Abstracts

P-27 THE LIFE STORY PROJECT: A REPARATIVE PROCESS
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10.1136/bmjspcare-2017-hospice.54

Life story work with people approaching end of life offers more than an opportunity to record a person’s history: it offers time to reflect, make sense, and reframe. Supported by a life story volunteer, loss and change are acknowledged and often remain central to their narrative. Yet the focus is on people’s lives, who they are, and what they have achieved. People articulate what is most important to them; their life is celebrated. It is a reparative process: people create and share their legacy looking to the past, the present and the future. The project has created a lasting, audible and visual archive of the patient’s life providing thoughts and memories for families to share. This presentation will draw on the literature and evidence base of narrative medicine. It describes the hospice Life Story pilot, people’s experience, and what we have learned from participants and our evaluation. We will illustrate this with vignettes, and how the project is being rolled out in the county. We will conclude with methodological and practice development opportunities, and key research questions.

P-29 DE WE PREPARE OUR PATIENTS FOR THEIR DIGITAL LEGACY?
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10.1136/bmjspcare-2017-hospice.56

Background Digital legacy is the digital content that we leave after death. Social media is becoming a more prominent part of our everyday lives. A recent report found that 94% digital consumers, aged 16–64, have at least one social media account, with one in every three minutes online devoted to social networking (GWI Social, 2017). It has been predicted that by 2098 Facebook could be the biggest virtual graveyard (The Telegraph, 2016). It is a forum where palliative care is prominent with 685 500 tweets in a two-year period relating to palliative care, from both health care professionals and the general public. (Nwosu et al, 2015). It has been seen as beneficial for a specialist palliative care team to gain insight to how a patient is feeling through their blog (Lowney & O’Brien, 2012). Dr. Kate Granger used social media to document her journey, which has given a unique insight of a doctor living with a terminal illness (Granger, 2014). However, use of social media can also have negative consequences; a father felt his son’s dying process had been violated by friends setting up a Facebook page to raise money for his children’s future school fees (Smith, 2011). The Digital Legacy Association – https://digitallegacyassociation.org/ – has produced a public awareness leaflet to help drive the importance of digital legacy forward, but as health care professionals do we assist this?

Question How well do we as palliative care professionals prepare patients for their digital legacy?

Methods An online questionnaire will be sent to doctors, nurses and social workers working at hospices within the West Midlands which they are asked to complete and submit within six weeks. The questionnaire asks about: their own use of social media; if they have thought about their own digital legacy and how a patient is feeling through their blog (Lowney & O’Brien, 2012). Dr. Kate Granger used social media to document her journey, which has given a unique insight of a doctor living with a terminal illness (Granger, 2014). However, use of social media can also have negative consequences; a father felt his son’s dying process had been violated by friends setting up a Facebook page to raise money for his children’s future school fees (Smith, 2011). The Digital Legacy Association – https://digitallegacyassociation.org/ – has produced a public awareness leaflet to help drive the importance of digital legacy forward, but as health care professionals do we assist this?

Results The results are pending and will be complete by August 2017.

P-28 THE ART OF DYING WELL
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The Catholic Church in England and Wales has brought the medieval manuscript Ars Moriendi – The Art of Dying – into the digital age, with a website – www.artofdyingwell.org – aimed at helping terminally ill people and their loved ones deal with death. Like the original 15th century work, The Art of Dying Well is intended to bring spiritual comfort and to offer practical guidance to people in the final stage of life. The modern – day version offers videos, animations and interviews with terminally ill people and their carers.

Who is it for?

• People who are dying
• People with a friend or relative who is dying/has died
• People who care for the dying in a professional context
• People who are surviving death, or battling a life threatening disease

The national conversation around death As well as developing the Art of Dying Well website and engaging in the digital conversation around death, the Art of Dying Well initiative is taking part in the national conversation around death and helping to raise ‘literacy levels’ on the topic of dying well and appreciation of spiritual care in the process. To date, the Art of Dying Well has and continues to receive significant coverage in the Guardian, Times, LBC radio, BBC News, BBC Five Live, BBC Radio 2, Vatican Radio, and the Catholic press.

What People Say ’It speaks powerfully into this awkward, immature silence around death. And I believe it has the potential to alleviate much suffering. I’ve seen it used with clinicians, families and patients. And I have seen it be a powerful help.’ Jim McManus, Director of Public Health, Hertfordshire County Council.

P-30 CHANGING ATTITUDES AND BEHAVIOURS TOWARDS DIGITAL LEGACY AND DIGITAL ASSETS
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10.1136/bmjspcare-2017-hospice.57

Background The Internet is the biggest and most ‘disruptive’ force since the industrial revolution. As a result, society is spending an ever increasing amount of time online. This has led to a range of benefits whilst changing the way in which society prepares for death, mourns and remembers the deceased into posterity. Each year the Digital Legacy Association carry out the Digital Death Survey.

Aims The aim of the Digital Death Survey is to explore society’s attitudes towards death and dying in today’s digital world. Asking questions through such a survey and openly publishing the results helps evoke discussions around ‘digital death’ and the implications not planning for death digitally
SAFEGUARDING FOR A DIGITAL SERVICE: THE SUE RYDER ONLINE COMMUNITY

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10.1136/bmjspcare-2017-hospice.58

Background The Sue Ryder Online Community is an online peer support service where people affected by terminal illness or bereavement exchange messages and support each other. The site is moderated to keep it safe and supportive. Because of the difficult subject matter, individuals may occasionally post about suicidal thoughts and feelings, and it is necessary to have a robust process for responding.

Aims To ensure that individuals considered at risk are supported and signposted to appropriate services, and that our approach is consistent.

Methods A decision flow chart helps moderators assess the level of risk and give an easy-to-follow process. Template responses and lists of signposting resources are used by moderators to support individuals and encourage them to seek specialist help – these are adapted and personalised in each case. Issues where an individual is considered at-risk are escalated to senior health and social care staff. Following assessment, in a very high-risk case, we consider, on a risk-based approach whether to break confidentiality and contact emergency services. These methods are in line with the best practice guidelines from the National Suicide Prevention Alliance.

Results In 2016/17, five issues required escalation, equivalent to 0.1% of posts. One of these individuals later confirmed they had got support from family members and the Samaritans.

Moderator Feedback ‘This process makes me feel much more confident. I know that if I spot something worrisome, I don’t need to panic – it’s a simple process, and I won’t be dealing with it on my own.’

Conclusion The safeguarding process appears effective, but we will be able to draw more conclusions in future, when there have been a greater number of issues escalated. We will review the process annually and review individual cases after three months.

DEVELOPING AN INNOVATIVE HOSPICE APP

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10.1136/bmjspcare-2017-hospice.59

Background Royal Trinity Hospice supports around 2500 patients a year, 80% of whom live in the community. Feedback from patients and carers was that it was difficult to get to grips with changing symptoms and medications, and to understand the support available at the hospice, particularly in the early days after being referred.

Aims The Royal Trinity Hospice app is designed to provide patients and carers living at home with the support and information they need, in a timely and accessible way.

Methods The content of the app was developed through collaboration between a multi-disciplinary team of staff at the hospice incorporating feedback from patients and carers. The app includes:

- Easy to understand information on medications and common symptoms.
- Advance care planning prompts which can be shared via email with relatives or hospice staff.
- A function to manage attendance at hospice outpatient groups and contact key hospice teams directly.
- Bereavement content for carers.

Challenges during the development process included a lack of skills and experience in digital product development, capacity challenges around generating content and securing buy-in among hospice staff.

Results The app was launched on iTunes in April 2017 and was downloaded 83 times in the first two months. Patients commented that it confirmed that they were receiving the best possible care. Carers commented that the information on symptoms was good to refer back to. Both patients and carers felt it would be of most benefit when they were first referred to the hospice.

Conclusions The app is still in its pilot phase. A full evaluation will be undertaken to disseminate learning, to understand the full impact on patient and carer outcomes and to determine whether the app merits further investment. However initial findings would indicate there is scope for hospices to enhance face-to-face care with digital tools.

E-LEARNING FOR THE VOLUNTEER WORKFORCE

Sarah Owens. Wigan and Leigh Hospice, Wigan, UK
10.1136/bmjspcare-2017-hospice.60

More than 125 000 volunteers in the UK contribute to hospice care in a wide range of roles (Hospice UK, 2006). Wigan and Leigh Hospice has over 750 volunteers who give their time in the varying departments within the hospice on a daily basis. As an organisation we felt it vital that we provide them with the skills that they needed to best fulfil their role. Initially this training was delivered face-to-face in groups, covering specific areas including health and safety, infection control and safeguarding. Topics that the paid staff completed, as although in a volunteer role, they are in effect working for the organisation so it was important that they received very similar information. This was effective and they found it helpful, however, a number of volunteers are in employment or studying so often found it difficult to attend a face-to-face sessions. On review it was thought that a more flexible way of delivering the training would be via an e-learning package that the volunteers could access within the hospice or from home at a time to suit them. A volunteer e-learning module was put together and it is expected that volunteers complete this every two years. The module sits on our mandatory training system which also acts as a learning management system holding