

RPU 119 December 2016

The theme of this month's Research and Policy Update is **End of Life (EoL) Care**. The research summaries provide a picture of the challenges and opportunities for Health and Social Care services that provide EoL care. The papers examine the following areas: incorporating an individual's social network in the approach to EoL care; prevention of unnecessary transitions to hospital at the end-of-life; the importance of an individual's spiritual and religious needs in EoL care; the approach of healthcare and homecare staff to EoL care for care home residents.

Specific knowledge and skills required of practitioners in EoL care feature across all of the summaries. There are also considerations in respect of integrated approaches and social capital.

Articles and Summaries

Towards a social model of end of life care (2014)

Brown L and Walter T, *British Journal of Social Work*, 44, 8, 2375-2390

Introduction: As the older UK population continues to grow the annual number of deaths is predicted to increase. This paper discusses the challenge presented to services responsible for end-of-life (EoL) care and examines increased use of community networks as part of an alternative model of EoL care.

Key words: Dying, social network, compassionate community, palliative care, mobilisation, informal care

Summary

A high number of people living in the UK die in hospital (approx. 60%), yet the majority would prefer to die at home (approx. 70%). Many are cared for at home in the period before a hospital death making it an important setting in EoL care. However, dying at home lead to individuals and their carers experiencing social isolation.

There is a role for social work in EoL care, especially as services are widened to include those who are dying without a terminal diagnosis. The social work profession has the opportunity to make valuable contributions to EoL care as new service models incorporate a social approach.

Models of EoL care

Palliative care is a comprehensive multi-disciplinary approach where holistic care for individuals with progressive illnesses (often, but not always at EoL) is provided by a team of professionals. The paper critiques the traditional model of palliative care, raising two key points. Firstly, it is unlikely that resources are available to widen this type of service to patients with a less certain end-of-life trajectory than terminally ill cancer patients. Secondly, care that is wholly provided by multi-professional teams carries the

message that EoL care is complex, requiring specialist skills which inadvertently disempowers patients and carers.

Palliative care replaces a medical model of EoL care with a holistic model, but one which is professionalised. A social model is relationship-based and requires the professional to empower the 'natural' networks of support for dying individuals and their carers.

The paper examines social networks and their mobilisation. There is evidence that successful implementation of 'network mobilisation' results in family members offering care and support and needing less input from practitioners. support of the individual. A network based model of support specific to EoL care has a particularly important role in normalising dying and supporting carers. There is evidence that when natural support networks are functioning in EoL care they can be explained as concentric circles; the resident carer supporting the individual, wider family supporting resident carer, neighbours and friends supporting the wider family, and professionals only being required for their expertise (usually medicine and nursing). In this model, the role of the professional is partially related to the delivery of specific services and partially to empower individuals to draw upon their natural networks.

A natural network's support capacity is not always clear and professionals need to estimate it carefully. For example, the likely timescale of a progressive illness and the care it entails may be a factor in the capacity of natural networks to provide support. Each individual's network needs to be assessed individually and networks should not be idealised. Overall, an EoL care model of natural networks with complementary professional provision is considered preferable to a model of provision that does not account for an individual's network at all.

Assessment of individual networks supports more targeted service provision, directing support towards those have limited networks or have exhausted their network's resources. There is more equity in this approach compared to a current situation; where those with greater social capital often have a better understanding of how to access professional services, receiving more than they identify as needing from a natural network model.

A number of recent examples of community network mobilisation in EoL care are discussed. The oldest project, Home Hospice in Sydney, Australia supports the individual and their main carer to mobilise their social network. Amongst the project outcomes, benefits to the carer are also highlighted, particularly reduced social isolation and the continuation of support for the carer after the death of the person they are caring for.

Challenges and opportunities for social work

Reciprocity is an element of social capital that raises questions in EoL care. It is unclear when or why friends or neighbours will continue to offer support individuals who cannot reciprocate, and so the practitioner will need to be flexible and responsive in their approach to assessment and care planning. Uncertainty in the trajectory of EoL care (for individuals without the kind of diagnosis and prognosis commonly associated

with cancer) requires more attention and research.

The notion that 'caring is a burden' is prevalent in the UK and may discourage carers from asking for support. Carers with primary responsibility may also view the co-ordination of their support network as burdensome and consider it as easier to do all of the caring themselves. It may be difficult for an individual without a main carer to co-ordinate their care from community networks.

Considering community networks as an innovation in social work, there are several potential reasons why it may not be effective. Service delivery itself presents a challenge, particularly ensuring that a service-led ethos does not creep back into community networks. Language is important; 'service-user' being a term that practitioners are very accustomed to using, but which also makes it more challenging to view people accessing services as individuals with a life outside services.

Informal networks of support can be unpredictable causing professionals to be scared of letting go of control. There is also uncertainty about whether the state can redefine the relationship between professionals, family and citizens or has a role in encouraging civil society.

The diversity of cultural approaches to care can make community mobilisation problematic. The paper gives examples of cultural attitudes and how they affect the approach to EoL care.

The skill set of practitioners is well suited and relevant to EoL care settings, but they could receive more training in how to mentor community network mobilisation.

A way forward

Professional interest in mobilising networks of support is moving in the same direction in both health and social care; making it an opportune time for practitioners to contribute their expertise and experience to discussion around EoL care that has to date been led by healthcare professionals. Individual champions in multi-disciplinary EoL care teams may be one way to promote specific issues, such as the enhancement of community networks.

Research into the role of networks of support in the community, residential and institutional settings is needed alongside the studies on professional EoL care.

Conclusion

There is potential in the social work profession to build and improve upon EoL care models developed in palliative care. Although not without its challenges, there are benefits to incorporating the strengths of families and communities in EoL support. Developing the potential of informal networks of support may contribute towards:

- Greater acceptance of dying
- More effective informal and professional support for family members
- Enablement of more individuals to exercise their choice to die at home

'Factors Associated with Transition from Community Settings to Hospital for Adults Aged 75 and Older: A Population-Based Mortality Follow-Back Survey (2016)

Bone AE et al. , *Journal of the American Geriatrics Society*

Introduction: A large study of the end-of-life (EoL) care of individuals aged 75 and over, looking specifically at the factors in transition from home to hospital as place of death. This paper identifies measures that services need to take to reduce transition from home to hospital for EoL care.

Key words: frail elderly, palliative care, terminal care, cross-sectional survey, mortality follow-back survey

Summary

In more developed countries, people aged 75 and over account for nearly two-thirds of all deaths, with patterns of disease and dying changing as populations age. Older people in ill health often have multiple conditions and frailty, adding complexity to the delivery of EoL care services. Development of appropriate EoL care policy and services entails understanding of how it is currently delivered.

Although the majority of older people wish to die at home, or usual place of care (often care homes), in developed countries the majority die in hospital. Transition to hospital for EoL care is challenging for individuals and their families, disrupting continuity of care and threatening care quality. Hospitalisation is also associated with a decline in physical and cognitive health in older people, which compromises safety and increases risk of mortality.

EoL care during inpatient hospital stays is a significant cost-driver and it is over-relied upon in wealthy countries. Improvements in specialist palliative care may have contributed to a reduction in the number of hospital deaths in the UK, but these improvements relate mainly to terminal cancer patients. Previous studies have not generally considered the effect of individual patients' and carers' concerns and preferences on EoL hospital transitions. This study examines a number of factors associated with transition to hospital for EoL care. It focusses upon environmental, individual and health factors in the last three months of life for people aged 75 and over.

Methodology and sample

The study method was population based and included two geographical areas (urban and rural) with a total population of over 1 million. The sample was drawn from the Office of National Statistics death registration data. Individuals' who registered a death that met the study criteria were surveyed about their decedent's EoL care.

The study sample consisted of 443 surveys completed by informants (the individuals who gave formal notification of death), most of whom were relatives of the decedent (usually child, spouse or partner). The split between respondents living in urban and rural areas was nearly equal (49.7% and 50.3% respectively).

The largest categories of decedents were women (59.1%), widowed (53.5%) and white (92.5%) and main underlying causes of death were:

- circulatory diseases
- respiratory conditions
- cancer
- dementia
- frailty

Frailty and dementia were a contributing cause of death in a significant number of cases.

Findings

Amongst the results of the survey, the study found that:

- Only 2% of the study sample reported that their decedent's wish was to die in hospital
- One-third of adults receiving EoL care died in hospital
- There was an apparent dependence on hospitals to provide EoL care for older people, particularly if they lived at home
- Nearly half the older people moved to hospital spent several weeks to a month there before dying
- Those with severe breathlessness, respiratory and circulatory disease were most likely to be transferred to hospital

Discussion

Breathlessness causes distress to individuals and their carers and there is a need for better care relating to breathlessness. Healthcare providers working in the community and specialising in breathlessness may reduce the number of transitions to hospital.

In respect of the study's limitations, it is noteworthy that appropriate and inappropriate hospital transitions were not distinguished from one another in analysis.

End-of-life trajectories are often hard to recognise and poorly anticipated in individuals with non-malignant respiratory conditions (such as Chronic Obstructive Pulmonary Disease), who are twice as likely to move to hospital at EoL as those with cancer.

The length of time between most individuals move to hospital and their death suggests that there is opportunity to anticipate the end-of-life and provide appropriate services, such as arrangement of palliative care or discussion of wishes.

Discussion of EoL care between the individual, health professional and key worker protects against transition to hospital. The key worker role has value in maintaining continuity of care in the community through timely access to services and better care coordination. Continuity is a crucial element of quality EoL care, particularly the continuity of the relationship between the individual and key healthcare professionals.

Professionals in EoL care also need to be more responsive to increased symptom distress and increase anticipatory planning. It is recommended that EoL care services place more emphasis on professionals' skills in coordinating care, communication, facilitating discussion and advanced care planning.

Spirituality and Religion in End-of-Life Care Ethics: The Challenge of Interfaith and Cross-Generational Matters (2015)

Nelson-Becker H et al., *The British Journal of Social Work*, 45, 1, 104-119

Introduction: *The importance of spirituality in end-of-life (EoL) care is increasingly recognised as populations age and diversity in spirituality grows. This paper expands upon the case studies it examines to inform recommendations regarding spiritual care.*

Key words: Social care, end-of-life ethics, spirituality, spiritual care, health care

Summary

The objective for individuals who are dying is to do so in a comfortable manner having had wishes their honoured. For some individuals spirituality is an important aspect of both quality of life and quality of death.

The role of religion is distinguished from spirituality. Religion is described as more organisationally orientated; relating to shared practices, beliefs and an ethical code that is conveyed over time.

Spiritual concerns are associated with a sense of connectedness, purpose, life meaning and transcendence of self and are central to some individual's experience of death. There is significant variation in the meaning of 'sacred' to individuals, partly due to the influence of culture and ethnicity as well as religion.

There is much variety and many dimensions to religion and spirituality, non-spiritual and secular views. Practitioners and healthcare workers need to remain open to the diversity and complexity of religion and spirituality in order to understand its role in EoL care.

Spirituality has been identified as an important factor in EoL care. There are models of care that include spirituality and suggest that integrating spirituality in care can promote healing beyond a medical response alone. For individuals making EoL decisions, spirituality has been identified as an important part of their care, with the sense of meaning and purpose it provides being associated with lower death anxiety, death avoidance and depression and greater subjective wellbeing.

Matters of spirituality are often not attended to in current medical systems. The paper draws the distinction between curing and healing; pointing out that curing is usually the focus of medical care, but where this is no longer possible, there may still be scope to heal. Social workers are in a good position to support healing, but like medical professionals, tend to be uncomfortable discussing religious and spiritual beliefs. This may result in missed opportunity to engage in a critical and component of care.

The paper discusses two clinical cases concerning spiritual care at the EoL. The first case examines religious

diversity in a cultural context and the potential for a cultural clash between the views of the health and social care professionals, family members and the patient. The second case explores the recognition and respect of a terminally ill child's spirituality, highlighting its importance to grieving family members and practitioners in the way they process cumulative trauma in work around end of life care.

Implications and conclusions

In the UK the diversity and the changing nature of spirituality and religious activity present a challenge when addressing related matters in a public field like social care.

Respect of the fundamental values of individuals and their families can be demonstrated by health and social care practitioners in systems that integrate spirituality and religion. The following are all identified as important considerations in EoL care: Opportunity to refer to spiritual leaders or clergy; therapeutic conversation with healthcare professionals; and for those who are not religious or spiritual, opportunity to explore existential beliefs.

Continuing changes in the population demographics place importance on practitioners' understanding of the ethnic and cultural influences in spirituality and religious belief. With reference to the first case study in the paper, the difference in value placed on autonomy is given as an example – although often central to the evaluation of ethical dilemmas in medicine, it may not be valued as highly as harmony in some cultures and religions. Customs relating to the end of life may also increase the quality of EoL care.

The second case study in the paper demonstrates the significance of a person-centred approach to practitioners' conversations about spirituality and religion. Being person-centred allows the practitioner to approach issues of spirituality and religion so that an individual can express their values, wishes, hopes and fears. The ethical principles underpinning person-centred approaches recognise the right of the individual to EoL care in accordance with their values and beliefs. Person-centred approaches redress professional-client power imbalances in EoL care which can give more weight to the professionals' views or opinions.

Awareness and responsiveness to the spiritual health of individuals can improve practitioners' understanding of their own attitudes towards the religion and spirituality. Seriously ill individuals value the opportunity to express their standpoint on spiritual matters. These conversations can inform practitioners' understanding of challenges facing individuals, such as the family dynamic in decision making.

Practitioners also need to develop self-awareness relating to the potential cumulative trauma of working with individuals at the end of life.

The paper identifies 11 specific steps that a practitioner can take to address spiritual needs in a health or social care setting:

1. Seek greater awareness of the individual's spiritual, religious or humanistic paradigms or attitudes
2. Ensure spiritual assessment occurs throughout the illness process
3. Determine the individual's EoL wishes in relation to religious and cultural beliefs
4. Develop knowledge and understanding about cultural and multi-faith traditions for health and EoL

care

5. Explore resources and coping strategies that relate to the individual's spirituality
6. Be compassionate
7. If required, help the individual connect with their religious community or refer to religious care services (such as chaplaincy)
8. Develop multi-disciplinary policies and procedures for spiritual care
9. Promote the establishment of broadly defined healing spaces in health care settings
10. Where there is decision-making conflict amongst family members provide support and offer to facilitate meetings
11. Remain aware of cumulative trauma of this kind of healthcare work and build and maintain emotional resilience

Health and social care practitioners can play a key role in support of the spiritual and religious choices that individuals make. Both patients and professionals gain benefit from improved spiritual environments in health and social care; particularly to ensure that individuals' lives are as fulfilled as possible at the end of life.

Living and dying: responsibility for end-of-life care in care homes without on-site nursing provision – a prospective study (2014)

Handley M et al., *Health and social Care in the Community* 22, 1, 22-29

Introduction: Most care homes for older people rely on primary healthcare for nursing, medical services and access to specialist services. Provision of these services is not co-ordinated, but individually negotiated and context specific. This paper examines end-of-life (EoL) care planning in relation to the characteristics of residents and the way care home and healthcare staff interpreted their responsibilities.

Key words: advance care planning, care home staff, district nurses, dying, end-of-life care, General Practitioners, residential care homes

Summary

Age and frailty are factors in the limited life expectancy of care home residents.

The potential value of a structured approach to EoL care planning has been identified in research and practice; in relation to a reduction in unplanned hospital admissions and staff confidence in delivering EoL care. There is less understanding of the way changes in health and other events affect the discussion about EoL care between residents, family and health and care professionals.

Method

Interviews were carried out with care home staff, district nurses, and GPs along with a mixed-method study of local health services and 6 care homes (in East England). Residents were tracked cross 1 year, reviewing

their care notes and medical records at 4 time points during the 12 month period. Where a resident died during the study period, additional data relating to the last 4 weeks of their life was gathered focussing on care, use of primary care and hospital admissions.

Findings

The mixture of provision and access to residential care was reflected in the study, with three homes in private ownership and three being provided not-for-profit organisations. One of the homes had completed accreditation as a Gold Standard Framework (GSF) provider which included training and integration of practices that related to EoL care.

Four care homes were visited by district nurses attached to GP services, with the remaining two visited by district nurse teams that had designated responsibilities for care homes.

74.4% of residents remained in the study for its duration. Reasons for not remaining included 23 deaths. Dementia was the most common health problem amongst residents and just under half of the care home records indicated co-morbidities.

A comparison of the data for residents living at the end of the study and those that had died showed no significant difference in age or time spent in residential care.

4 general trajectories of dying were identified:

- Anticipated dying with EoL care planning
- Unexpected dying due to acute illness or sudden death
- Uncertain death (difficult symptom management or uncertainty around diagnosis) leading to hospital admission and death in hospital
- Unpredicted death (acute conditions) leading to hospital admission and death in hospital

Care home and primary healthcare staff found it difficult to determine whether a resident was near death or not if they did not have a terminal health condition. Where death was classified as uncertain there were multiple visits from the GP, with residents presenting diverse, non-specific symptoms. Care home and primary healthcare staff tended to only see these residents as approaching the end-of-life with hindsight.

The importance of initiating discussions about EoL care was recognised by all of the professional interviewees. Two recurring themes were identified in this area: 'talking about dying' and 'integrating living and dying'.

Approaches to discussing EoL care differed across the care homes. Care home staff in all six homes expressed uncertainties about how to have conversations about dying. There was an expectation amongst care assistants that family members or other professionals would lead the conversations. All of the professionals interviewed showed a lack of clarity in their understanding about who should initiate EoL conversations and who should be involved. Another finding was specific to the role of relatives in conversations about dying; even when there was advanced care planning in place, if the family had not

been involved in the EoL discussion, clinicians sometimes felt pressured by them to act differently to the plan.

In terms of an integrated approach to living and dying, the need for EoL care was not always recognised. Even where signs of deterioration were noted within a care home (individual seeming to have ‘given up’ or being ‘off their feet’) this was not always shared with a healthcare professional. Care staff in the GSF home had a better understanding of the end stages of life, but also reported that there were times when it was difficult to recognise that someone was dying. Once it was recognised, the approaches to EoL care did not provide opportunity for the advanced planning to be proactive.

Discussion

Frontline staff in health and care value each other’s roles and can articulate what good EoL care looks like, however there are difficulties in providing proactive care. Challenges identified include:

- Recognising who has responsibility for discussing EoL care
- Taking an integrated approach to recognising deterioration in health
- Working with GPs and district nurses to review health and identify opportunities to discuss deterioration and advanced care planning

The value of collaboration between professional disciplines is important in the following areas:

- Planning that reflects an understanding of the pathways to dying and the older person’s experience
- How residents and families can be involved in EoL planning over time

Even the GSF home (where advanced care planning took place) did not discuss the plan with residents and their families. It was only put in place when it was recognised that an individual was dying. However, this did ensure more planned support from primary healthcare, more opportunity for care home staff’s reflection and more palliative care input.

Although primary healthcare professionals value the knowledge of care home staff they also had an expectation that they would lead on decision making relating to EoL care. There was no discussion about how to work collaboratively, even where concerns were identified about healthcare services’ capacity to provide ongoing support.

Conclusion

It is important for social care practitioners to recognise that there is significant uncertainty about EoL care for individuals in care homes without on-site nursing provision, particularly:

- How and when EoL is discussed
- How to recognise that an individual is dying when they do not have a terminal illness
- How care and treatment is negotiated

Where EoL planning is carried out it is often limited to the last days of life and does not appear to involve



engagement with the individual who is dying.

To better understand its impact on end of life care, there is a need for the everyday patterns and processes of work between care homes and primary health to be examined more closely.

Relevant RiPFA resources

[**Making an outcomes approach work in practice: Key Issue \(2014\)**](#)

[**Good assessment: Practitioners' Handbook \(2014\)**](#)

[**Supporting good assessment: Practice Tool \(2014\)**](#)

[**Good decision making: Practitioners' Handbook \(2013\)**](#)

[**Achieving outcomes through integrated working: Strategic Briefing \(2015\)**](#)

[**Enabling social care to thrive in an integrated environment: Leaders' Briefing \(2016\)**](#)

News and Parliamentary Business

Department of Health: Plan to reduce health and care red tape burden

Keywords: health and social care regulation; regulatory activity; performance information; burden reduction

Lord Prior, Minister for Health, is setting up a panel to review the burdens and benefits of current regulatory activity around health and social care. The Burden Reduction Challenge Panel will work with working in conjunction with NHS Providers, NHS Confederation, Care England and utilise evidence from health professionals to make their judgements. Any activity which they feel represents unnecessary regulatory burden on front line staff will be either amended or removed with the aim of increasing focus on patient contact and care.

<https://www.gov.uk/government/news/plan-to-reduce-health-and-care-red-tape-burden>

NatCen: Attitudes to dementia Findings from the 2015 British Social Attitudes survey

Keywords: dementia; public awareness; social attitudes; research

The 2015 British Social Attitudes Survey contained a section on attitudes towards dementia. The findings indicate that whilst many people have known someone with dementia and appear to be aware of the symptoms there is less awareness of the risk factors associated with the condition. Evidence of stigma surrounding dementia was also found.

<http://www.bsa.natcen.ac.uk/media/39130/bsa-33-attitudes-to-dementia.pdf>

Government Actuary's Department (GAD): A Cohort Approach to Social Care Funding

Keywords: social care; funding; social economics

In this paper the GAD discusses the extent to which each of the generations or cohorts within society might be able to fund their own social care needs when these arise. They propose that different solutions to issues of social care funding are required for each cohort. "a cohort approach to social care funding".

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/553405/Cohort_approach_per.pdf

Cabinet Office: Community resilience framework for practitioners

Keywords: communityresilience; emergency planning; disaster recovery

This guidance issued by the Cabinet office aims to promote communities which are resilient to emergencies or disasters. Looking at how to promote and support resilience in terms of communities, the businesses and individuals within them it outlines steps to increase resilience. Whilst not specifically aimed at support

for those in receipt of social care or health the document is still relevant in terms of creating communities which can support everyone within them during times of crisis – and social care and health organisations have a definite part to play.

<https://www.gov.uk/government/publications/community-resilience-framework-for-practitioners>

Department of Communities and Local Government: Homelessness Reduction Private Members Bill

Keywords: homelessness; rough sleeping; housing; legislation; prevention

The Bill aims to “significantly reform England’s homelessness legislation, ensuring that more people get the help they need to prevent them from becoming homeless in the first place”. It proposes a change to [Part 7 of the Housing Act 1996](#) by placing duties on local authorities to use early intervention strategies to prevent people becoming homeless and provide homelessness services to all those affected. It follows a commitment made by government in early October 2016 to a £40 million homelessness prevention programme.

<http://services.parliament.uk/bills/2016-17/homelessnessreduction.html>

Home Office: Action Against Hate The UK Government’s plan for tackling hate crime

Keywords: hate crime; discrimination; bullying; abuse; safeguarding; prejudice

The document sets out the government action plan for addressing hate crime to May 2020. It covers all areas of potential hate crime including that directed at anyone with a disability including physical disability, learning disability or mental health problems.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/543679/Action_Against_Hate_-_UK_Government_s_Plan_to_Tackle_Hate_Crime_2016.pdf

Public Administration and Constitutional Affairs Committee (PACAC): Follow-up to PHSO report on unsafe discharge from hospital Fifth Report of Session 2016–17

Keywords: Hospital discharge; delayed discharge; social care needs; community care

This House of Commons Select Committee report presents the findings of an inquiry by the PACAC into unsafe hospital discharge which was triggered by the initial report from the Parliamentary and Health Service Ombudsman (PHSO). The PACAC findings suggest that failures highlighted by PHSO are more widely experienced rather than isolated occurrences. They concluded that best practice guidance is not being implemented consistently around the country, and identify the key barriers as “pressures on resources and capacity” and “a lack of integration”.



<http://www.publications.parliament.uk/pa/cm201617/cmselect/cmpubadm/97/97.pdf>

Department of Health: Accelerate Access Review - Final Report Review of innovative medicines and medical technologies

Keywords: improvement; care; transformation; health; NHS

This independently chaired review was charged with identifying ways of facilitating patient access to the best possible medicines and medical technologies available. Undertaken over the last two years and taking account of the views of over 600 people and organisations the recommendations shape “an ambitious framework” for transformation.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/562101/AAR_final_report_A.pdf

Consultations, Reports and Reviews

Care Quality Commission (CQC): State of Health Care and Adult Social Care in England Report 2015/16

Keywords: social care; regulation; quality; performance; commissioning; funding

CQC has released its annual report into the state of health and social care in England. The report finds that “despite increasingly challenging circumstances, much good care is being delivered and encouraging levels of improvement are taking place.” It does question how sustainable this position is however and identifies evidence of reduction in quality reporting the fragility of the care market having an impact on people in receipt of care; providers struggling to improve their rating beyond ‘requires improvement’; and warns of the approach of a potential ‘tipping point’.

<https://www.gov.uk/government/publications/accelerated-access-review-final-report>

You can view the Association of Directors of Social Services (ADASS) response to this report here

<https://www.adass.org.uk/adass-responds-to-cqc-state-of-care-report/>

Public Health England: Dying with dementia

Keywords: dementia; end of life care; palliative care

Several resources have been jointly produced by the Dementia Intelligence Network (DIN) and with the National End of Life Care Intelligence Network (NEoLCIN). These analyse national data on deaths of people with dementia in 2012-14 with a view to understanding who dies with dementia, where people with dementia die, what they die of and whether this has changed over time. The aim of the resource is to provide robust information to support the development and delivery of high-quality end of life care for people with dementia.

<http://www.yhpho.org.uk/resource/view.aspx?RID=237877>

University College London: Inequalities In Mental Health, Cognitive Impairment And Dementia Among Older People

Keywords: mental health; dementia; cognitive impairment; older people

This report looks at the prevalence of poor mental health, the onset of cognitive impairments and dementia across the population of England and the factors which can exacerbate this. The conclusion being that there is a disproportionality high likelihood of developing one of these issues for those lower socio-economic groups. It presents a short precis of social determinates relating to increased risk of poor mental health, the onset of cognitive impairments and dementia looking at how developing ‘cognitive reserve’ can help delay onset of these conditions and/or support people to cope better with them should they occur.

<https://www.instituteofhealthequity.org/projects/inequalities-in-mental-health-cognitive-impairment-and-dementia-among-older-people/inequalities-in-mental-health-cognitive-impairment-and-dementia-among-older-people.pdf>

British Medical Association (BMA): Growing Older in the UK

Keywords: aging; health and wellbeing; older people; later life

This paper, part of series of briefings by the BMA, looks at the pressures on health services in the UK. It focuses on supporting the needs of an increasingly aging population who are more likely to develop multiple long term conditions.

<https://www.bma.org.uk/-/media/files/pdfs/collective%20voice/policy%20research/public%20and%20population%20health/background-and-introduction-final.pdf>

International Longevity Centre – UK (ILC-UK): Still not ready for aging?

Keywords: adult social care; public policy; funding; aging

The ILC has published this the 2016 manifesto of the Ready for Aging Alliance (members are Age UK, Alzheimer’s Society, Anchor, Carers UK, Centre for Policy on Ageing, Independent Age, Joseph Rowntree Foundation and ILC-UK). The document focuses on the challenges facing the UK as the proportion of people in society living longer increases. Key areas identified include demographic change; the social care funding gap; health and social care workforce shortages; levels of personal savings / pensions; housing; employment of older people; loneliness and isolation. The alliance calls for the government to take urgent action to address these.

http://www.ilcuk.org.uk/images/uploads/publication-pdfs/Still_not_ready_for_ageing.pdf

Age UK: Hidden in plain sight – The unmet mental health needs of older people

Keywords: mental health; older people; later life; comorbidity

Findings from this work done by Age UK suggest inequalities exist around the treatment of older people with mental health needs, particularly those who also have physical health needs.

http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Policy/health-and-wellbeing/Hidden_in_plain_sight_older_peoples_mental_health.pdf?dtrk=true&utm_source=The%20King%27s%20Fund%20newsletters&utm_medium=email&utm_campaign=7626347_NEWSL_HMP%202016-10-14&dm_i=21A8,4|GIZ,NB3Z11,GTX7Y,1

Social Enterprise UK: The Social Value Difference in Health and Care Commissioning

Keywords: social value; social care; health; commissioning; wellbeing; prevention

This report presents evidence of the impact that commissioning for social value can make to the general health and wellbeing of communities. It shares learning from twelve local areas demonstrating how to make the most of social value.

http://socialenterprise.org.uk/uploads/editor/files/Publications/SocialValueDifference_Health_SEUK2016final.pdf?utm_source=The%20King%27s%20Fund%20newsletters&utm_medium=email&utm_campaign=7648874_NEWSL_HMP%202016-10-21&dm_i=21A8,4|XWQ,NB3Z11,GWA1P,1

Skills for Care (SfC): The state of the adult social care sector and workforce in England

Keywords: workforce; statistics; workforce planning; workforce development

SfC have published their annual report analysing data collected via the National Minimum Dataset for Social Care (NMDS-SC).

<https://www.nmds-sc-online.org.uk/Get.aspx?id=980099>

King's College London: Social work research with adults – The state we're in

Keywords: research; social care; older people

A discussion paper from King's College looking at the current position in terms of adult social care research. The key recommendation calls for clear identification of research priorities in this area to establish what needs to be done but also work to assure capacity; resources; engagement; dissemination and leadership.

<http://www.kcl.ac.uk/sspp/policy-institute/publications/Social-work-research-with-adults-in-England---the-state-were-in.pdf>

Carers UK: Pressure Points – Carers and the NHS

Keywords: Carers; caring; emergency; health and wellbeing; NHS

Findings from research commissioned by Carers UK suggest that difficulties accessing primary and community care is resulting in carers resorting to taking their loved one to accident and emergency. Recommendations to alleviate the pressures include a call for increased social care funding.

http://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=5766

British Association of Social Workers (BASW): Report on the findings of the BASW England survey on members' experiences of implementation of the Care Act

Keywords: Care Act 2014; implementation; transformation; adult social care

BASW has published the results of a survey their member requesting their views on the impact of implementation of the Care Act 2014. 95 people responded and the views suggest that whilst they feel the Act is helping to improve practice, especially in terms of making safeguarding personal, and to ensure people's needs are met. However, in relation to promoting wellbeing and prevention "support was limited by lack of resource".

http://cdn.basw.co.uk/upload/basw_92637-9.pdf

The King's Fund: Policy changes to implement the NHS five year forward view: a progress report

Keywords: NHS transformation; five year forward view; health; social care

The King's Fund have undertaken a review of implementation of the NHS Five Year Forward View looking at what has been achieved and what is still to do. They conclude that progress is mixed with lack of funding to support change being a key concern.

<https://www.kingsfund.org.uk/projects/five-year-forward-view-progress-report>

Local Government Association (LGA): Efficiency opportunities through health and social care integration Delivering more sustainable health and care

Keywords: health; social care; transformation; integration; funding; efficiencies

LGA in conjunction with Newton's Europe and local authorities have undertake a piece of work to assess the potential for efficiency savings offered by improved integration with health. Key messages focus on using the right care pathways; consistent decision making; maximising avoidable admissions; effective discharge planning and strong presentation.

https://www.newtoneurope.info/lga/downloads/Productivity-and-commissioning-LGA-Efficiency-opportunities-through-integration.pdf?utm_source=The%20King%27s%20Fund%20newsletters&utm_medium=email&utm_campaign=7668849_NEWSL_HMP%202016-10-28&dm_i=21A8,4KDBL,NB3Z11,GZ0U6,1

United Kingdom Home Care Association (UKHCA): The Homecare Deficit 2016 - A report on the funding of older people's homecare across the United Kingdom

Keywords: care provision; funding; homecare; commissioning; workforce remuneration

This is the second annual report by the UKHCA analysing the price paid for home care across the UK. The recommendations include a call for commissioners to review prices paid; consider rates which reflect running costs and support at least National Minimum Wage; better ensure contracts are sustainable and can deliver quality services.

http://www.ukhca.co.uk/pdfs/ukhca_homecare_deficit_2016_final.pdf

The King's Fund: New care models Emerging innovations in governance and organisational form

Keywords: health; social care; integration; transformation; innovation

This King's Fund report looks at learning from development of new models of care at 23 vanguard sites. Many of the key messages centre on budgets and the potential that drawing together different funding stream might have. Integration of health and social care features strongly as an aspiration but one which has seen only a small amount of progress.

https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/New_care_models_Kings_Fund_Oct_2016.pdf

Health and Care Professions Council (HCPC): Consultations

Keywords: social media; confidentiality; continuing professional development; registration;

HCPC has launched consultations in relation to guidance on the following three topics:

- social media – new
- continual professional development (CPD) – revised
- confidentiality – revised

Closing date for all three consultations is Friday 13th January 2017.

Social Media - <http://www.hcpc-uk.org/aboutus/consultations/index.asp?id=221>

CPD - <http://www.hcpc-uk.org/aboutus/consultations/index.asp?id=218>

Confidentiality - <http://www.hcpcuk.org/aboutus/consultations/index.asp?id=222>

Work and Health Green Paper: Consultation

Key words: work, health, disability, employment, equality, wellbeing, outcomes

On 31 October 2016 The Department of Work and Pensions and the Department of Health launched a Green Paper and consultation to help more disabled people and those with long term conditions, into work.

Proposals include:

- a review of Statutory Sick Pay and GP fit notes to support workers back into their jobs faster and for longer;
- encouraging Jobcentre Plus work coaches to signpost claimants to therapy;
- the launch of a consultation on Work Capability Assessment reform;
- encouraging employers to work with their employees with long-term health conditions to stop them from falling out of work; and
- a wide-ranging debate about recognising the value of work as a health outcome.

Please take part in the consultation using this link, and encourage others to too.

[Work, health and disability: improving lives](#)

The consultation runs from 31 October 2016 to 17 February 2017.

Structures, Initiatives and Guidance

NHS England: Enhanced Health in Care Homes (EHCH) Framework

Keywords: residential care; nursing care; health; wellbeing; care homes; integration

This framework produced by NHS England is the result of ongoing work by six vanguards within the EHCH programme of the NHS Five Year Forward View. The six sites are spread across the country and local authorities, social care partners and the NHS have worked together to improve health outcomes, reduce unplanned or unnecessary hospital admissions and medication management. The aim is for the framework to be adopted across England. A self-assessment framework document is due to be issued later in 2016 to support evaluation of implementation.

<https://www.england.nhs.uk/wp-content/uploads/2016/09/ehch-framework-v2.pdf>

Department of Health: Care and support statutory guidance

Keywords: social care; Care Act 2014; statutory guidance; care and support

The Department of Health has issued a revised version of the statutory guidance relating to the Care Act 2014. Changes have been made to Chapters 2; 6; 8; 9; 18; 23 and Annex C.

The full updated guidance which supersedes that published in March 2016 can be accessed here

<https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

In Control: Innovations in Dementia

Keywords: dementia; commissioning; community capacity; service development; support

Sponsored by Alternative Futures Group this e-book is aimed at those developing person-centred dementia support services in the community. It also looks at support which, whilst not specifically designed for people with dementia, has the potential to be applicable if adapted. The publication contains examples of initiatives from around the country and includes contact details for those implementing the approaches that are willing to share their experiences in more detail.

<http://www.in-control.org.uk/news/in-control-news/innovations-in-dementia.aspx>

Home Office: Modern Slavery – Duty to Notify

Keywords: modern slavery; human trafficking; abuse; safeguarding

Promotional material, posters / factsheet, explaining the ‘duty to notify’ the Home Office of suspected cases of modern slavery as set out in the Modern Slavery Act 2015. The process and forms to use for notification are also explained.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/560826/6.2286_HO_LL_factsheet_duty_to_notify_copy_V3.pdf

Local Government Association (LGA): Don’t be left in the dark – what is social care?

Keywords: public information; adult social care; Care Act 2014; entitlements; eligibility

Document aimed at the general public and users of social care explaining what social care is and what to expect in terms of assessment and eligibility. The document also explains the differences between social care and health as well as looking at social care funding and the challenges being faced by Local Authorities.

http://www.local.gov.uk/web/guest/publications/-/journal_content/56/10180/8012064/PUBLICATION

Local Government Association (LGA): Helping people look after themselves – A guide on self-care

Keywords: health and social care; self-care; support; choice; control; public health

This guidance produced by the LGA looks to explain what self-care is, what the potential benefits are and the role that Local Authority Public Health functions play in supporting people to self-care more effectively. Several case studies outlining innovative programmes from around England are included.

http://www.local.gov.uk/web/guest/publications/-/journal_content/56/10180/8009922/PUBLICATION

Local Government Association (LGA): Health in all policies (HiAP) – A manual for local government

Keywords: public health; partnership working; policy development

HiAP is an approach whereby considering the health implications of all aspects of a council's policies and decisions becomes established practice. This document presents the arguments for this approach and makes suggestions as to how it can be implemented locally.

http://www.local.gov.uk/web/guest/publications/-/journal_content/56/10180/7970816/PUBLICATION

NHS England: Quick Guide - Discharge to Assess

Keywords: Hospital discharge; delayed discharge; social care needs; community care

This guide has been jointly produced by NHS England, the Association of Directors of Adult Social Services (ADASS), Care Provider Alliance, Department of Health, NHS Improvement, Local Government Association (LGA), NHS Emergency Care Improvement Programme, and Housing LIN. It presents examples of how services can work together to minimise the amount of time a person spends in hospital whilst ensuring they have appropriate support to return home safely.

<http://www.nhs.uk/NHSEngland/keogh-review/Documents/quick-guides/QuickGuide-discharge-to-access.pdf>

Improvement Hub Scotland (ihub): Personal Outcomes

Keywords: outcomes; personalisation; adult social care; Scotland

Ihub is a dedicated resource to drive improvement in health and social care in Scotland. Recently added to the site is a series of resources which focus on personal outcomes. Developed in-conjunction with local councils, academics and funded by the Economic and Social Research Council (ESRC) the resources present learning from the Meaningful and Measurable project which looked at the quality and relevance / usability of personal outcomes information collected during conversations.

<http://ihub.scot/a-z-programmes/personal-outcomes/>

National Voices: Involving patients and citizens: I Statements for research and innovation

Keywords: innovation; research; engagement; public involvement

National Voices have produced this guidance on involving patients and the public in research as part of the Accelerated Access Review project. Whilst primarily aimed at research being undertaken in the NHS the principles are transferable to social care research.



http://www.nationalvoices.org.uk/sites/default/files/public/publications/involving_patients_and_service_users_-_i_statements_for_research_and_innovation_oct_2016_0.pdf?utm_source=The%20King%27s%20Fund%20newsletters&utm_medium=email&utm_campaign=7668849_NEWSL_HMP%202016-10-28&dm_i=21A8,4KDBL,NB3Z11,GXY17,1

Skills for Care (SfC): Toolkit - Recruiting for values and behaviours in social care

Keywords: recruitment; retention; values; social work; social care; workforce

SfC have produce a toolkit designed to support employers recruit staff with the right values and behaviours to deliver quality social care services.

http://www.skillsforcare.org.uk/Recruitment-retention/Values-based-recruitment-and-retention/Recruiting-for-values-and-behaviours-in-social-care.aspx?utm_source=The%20King%27s%20Fund%20newsletters&utm_medium=email&utm_campaign=7658427_NEWSL_HMP%202016-10-25&dm_i=21A8,4K5A3,NB3Z11,GXALZ,1

British Institute of Human Rights (BIHR): Mental Health, Mental Capacity and Human Rights – A practitioner’s guide

Keywords: Mental Health; mental capacity; human rights; legislation

This resource, aimed at practitioners, looks at the human rights perspective when supporting people with mental health and/or mental capacity issues. It is the first of eight booklets on this topic.

<https://www.bihr.org.uk/connecting-human-rights-to-the-frontline-resources>

Public Health England (PHE): Integrating home adaptations for better health and wellbeing outcomes

Keywords: adaptations; occupational therapy; disabled facilities grant; DFG; integration; better care fund

PHE have produced several briefings on the use of home adaptations to improve health and wellbeing. These include providing guidance on changes to funding for home adaptations including how these can be delivered via integration as well as links to the Care Act 2014.

https://www.gov.uk/government/publications/integrating-home-adaptations-for-better-health-and-wellbeing-outcomes?utm_source=The%20King%27s%20Fund%20newsletters&utm_medium=email&utm_campaign=7578481_NEWSL_HWB%202016-10-10&dm_i=21A8,4IFLD,NB3Z11,GOU35,1