



Digital Legacy Conference at the EAPC World Congress in Berlin in May 2019



European Association for Palliative Care
One Voice, One Vision in Palliative Care

Programme for Digital Legacy Conference on Friday 24th May 2019 at EAPC 2019 in Berlin

18:30-18:45 Refreshments And Networking

You will be greeted with food and drink. If you or your organisation would like to be warmly welcomed by the 200 attendees by sponsoring the refreshments get in touch.

18:30-18:45 Welcome & Introduction

An introduction to the subject matters and terms 'digital assets' and 'digital legacy'. How these subjects relate to end of life care

18:45-19:05 Do we prepare patients for their digital legacy? A survey of palliative care professionals
Coop H., Marlow C., West Midlands Collaborative Actioning Research in End of life and Supportive care (WM CARES)

Social media is becoming a more prominent part of our everyday lives. As a consequence we will be leaving a digital legacy after death. Digital legacy is the digital information that is available about someone following their death, which may include website or blog listings, social media profiles, photos, videos and gaming profiles. Many will find it a comfort that their legacy remains on social media but there can also be negative consequences in relation to death, dying and bereavement. This survey was carried out to establish whether we prepare patients for their digital legacy within the West Midlands. An online survey was sent to 11 hospices within the West Midlands, UK, over a 6 week period in 2017. The survey was circulated by the hospices to the doctors, nurses and social workers.

210 responses were collected (35% response rate). 96% had never discussed digital legacy with patients. Reasons for not having such discussions largely related to it not being considered, lack of knowledge about digital legacy or it not being felt to be appropriate or important.

This survey of health and social care professionals shows that we do not discuss digital legacy with patients. There is a potential unmet need that we are not addressing for patients. There is an education need across the region to raise awareness and confidence of digital legacy.

19:05-19:25 Sque Twitterati ad Mortem

Dr Ollie Minton (Macmillan consultant in palliative medicine Brighton and Sussex University hospitals)

Ollie will share experiences to encourage more sharing of data, opinions and joining a growing palliative multidisciplinary team (MDT) online. He will explore the impact that professionals can have in the media and the opportunities that the internet offers in relation to funding/ advance care planning / organ donation / research updates and blogs.

Case studies will include Mark Taubert's globally recognised letter to David Bowie. Others will include blogs in the BMJ supportive care (OM) and other sources .

Ollie will question the interactive nature of online and how this can improve aspects ranging from patient satisfaction to promoting the work of a healthcare professional. His theoretical probing will ask "how can online actions be counted and quantified?" and "What value could Public Health England assign to a professionals digital footprint, interactions and engagement".

19:25-19:45 Digital Legacy and Future Care Planning - Stories from a cancer hospital

Dr Mark Taubert

The use of internet enabled devices by patients at the hospital/hospice bedside appears to be increasing. Digital connections are everywhere, and can bring new opportunities when we are seriously ill. But what makes a good digital death? And how can digital media bring meaning during serious life-limiting illness?

In this talk, Dr Mark Taubert will outline his personal and professional experience with patients, carers, researchers and fellow healthcare professionals working in palliative care, and how since 2013 he has tried to make good use of new media. The taboo around death and dying is seemingly starting to crumble on Youtube, Instagram, Facebook and Twitter with many more opportunities for us in palliative care to influence debate. How celebrities die, for instance, is increasingly commented on, but Mark will also tell stories from the wards and clinics, where people have asked him questions about what they should do with digital content when faced with the end of their lives.

Mark is a palliative care doctor at Velindre NHS Trust cancer hospital in Cardiff (UK) and a senior lecturer at Cardiff University. He is national strategic lead for advance and future care planning in Wales and holds roles with the Bevan Commission, Byw Nawr and the End of Life Care board in Wales. Mark is a regular speaker and editor in areas relating to palliative care, digital media, resuscitation and end of life care. He also contributed to a BBC Radio 4 programme in the UK called "My Digital Legacy" in 2017 with the presenter Joan Bakewell . Mark will illustrate a story of a patient he worked with who created digital legacy content in the form of videos and messages, to be viewed at significant future dates in his family's life. The journey to achieve this was in many ways harder than achieving good symptom control and took a significant emotional toll, but was what the patient truly wanted. The story was reported on by BBC World in 2019, as part of a report about digital legacy.

19:45-20:05 Kids These Days: Caring for Parents Who Are Patients in the Internet Age.

Dr Jacob Strand MD (Mayo Clinic School of Medicine. Triple boarded in palliative & hospice care, child & adolescent psychiatry and adult psychiatry, founder of the Center for Palliative Psychiatry and Medical Director of Palliative Care at CJW Medical Center in Richmond, Virginia, USA. David's interest is in empowering patients to talk about 'unmentionables' in healthcare and the relationship between technology and medical care).

Discussion of the complexities in caring for parents who are patients in the age of online patient support platforms, virtual grief support groups and Dr. Google.

This session will engage participants in a case-based discussion of working with this patient population surrounding topics such as

- 1) Finding information about death and dying online.
- 2) Terminal illness support online
- 3) Grieving online
- 4) Additional attention will be given to strategies for engaging interdisciplinary resources in attending to these needs

20:05-20:25 Digital legacy And Advance Care Planning

Jacob James Norris (founder of the Digital Legacy Association and the Digital Legacy Conference. Lecturer at University College London)

James' abstract will examine how the role of the healthcare and social care professional is changing following recent changes in attitudes and behaviours around end of life planning, death and the internet.

He will use year on year data from the digital death survey to further evaluate how professionals are embracing recent technological and communicative developments to better support patients with their digital assets and their digital legacy. It will question how technology is changing the ways in which the general public plan for death and how this relates to both advance care planning and documenting other important areas within a Last Will & Testament. Case studies will lead to a critical analysis around the impact of grieving online and the influence and importance of digital dead.

Digital assets and digital legacy resources currently being used by clinicians and the general public will be reviewed and discussed. Online planning tools that assist patients and the general public to plan for their digital death, and tools that enable the deceased to interact with their loved ones 'into perpetuity', will evoke ethical, moral and sociological questions.

The session will conclude with the question; "should conversations around someone's digital wishes form part of a holistic approach to advance care planning or should this area be addressed somewhere else?"

20:25-21:00 Panel Discussion

Four speakers (TBA) will be invited on stage for the panel conversation. The theme of the panel discussion will be 'how to better support patients and families with digital assets and digital legacy'. This is an area that brings up questions surrounding ownership, legalities, safeguarding, the role of palliative, spiritual and family support. Expect a lively debate, innovation and new ideas.

21:00 Close