Who Do you Think you Are?
Anticipatory Digital Legacy Planning and How it Can Work

Norris J.1, Strand J.2, Aubert M.3
1Digital Legacy Association, London, United Kingdom, 2Mayo Clinic, Rochester, MN, United States, 3Velindre NHS Trust, Cardiff, United Kingdom
Presenting author email address: james@digitallegacyassociation.org

The adoption of the Internet and subsequent communication tools like smartphones and social networks has transformed our lives. There is real value and significant substance attributed to each individual’s digital assets and the information that they leave in a digital format when they die. This can be of significant value to palliative care professionals, and existing data suggest that legacy interventions are beneficial when approaching the end of life. Upon death much of this information will form part of the deceased person’s overall estate; in essence, it becomes their very own digital legacy and can be important in the grieving process. The information left behind (the digital remains) is stored on social media accounts, websites, blogs, PayPal accounts, an iTunes library and devices like mobile phones, hard drives, tablets and computers. The importance and value of this information is significant and can form part of a cultural heritage when accessible for future generations.

Most people, if they do any planning at all for what happens in the time after they die, focus on their physical possessions, and not what is stored digitally.

Should providing advice about such matters fall into the remit of the social, supportive and palliative care world? If so, how can this care be provided and to what extent? If not, who will carry out this task and then signpost patients to suitable areas of support? Palliative medicine teams are tasked to support the psychosocial, spiritual as well as the physical aspects of a patient’s care. Care is also necessarily targeted at supporting families. Providing legacy planning, including digital legacy work can be considered part of the realm of palliative care team engagement.

The Digital Legacy Association’s mission is to raise standards within end-of-life and palliative care in areas of digital asset and digital legacy management and planning. Much of their work revolves around training and defining best practice.