



Ben Gold/Marie Curie

End-of-life care research

Care and support
through terminal illness



End-of-life care research at

Research overview

Official projections for the UK show that, with a growing elderly population, the number of people living with complex terminal illnesses will increase significantly.

This means that a greater number of people will require end-of-life care. Yet research in palliative and end-of-life care remains significantly underfunded, with less than **1%** of total health research funding being spent on relevant research.¹

The following studies show some of the many research areas that are benefiting from your kind support.

The role that Marie Curie plays in research



Lynn Ballingall/Marie Curie

Since our early days Marie Curie has recognised how vital the study of palliative and end-of-life care is. We are always looking to improve care and support for people living with a terminal illness, their carers, families and friends.

We want to be able to provide the most effective pain and symptom relief possible and to do everything

we can to help people maintain their dignity and self-respect.

Advancing research is and will continue to be essential in our delivery of the highest quality care.

Marie Curie is the largest charitable funder of end-of-life care research in the UK. We invest around £3 million each year in grants and a network of research leads in our hospices, and through our own research centres at University College London and Cardiff University.

¹UK Health Research Analysis 2014 (UK Clinical Research Collaboration, 2015)

4,213

PEOPLE

Between April 2017 and March 2018, 4,213 people took part in research studies funded by Marie Curie or carried out by our researchers.

Marie Curie

1. Improving the care of people with advanced dementia in nursing homes

Pete Jones/Marie Curie



Lead researcher

Dr Liz Sampson, Clinical Reader, Marie Curie Palliative Care Research Department, University College London

Project summary

There has been little evidence-based research on how to improve dementia care and many nursing home staff are currently struggling to meet the needs of people living with advanced dementia. Given that around 80% of the 400,000² people living in nursing homes have the condition, with this number set to quadruple in coming years, such research is vital. Our study tested a new 'Compassion' model of care (Care of Memory Problems in Advanced Stages: Improving our Knowledge) in two nursing homes over six months. This involved looking at the barriers that prevent people with advanced dementia getting better end-of-life care and how these could be overcome.

Making an impact

The Compassion model of care helps nursing home staff better meet the needs of those with advanced dementia. This research also highlighted the importance of GPs, geriatricians, palliative and mental health nurses working together so that patients have the best quality of life possible through personalised care. As a result of this study, a training manual has been developed to help nursing homes implement this model of care and improve practice.

² Alzheimer's Society. Dementia 2014: Opportunity for change. 2014 September.

2. Research into non-cancer conditions: Chronic obstructive pulmonary disease

Pete Jones/Marie Curie



Lead researcher

Dr Morag Farquhar, University of East Anglia

Project summary

This study looked at ways to improve the support given to people with advanced Chronic Obstructive Pulmonary Disease (COPD), as well as their carers. Evidence shows that the needs of people living with this chronic lung condition, who often struggle to breathe, were not always being met. Patients also faced numerous barriers when it came to getting additional help and support, which can put a large strain on their family.

Making an impact

By identifying the specific barriers to care for people with COPD, Dr Farquhar and her team have now developed a more person-centred care approach to help doctors initiate conversations with their patients. This will give patient and carer relief and reassurance by ensuring their needs are identified more easily and accurately by healthcare professionals.

3. Supporting carers and those they care for



Researchers

Professor Gunn Grande,
University of Manchester

Dr Gail Ewing, University of Cambridge

Project summary

If a loved one is terminally ill, families often want them to be discharged from hospital so they can be cared for at home. However many families may not fully understand the implications and responsibilities of being a full time carer.

This important research, conducted across three NHS trusts, looked at how healthcare professionals can best talk to a carer about the challenges ahead and offer them support.

Making an impact

The researchers looked at whether a question and answer tool could help to encourage conversations about the reality of caregiving at home when someone leaves hospital. This has already been implemented in some hospitals across the UK. We have shown that by preparing families and carers, we can increase their confidence in caring for their loved one, reducing the chance of both a breakdown in care and a patient's emergency readmission to hospital, which is often the last thing they want.



62

INSTANCES

Our researchers reported 62 instances of influencing policy and practice, adding value to research and making a difference nationally.

4. Improving the care of prostate cancer patients with late gastrointestinal symptoms after radiotherapy

Researchers

Professor Annmarie Nelson, Dr Anthony Byrne, Marie Curie Palliative Care Research Centre, Cardiff

Project summary

Each year in the UK, 17,000 men receive pelvic radiotherapy for prostate cancer. Around 40% of them will go on to experience moderate to severe changes in their bowel function. Currently these symptoms often go under-reported and under-recognised and can be very distressing for the individual. This study aimed to give healthcare professionals a screening tool – called Alert-B – which they could use to identify patients with gastrointestinal problems so they could get the treatment they needed to live more comfortably and independently.

Making an impact

Hundreds of patients have now been screened using Alert-B at clinics in Cardiff, Brighton and Sheffield and this is set to expand further, with plans to implement Alert-B on a national electronic patient portal.

Marie Curie research has provided vital support to these patients in helping them manage their symptoms, which is why the value of this work has been recognised by its nomination for an NHS award.

Continued...

Our research means more people can have better end-of-life care

“It is extremely important that we continue to support research into palliative and end-of-life care for people living with a terminal illness and their loved ones. Research informs our work and helps us influence the development of future national policy so we can reach the diverse range of people and communities that need our help across the UK.”



Anne Cleary,
Director of Nursing

Why your support matters

Your gifts help Marie Curie Nurses offer their amazing care to more people living with a terminal illness. Marie Curie research helps our nurses to deliver the highest standard of palliative care.

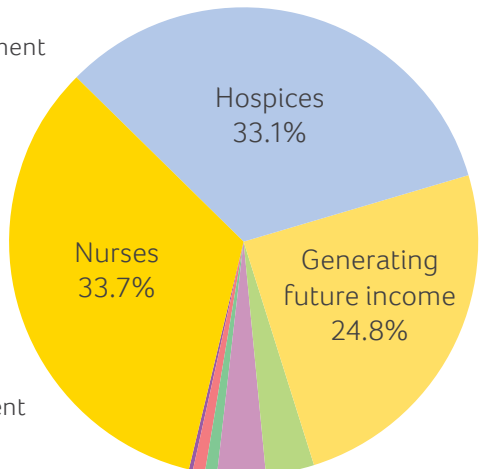
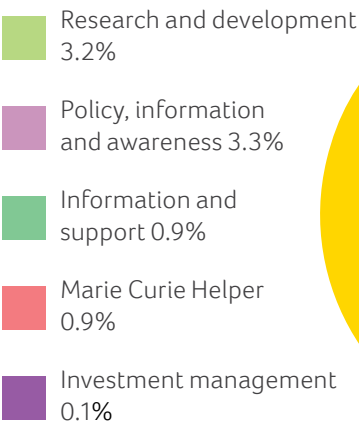


“Palliative and end-of-life care research is significantly underfunded. Our vital research helps make a difference to clinical practice.”

Professor Annmarie Nelson,
Marie Curie Palliative Care
Research Centre, Cardiff

Thank you

Your kind gifts make Marie Curie’s work possible. As a much-valued supporter, we wanted you to know more about Marie Curie’s end-of-life care research. Although this is a small area of our work, our research informs and helps Marie Curie Nurses to give the very best care in someone’s final days.







Thank you for making everything that we do possible.

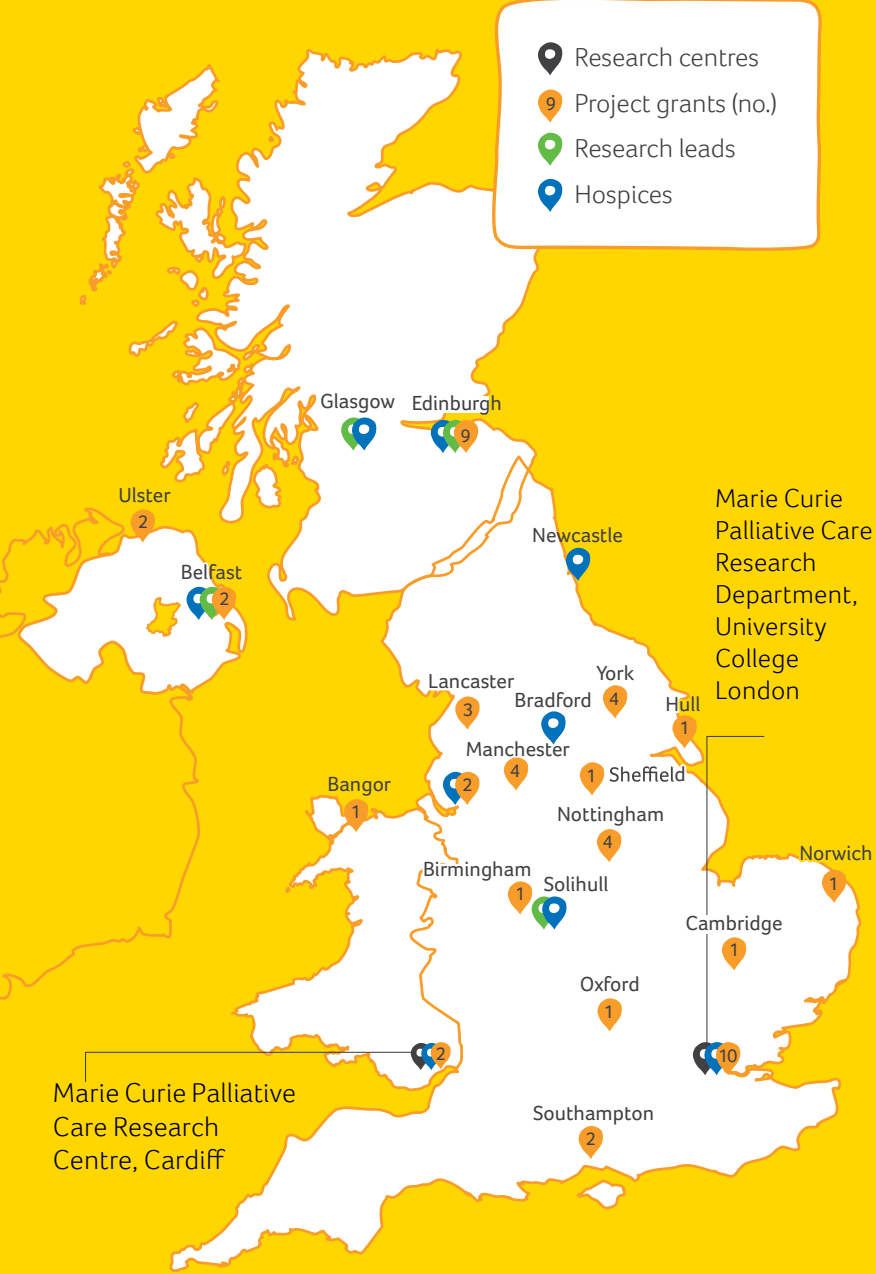
79 PAPERS

Marie Curie-funded researchers published 79 papers in peer-reviewed journals in 2017. We have made 75% openly available so far so that findings can be shared widely and have the greatest impact.



Marie Curie research activities by location

-  Research centres
-  Project grants (no.)
-  Research leads
-  Hospices



Marie Curie Palliative Care Research Department, University College London

Marie Curie Palliative Care Research Centre, Cardiff

Cardiff University team



University College London team

