Clinical Effectiveness Bulletin for NHS Primary Care in North Staffordshire

Special Edition: *I didn't want that;* Palliative and End of Life Care



This is a collection of resources relating to the Palliative and End of Life Care Conference, held on Thursday 11th May at the Moat House, Stoke on Trent. This bulletin includes a number of frameworks, documents and videos which were discussed by the many inspirational speakers at the conference. It is not intended to be a definitive list, many fantastic resources were shared during the day, and there was not room to list them all here.

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Bulletin produced by NHS Outreach Librarians Tel: 01782 679564 or 0300 123 1535 ext/FeatureNet 8429 E-mail: <u>Sally.Thomas2@ssotp.nhs.uk</u> or <u>clareh.powell@northstaffs.nhs.uk</u>

> North Staffs Health Library Tel: 01782 679500 Fax: 01782 679582 E-mail: health.library@keele.ac.uk



Frameworks and Guidance

Treatment and care towards the end of life: good practice in decision making GMC

The GMC's guidance for meeting legal obligations, as well as meeting patients' needs and wishes.

http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_guidance.asp

Palliative and End of Life Care RCGP

In 2013, RCGP entered into a three year partnership with Marie Curie to improve the palliative and end of life care provided to patients by GPs. Resources include a Palliative and End of Life Care Toolkit, frameworks and guidelines.

http://www.rcgp.org.uk/clinical-and-research/clinical-resources/end-of-life-care-resources-forgps.aspx

Advanced Care Planning

Gold Standards Framework

Resources include forms for documenting end of life discussions and a video guide to advanced care planning in 5 simple steps.

http://www.goldstandardsframework.org.uk/advance-care-planning

The AMBER care bundle

Guy's and St Thomas' Hospital Trust

The AMBER care bundle is a simple approach used in hospitals when clinicians are uncertain whether a patient may recover, and are concerned that they may only have a few months left to live.

http://www.ambercarebundle.org/homepage.aspx

NICE Palliative care Clinical Knowledge Summary

Guidance covering general care, prognostication and communication. <u>https://cks.nice.org.uk/palliative-care-general-issues</u>

Getting it right every time. Fundamentals of Nursing Care at the end of life. Royal College of Nursing

A resource developed to assist nurses and health care assistants across all health care settings, caring for people in the last year of their life.

https://www.rcn.org.uk/professional-development/publications/pub-004871

Having the discussions, videos and plays

Homeward Bound-A play about relationships, love, empathy and compassion. NCPC

This play is designed to share the story of Lesley and Seth Goodburn (played by Brian Daniels and Sophie Turner). The play has been written to give people, especially health and social care professionals, the opportunity to reflect on the importance of compassionate person and family centred care at the end of life and to help individuals to understand how little things mean a lot to the person who is dying and to their family. http://www.ncpc.org.uk/homewardboundresource

Ain't the Way to Die Z Dogg MD

Z Dogg MD's unique take on the taboo around death and dying, and how this prevents carers and clinicians from providing patients with a good death. http://zdoggmd.com/aint-the-way-to-die/

'A Party for Kath' Dying Matters

'A Party for Kath' is an award-winning, five-minute film produced by the Dying Matters Coalition to demonstrate the benefits of greater openness around death and dying. <u>http://www.dyingmatters.org/page/party-kath</u>

Palliative care for LGBT communities

ACCESSCare for lesbian, gay, bisexual and trans people facing advanced illness and bereavement

King's College London

This project (2014-2016), led by Dr Richard Harding, and funded by Marie Curie, aimed to improve palliative care for people who identify as lesbian, gay, bisexual and/or trans (LGBT) and are in the later stages of a life-limiting illness. Links to a range of resources and research are available from the ACCESSCare webpage.

http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/living/access/index.aspx

Palliative & End-of-Life Care for LGBT People King's College London

A guide for lesbian, gay, bisexual and/or trans people facing advanced illness. https://pos-pal.org/h/file_pdf.php?f=LGBT_Resource-Online_Version.pdf

Improving Care- campaigners and carer's voices

Tommy on Tour Tommy Whitelaw

This website belongs to Tommy Whitelaw, whose mission is to raise awareness of dementia. His website contains some useful information, and his keynote speech to the RCN congress can be seen via the link below.

http://tommy-on-tour-2011.blogspot.co.uk/

https://www2.rcn.org.uk/newsevents/congress/2016/news/keynote-speech-from-tommywhitelaw

Hello My Name Is...

Dr Kate Granger started this campaign to improve care during her battle with terminal illness. Although she sadly passed away last year, her work lives on. <u>http://hellomynameis.org.uk/home</u>

Useful websites

The National Council for Palliative Care

http://www.ncpc.org.uk/

Macmillan

http://www.macmillan.org.uk/information-and-support/treating/treatment-decisions/questionsto-ask/questions-supportive-palliative-care.html

Social Care Institute for Excellence

http://www.scie-socialcareonline.org.uk/ http://www.scie.org.uk/

Dignity in Care

http://www.dignityincare.org.uk/