

SPIRITUAL SUPPORT IN END STAGE HEART FAILURE: A RANDOMISED CONTROLLED FEASIBILITY STUDY

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Dr Jackie Miles, BSc, RGN, PhD, MBE. R&D ABUHB

Overview

- 1. Why is it needed?
- 2. Our studies: what we did and what we found
- 3. Where do we go from here?

Other research team members

- Professor David Cohen (health economist)
- Dr Paul Jarvis (statistician)
- Jan Hillman (psychosocial counsellor)
- Rev Michael Marsden (chaplain)
- Jane Brooks (Nurse lead)
- Drs Huw Morgan, Barry Bowden (volunteer trainers)
- Dr Stephen Hutchison (Consultant Cardiologist)

Nevill Hall Hospital, Abergavenny



USW, Pontypridd



1. Why is it needed?

- Evidence base
- Spiritual care: part of healthcare policy
- Poor care: Francis, Andrews, Winterbourne
- What's important to patients



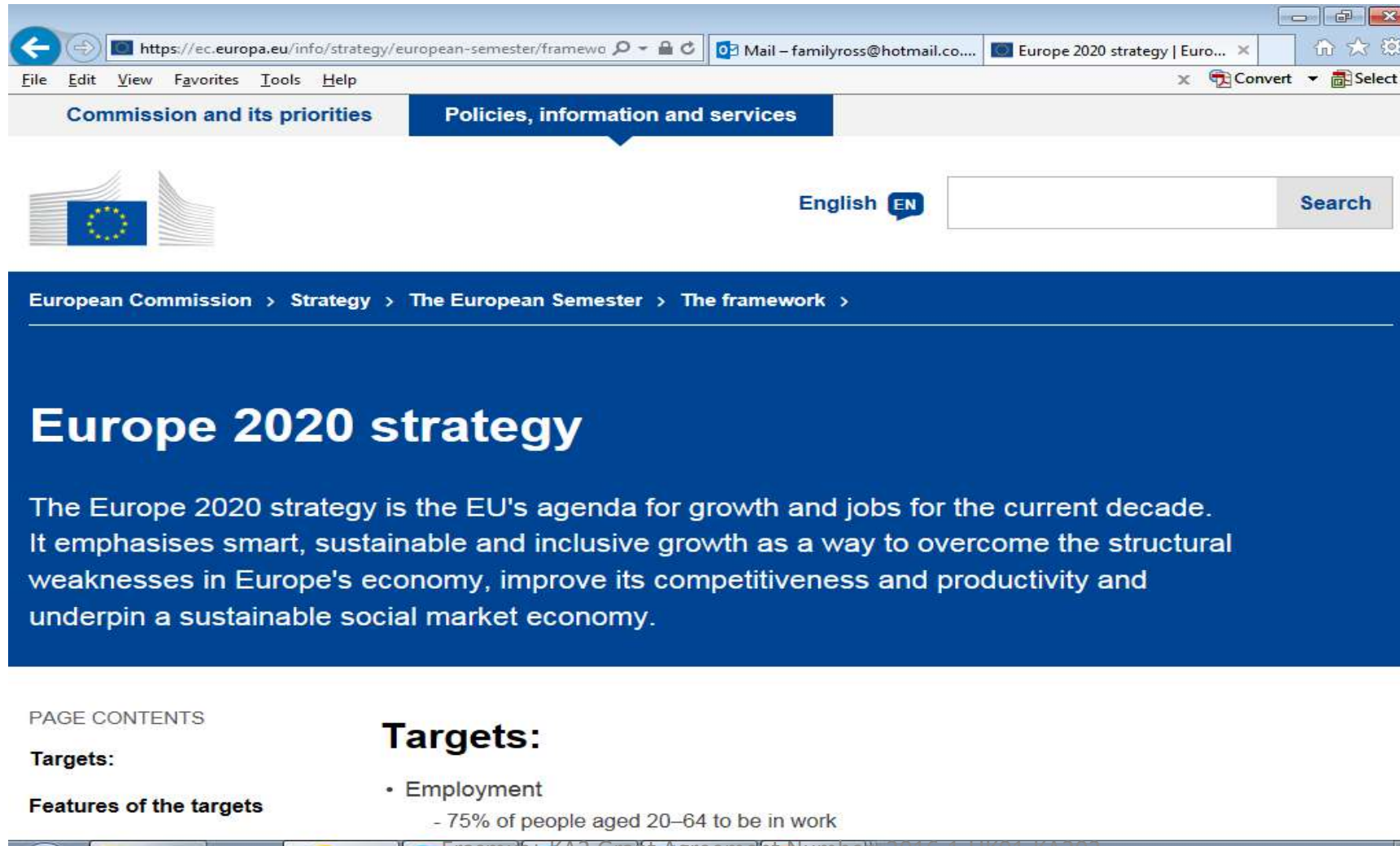
Evidence: spirituality - QOL

- 13 studies e.g.
- Brady et al (1999) A case for including spirituality in quality of life measurement in oncology. *Psychooncology*, 8, 417-428
- Walsh K, King M, Jones L et al. Spiritual beliefs may affect outcome of bereavement: prospective study. *BMJ* 2002; 324:1551-1554.
- McClain CS, Rosenfeld B and Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients. *Lancet* 2003; 361:1603-1607.

Evidence: Spirituality - mental health (depression, anxiety)

- 5 studies e.g.
- McClain CS, Rosenfeld B and Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients. *Lancet* 2003; 361:1603-1607.
- Bekelman et al (2007) Spiritual wellbeing and depression in patients with heart failure. *J Gen Intern Med*, 22, 470-477
- Nelson et al (2002) Spirituality, religion and depression in the terminally ill. *Psychosomatics*, 43, 213-220

Policy



The screenshot shows a web browser window displaying the European Commission's website. The address bar shows the URL: <https://ec.europa.eu/info/strategy/european-semester/framework>. The page has a blue header with the text "Commission and its priorities" and "Policies, information and services". Below the header is a search bar with the text "English EN" and a "Search" button. The main content area has a blue background with the text "Europe 2020 strategy" and a description: "The Europe 2020 strategy is the EU's agenda for growth and jobs for the current decade. It emphasises smart, sustainable and inclusive growth as a way to overcome the structural weaknesses in Europe's economy, improve its competitiveness and productivity and underpin a sustainable social market economy."

European Commission > Strategy > The European Semester > The framework >

Europe 2020 strategy

The Europe 2020 strategy is the EU's agenda for growth and jobs for the current decade. It emphasises smart, sustainable and inclusive growth as a way to overcome the structural weaknesses in Europe's economy, improve its competitiveness and productivity and underpin a sustainable social market economy.

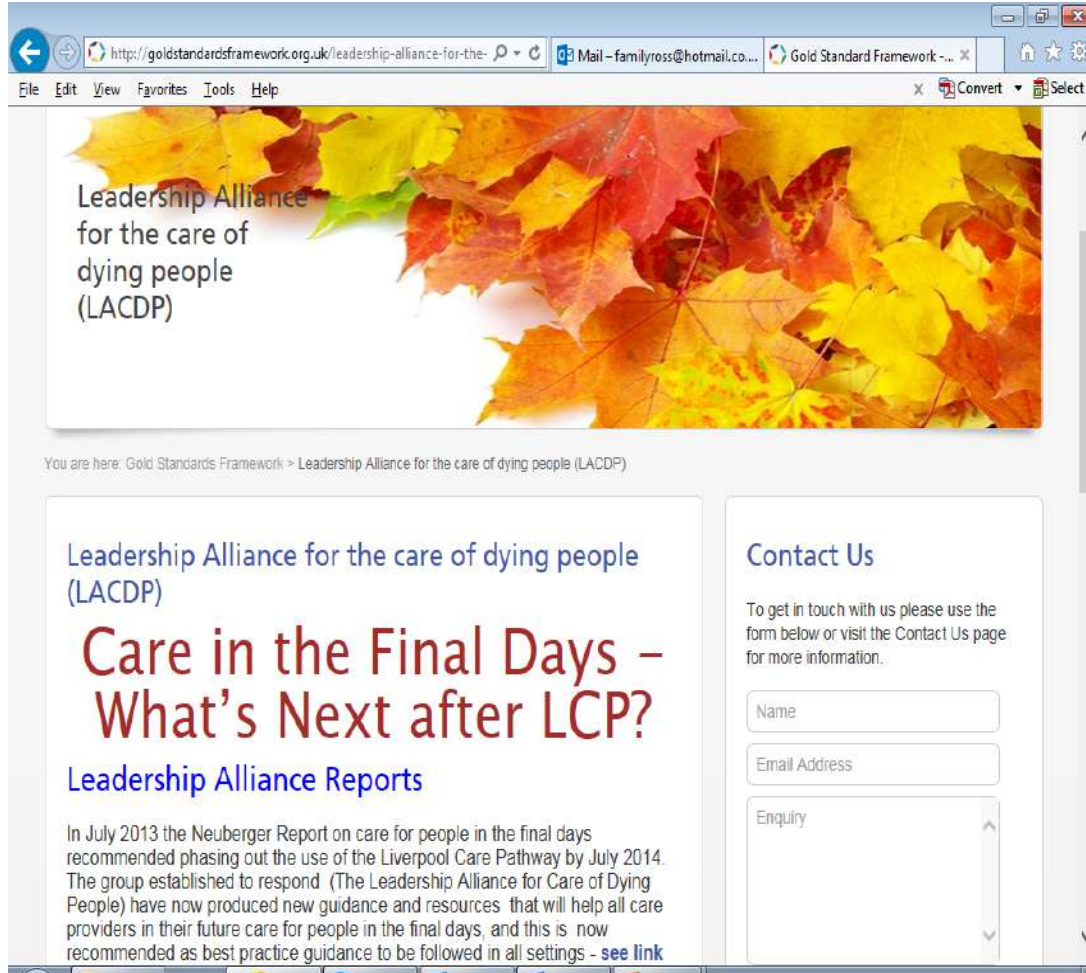
PAGE CONTENTS

Targets:

- Employment
 - 75% of people aged 20–64 to be in work

Features of the targets

Policy: LACDP 2014



Leadership Alliance for the care of dying people (LACDP)

You are here: Gold Standards Framework > Leadership Alliance for the care of dying people (LACDP)

Leadership Alliance for the care of dying people (LACDP)

Care in the Final Days – What's Next after LCP?

Leadership Alliance Reports

In July 2013 the Neuberger Report on care for people in the final days recommended phasing out the use of the Liverpool Care Pathway by July 2014. The group established to respond (The Leadership Alliance for Care of Dying People) have now produced new guidance and resources that will help all care providers in their future care for people in the final days, and this is now recommended as best practice guidance to be followed in all settings - [see link](#)

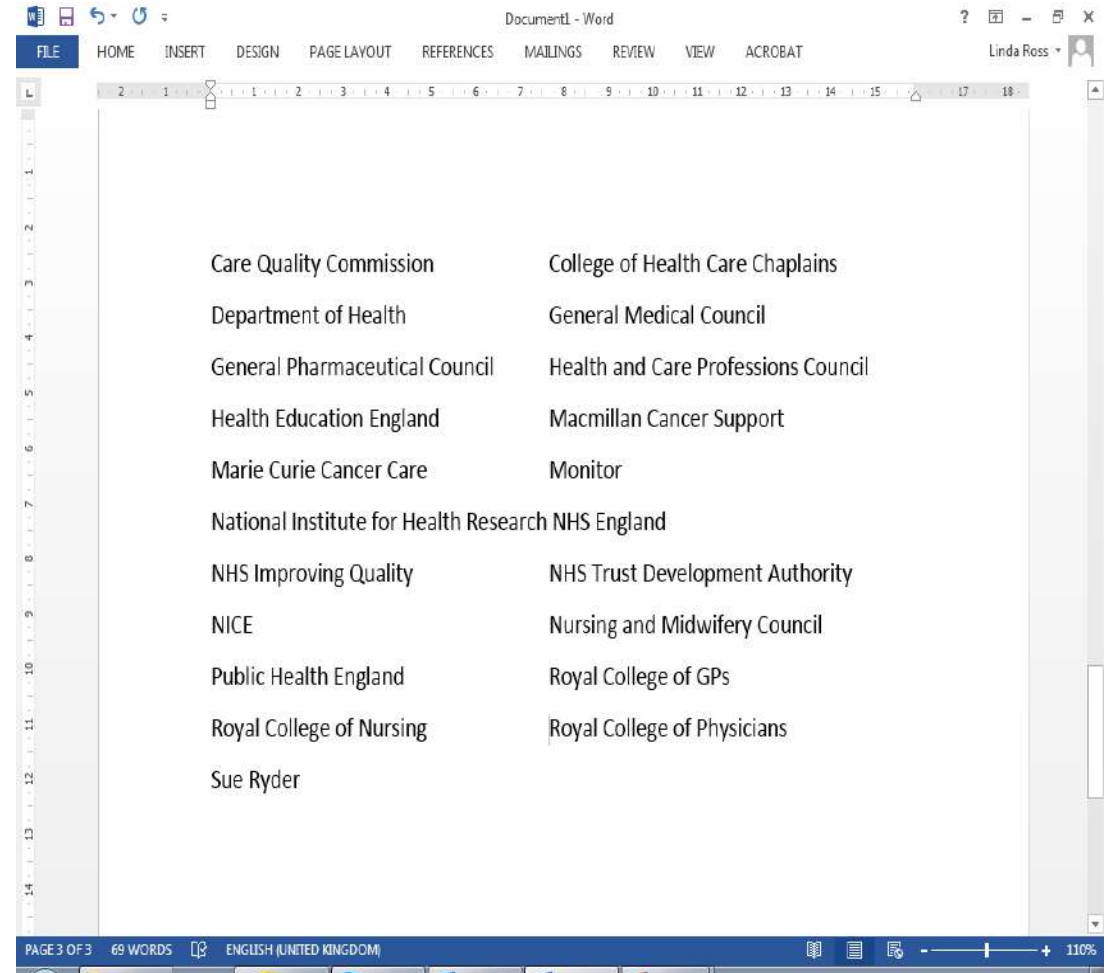
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Enquiry



Care Quality Commission

Department of Health

General Pharmaceutical Council

Health Education England

Marie Curie Cancer Care

National Institute for Health Research NHS England

NHS Improving Quality

NICE

Public Health England

Royal College of Nursing

Sue Ryder

College of Health Care Chaplains

General Medical Council

Health and Care Professions Council

Macmillan Cancer Support

Monitor

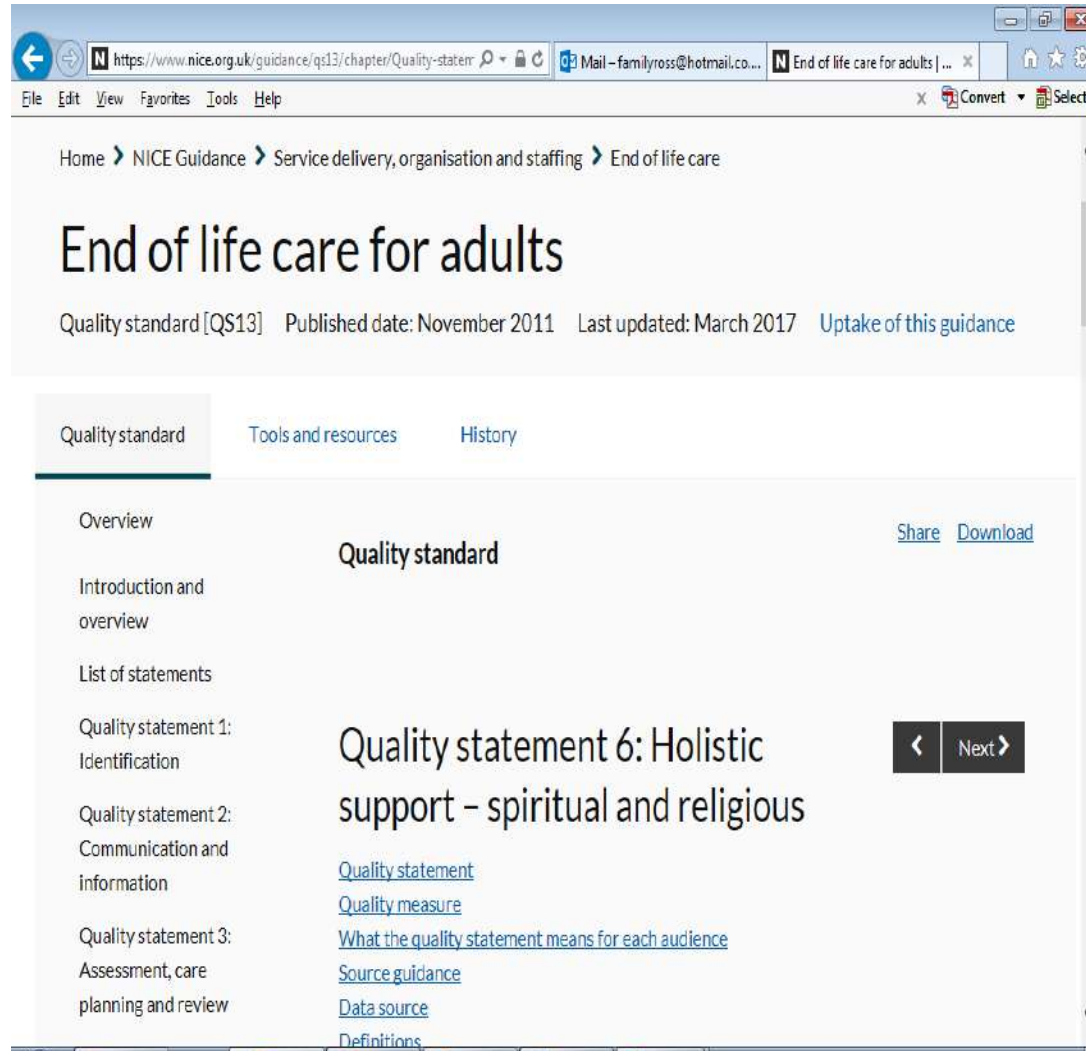
NHS Trust Development Authority

Nursing and Midwifery Council

Royal College of GPs

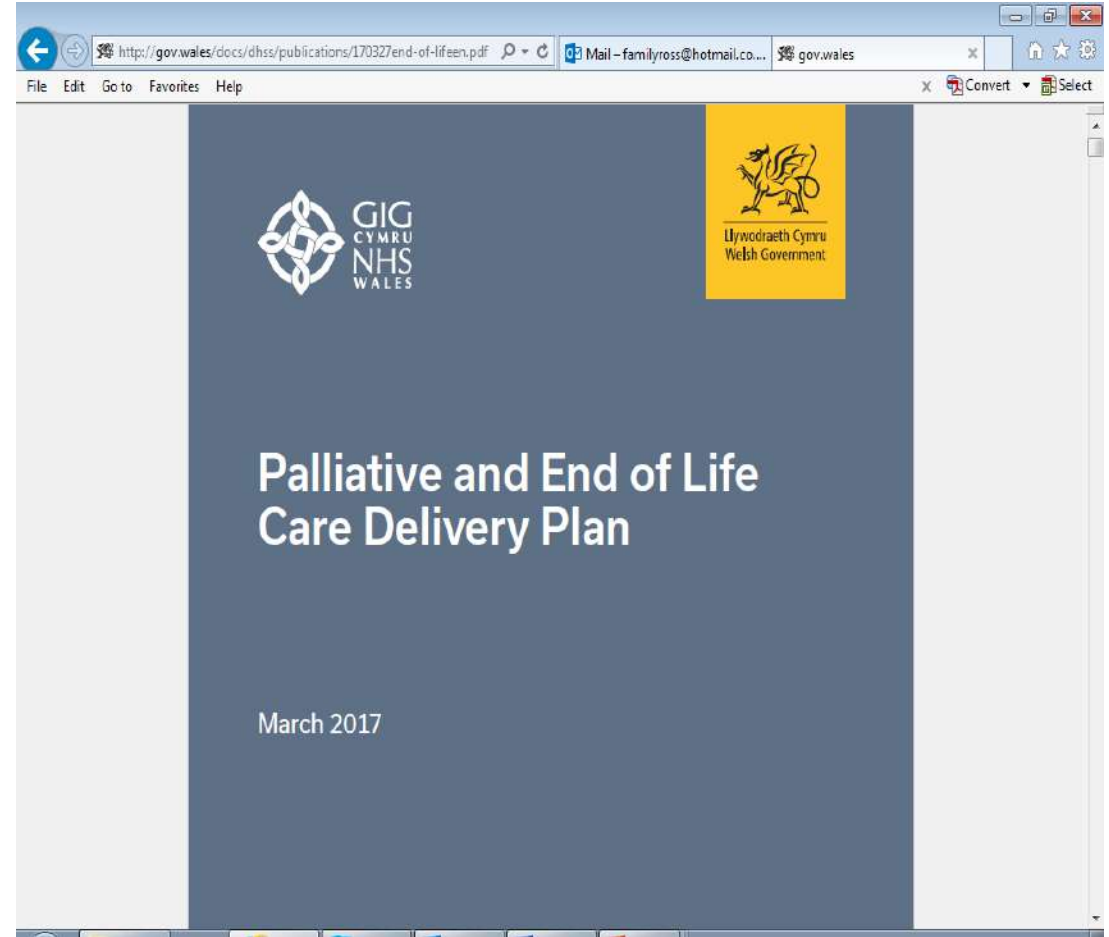
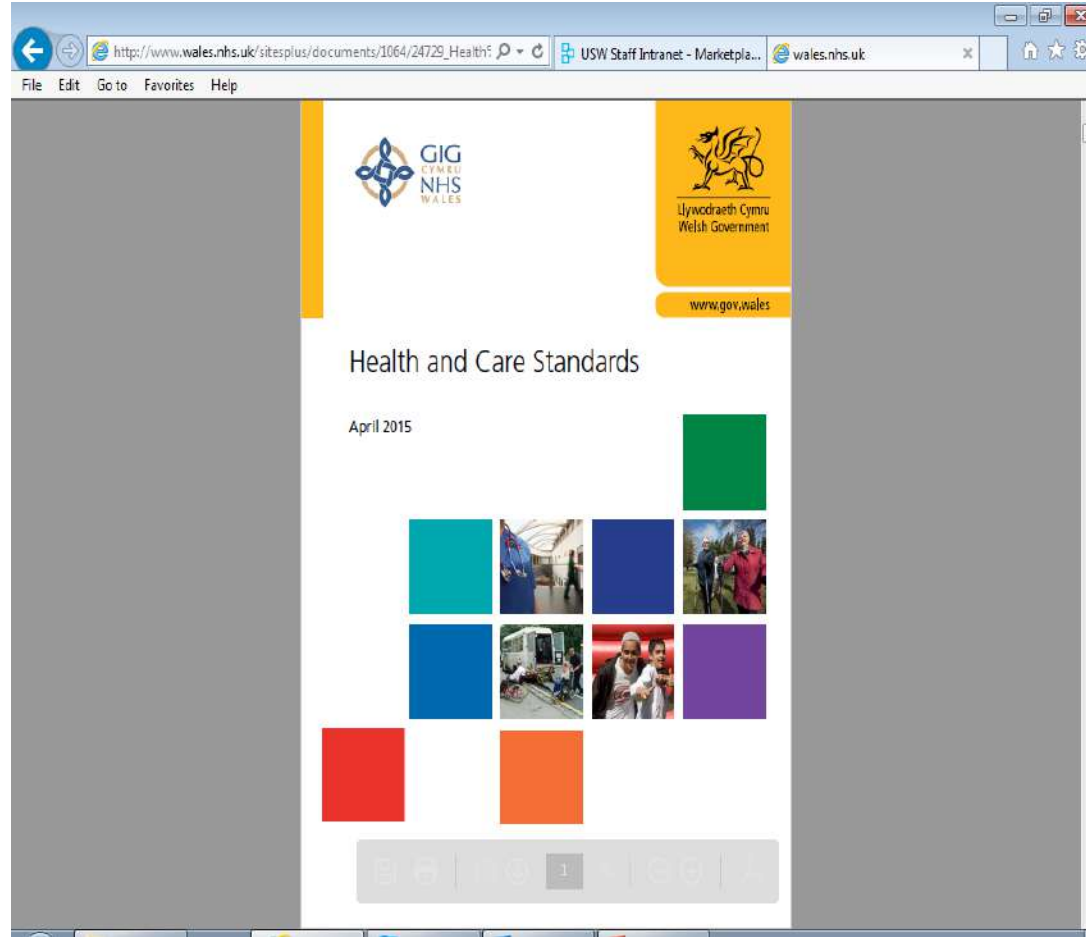
Royal College of Physicians

PAGE 3 OF 3 69 WORDS ENGLISH (UNITED KINGDOM) 110%



- **Quality statement**
- People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

Policy: Wales



Poor care

https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-services-for-people-with-learning-disabilities-and-or-autism.pdf

Mail - familyross@hotmail.co.uk

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WINTERBOURNE VIEW – TIME FOR CHANGE

Transforming the commissioning
of services for people with learning
disabilities and/or autism

http://www.bbc.co.uk/news/uk-wales-south-east-wales-27390919

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Abertawe Bro Morgannwg: Care failings at hospitals 'shock'

13 May 2014 | South East Wales

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Pensioner Lilian Williams was seriously neglected at two hospitals before she died. (Report: 31 October 2013)

http://www.bbc.co.uk/news/world-middle-east-39062221

spitals have been criticised in an

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Centrist Emmanuel Macron will take on the far-right's Marine Le Pen in France's run-off election.
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- The land that used to belong to IS**
3 hours ago
- Nightclub 'acid attack' accused in court**
22 minutes ago

Features



The Holocaust: Who are the missing million?

Recent Reports



National care of the dying audit for hospitals, England

Discussions between clinicians and patients regarding spirituality in end-of-life care only occurs in 15 per cent of cases, and in an additional 27% of cases, people important to the patient had these discussions. This suggests that only in 42% of cases the patient and those important to them were asked about their spiritual needs



**End of Life Care Audit –
Dying in Hospital**
National report for England 2016



What's important to patients

The image displays two side-by-side screenshots of journal articles from Wiley Online Library. Both articles are by Linda Ross and focus on spiritual care in nursing.

Left Screenshot: Journal of Advanced Nursing (JAN)

- Article Title:** Elderly patients' perceptions of their spiritual needs and care: a pilot study
- Author:** Linda A. Ross (nee Waugh) BA RGN PhD
- First published:** October 1997
- DOI:** 10.1046/j.1365-2648.1997.00393.x
- Cited by (CrossRef):** 23 articles
- Abstract:** This paper describes a pilot study, in a small sample of elderly patients, designed to ascertain their perceptions of their spiritual needs and care. According to the nursing literature, spiritual care is part of the nurse's role. But it is not clear what spiritual needs are or how nurses are expected to give spiritual care. Ten patients from a care of the elderly assessment unit located in a hospital in Edinburgh, Scotland were interviewed about their spiritual needs in the

Right Screenshot: Journal of Nursing Management

- Article Title:** Spiritual needs and spiritual support preferences of people with end-stage heart failure and their carers: implications for nurse managers
- Authors:** Linda Ross BA, RGN, PhD, Jacky Austin MBE, PhD, BSc (Hons), RGN
- First published:** 17 July 2013
- DOI:** 10.1111/jonm.12087
- Cited by (CrossRef):** 5 articles
- Abstract:** Background
Spiritual care is an important element of holistic care but has received little attention within

Evidence: spiritual support

- 8 studies e.g
- Balboni et al (2010) provision of spiritual care to patients with advanced cancer: associations with medical care and QOL near death. J Clin Oncol, 28, 445-452
- BUT unmet spiritual needs associated with poorer QOL (Astrow et al 2007)

European Association of Palliative Care

- ‘Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek **meaning, purpose** and **transcendence**, and the way they **connect** to the moment, to self, to others, to nature, to the significant and/or the sacred.

The spiritual field is multidimensional:

- **1.Existential challenges** (e.g. questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy).
- **2.Value based considerations and attitudes** (what is most important for each person, such as relations to oneself, family, friends, work, things nature, art and culture, ethics and morals, and life itself).
- **3.Religious considerations and foundations** (faith, beliefs and practices, the relationship with God or the ultimate).
- <http://www.eapcnet.eu/Themes/ProjectsTaskforces/EAPCTaskforces/SpiritualCareinPalliativeCare.aspx>
accessed 9/1/18
- Puchalski et al (2014) Improving the spiritual dimension of whole person care: reaching national and international consensus. J Palliat Med,17, 642-656

2. Our studies: what we did and what we found



Study 1: Multidisciplinary cardiac rehabilitation

BHF Excellence Award 2006



- Austin J, Williams WR, Ross L, Moseley L, Hutchinson S. (2005) **Randomised controlled trial of cardiac rehabilitation in elderly patients with heart failure.** European Journal of Heart Failure, 7, 411-417.

2nd: interviews with 16 NYHA IV heart failure patients/carers on 4 occasions over a year in 2008/9 about their spiritual needs and spiritual support preferences

(Ross L and Austin J (2013) Journal of Nursing Management, 23, 1, 87-95)

Key findings	What's needed
Uncoordinated disjointed care. Unmet needs e.g. house aids, O2	Care coordinator
Poor/conflicting information	
Difficulty accessing care e.g. transport, long walk to clinic	
Co-morbidity and number of consultants involved	
Physical symptoms burdensome	Different care model
Psychological symptoms burdensome (loneliness, depression, anxiety)	Signposting to other services (social prescription) including voluntary sector
Spiritual needs not addressed but important. No-one to talk to about 'all of me', death, dying, what lies beyond, my future, what does my life mean, regrets, loss of hope, disconnection from people, activities, faith groups/God	Spiritual support



Publication



- Ross L & Austin J (2013) Spiritual needs and spiritual support preferences of people with end-stage heart failure and their carers: implications for nurse managers. JNM, DOI: 10.1111/jonm.12087

Study 3: 2010-2011

Addressing these needs/ service provision



Study 4: 2014-2016

REPORT

SPIRITUAL SUPPORT IN END STAGE HEART FAILURE: A RANDOMISED CONTROLLED FEASIBILITY STUDY

Linda Ross, Reader¹

Jackie Austin, Consultant Nurse²

Paul Jarvis, Statistician¹

Sara Pickett, Health Economist³

Aims

1. To make recommendations to inform the design of a future RCT to investigate the effect of spiritual support on specified outcomes in patients with end stage heart failure e.g. uptake/drop-out rates, time, effort, questionnaire information etc
2. To investigate the effect and cost effectiveness of spiritual support on spiritual wellbeing, health related QOL, anxiety/depression if the sample size was sufficient, or to explore trends worthy of further investigation if the sample size was insufficient.

Method

47 patients with end stage heart failure (NYHA 3b/IV)

25 standard care

22 standard care + spiritual support
(1 hr discussion with trained volunteer)

Measures completed at 0, 2, 4, 6 months



Measures

- Spiritual wellbeing: WHO SRPB QOL Field Test Instrument
- Anxiety, depression: HAD
- Health related QOL: EQ5D (EuroQol)
- NHS Resource Use Questionnaire
- Confounding factors (changes in circumstances, life events, symptoms, medication)
- Demographics
- Satisfaction with service (intervention group)



Primary findings (Aim 1)

1. Recruitment: 133 invited, 104 accepted pack, 47 enrolled (uptake 35%), 38 took part (18 control, 20 intervention)

15 (32%) dropped out (9 baseline, 3 at mth 2, 3 at mth 4)

31 complete data sets (all 4 time points)

2. Data collection took longer than expected:

18 mths to recruit 47 and 2 yrs to collect data

9 months to recruit 65 and 15 mths to collect data

3. Considerable effort needed



4. Measures suitable: Kansas City? Spiritual wellbeing?
5. Information about WHO-SRPB: change in scores with an intervention. Useful for calculating effect size in follow-on study
6. Nurses initially uncomfortable with/lacked confidence in having end of life conversations
7. Spiritual support was valued by those receiving it



Secondary findings (Aim 2)

1. Spiritual wellbeing negatively correlated with anxiety (Rho ranging from -.306 to -.385, $p < 0.05$) and depression (Rho ranging from -.342 to -.648, $p < 0.05$)
2. No significant effects were identified for the intervention (spiritual support) on spiritual wellbeing, QOL, anxiety or depression.

BUT, trends worthy of further exploration

-Positive effect of SS on QOL (+4 in intervention group, -8 in control group) and anxiety (-1.2 in intervention group and +0.8 in control group) at 0-2 months but not on depression or SWB.

- Negative effect (increased depression $+0.9$) of withdrawal of SS from experimental group at study end (months 4-6).

- Lower health resource cost per experimental patient (£204) over the study period; SS may be cost effective if rolled out to more patients within routine care.



3. Where do we go from here?



Gaps identified from our studies

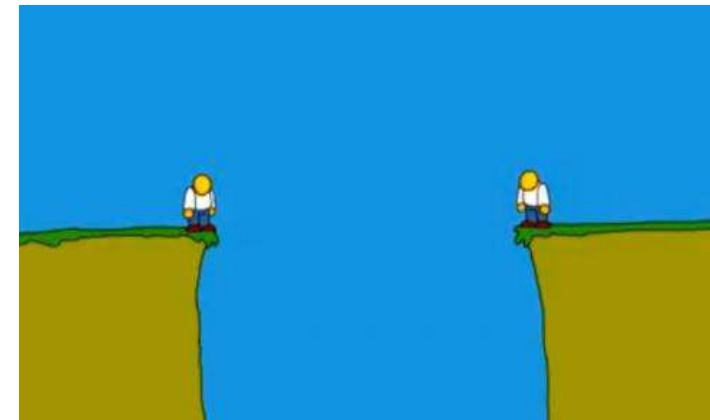
- Spiritual support valued but needs further testing
- Care co-ordination
- Signposting to other services
- Different care model



Literature & current policy: the gaps

CARE

- **Early identification** of palliative care needs ('streamlined assessment')
- **Holistic assessment** of pt and family. 'finding out what's most important to the person'. **Needs led.**
- Involving carers and voluntary organisations.
- 'The big conversation'
- **Extending the reach** to non-cancer groups i.e. heart failure
- **New care pathways:** 'novel service development', innovative care models', 'integrated care models', based on NICE guidelines and quality statements, partnerships e.g. cardiology and palliative care
- Preferred place of care/death.
- Need for **ACP**
- Need for **care co-ordinator**
- Co-production.
- Prudent healthcare.
- Need for **staff training** in end of life conversations



New RCT: different care model

- Holistic, ensuring the inclusion of spiritual support
- Needs led for patients and carers: using PROMS (in 4 domains) to assess need and guide care
- Co-ordination of care: PROMS feeding into monthly MDT meetings to ensure what's important to patients (in 4 domains) is top of the agenda. Signposting.
- Fidelity: ensuring we deliver what we are meant to



- The team:



HF nurses

Cardiologists

Palliative care teams

ACP team

GP palliative care leads

Marie Curie/Velindre/HOtV

British Heart Foundation

Patients/carers

Quality Improvement Team

Chaplaincy

Clinical Trials Unit

Stats, Health Economics

Study 5

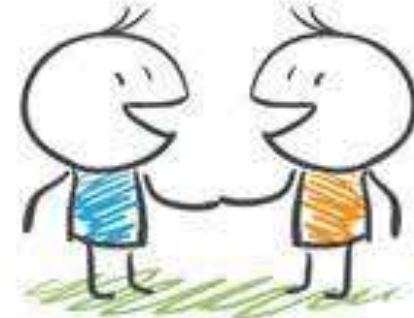
Does a PROMS based needs led care model incorporating Spiritual Support improve QOL of patients with heart failure and their carers?

Needs led care

Person centred care (patient and carer)

Co-production

Prudent healthcare



Training/education

‘Nursing and midwifery students’ perceptions of spirituality, spiritual care, and spiritual care competency: a prospective, longitudinal, correlational European study’

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