/content/early/2013/02/12/bjsw.bct017.full.pdf+html>

### Innovative collaborative work with St. Columba's Hospice



**Funder:** Creative Scotland  
**Research team:**

Erna Haraldsdottir, Marilyn Kendall, Amy Hardie

Strathcarron Hospice is collaborating in an innovative project working with Amy Hardie to make a film that will be shown in cinema and BBC television in 2015. Patients and staff are the main characters in the film which reflects the life story of 6 patients as well as hospice life. The film challenges the taboo around death, dying and hospices and is called "Singing Hospice". Erna Haraldsdottir has now moved to lead the Education Department at St. Columba's Hospice where she will facilitate research, while being an active member of our research group.

### Health promoting palliative care at St Joseph's Hospice, London



**Funder:** St Joseph's Hospice  
**PhD candidate:** Libby Sallnow  
**Supervisors:** Allan Kellehear, Heather Richardson, Scott Murray

Community engagement initiatives have great potential to help people live to the full at the end of life. Medical care, whether provided by hospices, hospitals or primary care comprises only one component of broad support a dying person and their family and friends need. Examples of empowered communities providing much of this social and supportive care exist in some economically poorer countries and now in the UK. This doctoral study is evaluating one such initiative at St Joseph's Hospice in London. Libby has recently published two papers to help build up the evidence base. <http://pmj.sagepub.com/content/early/2015/08/04/0269216315599869.full.pdf+html>

### Contact

For a list of recent publications please see:  
[http://www.cphs.mvm.ed.ac.uk/groups/ppcrg/projects\\_keypub.php](http://www.cphs.mvm.ed.ac.uk/groups/ppcrg/projects_keypub.php)

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