

The Digital Legacy Association

Digital Asset & Digital End of Life Framework (last updated May 2018)

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The world is changing

The ways we interact with one another have changed. It is paramount that healthcare, hospice, bereavement and palliative care professionals understand the importance of the technological revolution. Whatever their personal experiences and attitudes, it is paramount that each professional working in healthcare, hospice, bereavement and palliative care understands the importance of the technological revolution.



This framework provides simple ways for professionals to better support people in any area relating to death, dying and the Internet. This includes those nearing the end of their lives, their families, and the bereaved

About this Framework

This framework was first launched in 2015 at Hospice UK's annual conference in Liverpool, UK. In 2017 it was reviewed and updated by James Norris, Lucy Watts MBE and Dr. Elaine Kasket of the Digital Legacy Association.

Contributors

We would like to thank the following for their support and contributions into the development of this framework: The Digital Legacy Association, St Christopher's Hospice, Hospice UK, Dying Matters, Together for Short Lives, Cruse Bereavement Care, West Midland Care and Byw Nawr. We would also like to thank Dr. Mark Taubert, Susan Morris, Richard Putt, Lucy Watts MBE, Dr Ros Taylor MBE, and Dr. Ollie Minton for their ongoing support and guidance.

About

What is a Digital Legacy and what are Digital Assets?

What is a digital legacy?

Someone's digital legacy is the information about that person that remains after they die. During a person's life they can help create, co-create and develop their digital legacy through interactions they have both online and offline.



Ben Birch's Digital Legacy

Ben Birch died of Sudden Adult Death Syndrome (SADS) in 2013. During Ben's life he cocreated part of his digital legacy by interacting with his friends and publishing information on Facebook. Photos and videos of Ben that have been uploaded to Facebook and other online platforms are still accessible to his friends and family. Ben's Facebook account now makes up a large part of his digital legacy.

After Ben's death a Fantasy Football league in Ben's memory. Fantasy Football is an online game that Ben used to play. Over 30 of Ben's friends play in this league, which helps raise money for the charity Cardiac Risk in the Young (CRY). The fantasy football league set up to remember Ben forms part of his digital legacy.

Ben was a freelance cameraman and was working for the TV show 'Big Brother' at the time of his death. A memorial message was included in one of Big Brother's closing credits in the weeks that followed his unexpected death. Messages of support after the TV show were posted on different social media sites, which again contributed to his digital legacy.

Digital Assets

Digital assets are possessions that are made from computer code and exist in different formats. A digital music format may for example be a MP3 format (or file) and a digital photo may exist as a JPEG file.

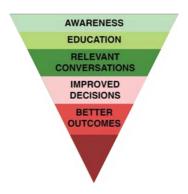
Digital assets include purchased music or movie files. Personal digital photos, documents and videos are also classed as digital assets. Digital assets can be stored on cloud services like Facebook, Instagram and Dropbox (sometimes referred to as 'in the cloud'). They can also be saved on digital devices like mobile phones, computers and laptops.

About The Digital Legacy Association

The Digital Legacy Association supports healthcare, legal and social care professionals with digital estate planning, digital legacy and bereavement. We also support the general public through campaigning, support literature, online tutorials and lobbying.

Our work includes:

- Campaigning and raising awareness around digital assets and digital legacy.
- Advising the British government (Law Commission) to improve UK law.
- Advising the Law Society to improve solicitor guidelines.
- Working with NHS England and NHS Wales to develop toolkits and improve standards.
- Providing frameworks for healthcare professionals and carers to follow.
- Providing training courses and developing best practice for healthcare, social care, legal, funeral, bereavement and celebrant sectors.
- Working with hospices and charities to develop their own processes in relation to digital assets and digital legacy support.
- Contributing to and reviewing scientific papers.
- Running an annual survey exploring public and professional attitudes towards death and bereavement, in the context of the Internet and the part it plays in society.
- Providing content and wider discussions around end-of-life care.
- Partnering with technology providers and devising programmes that utilise technology, social media and connected devices within the hospice sector.
- Speaking at conferences and events.
- Organising the annual 'Digital Legacy Conference' to discuss and celebrate excellence within these new and exciting areas.



Digital Legacy Association

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www.DigitalLegacyAssocation.org

www.Facebook.com/DigitalLegacyAssociation

www.Twitter.com/DigitalLegacyCo

Why digital assets and digital legacy is important within a hospice and healthcare context

"Ensuring people understand how to protect and pass on their digital legacy is an increasingly important issue, which is why we are delighted that the Digital Legacy Association has been launched. Talking more openly about dying, death and bereavement benefits us all, as does putting plans in place for when we are dying, and for after our death." - Claire Henry, Chief Executive of the Dying Matters Coalition

Dying Matters aims to raise public awareness about the importance of talking openly about dying, death and bereavement and of making end of life wishes known. It is led by the National Council for Palliative Care.

"Social media has a key place in our lives now, and we are learning that it becomes even more crucial as people face the end of their lives. It helps patients stay connected and boosts self esteem. But patients and those special to them don't know how to manage this personal vital resource after a death – memories, music, photos and messages are lost. We are delighted that the Digital Legacy Association is being launched at our annual Hospice UK Conference for over 700 staff working with families at the end of life'

- Dr Ros Taylor MBE National Director for Hospice Care, Hospice UK

Hospice UK is the national charity for hospice care. They champion and support the work of more than 200 member organisations, which provide hospice care across the UK, so that they can deliver the highest quality of care to people with terminal or life-limiting conditions, and support their families.

"In recent years, the ways people choose to remember deceased family members and friends has changed. Trips to the cemetery are replaced by online memorials and social media sites which can be updated regularly and accessed freely.

Healthcare professionals need to engage with service users to discuss digital legacies.

This, in turn, builds confidence in discussing dying, death and bereavement. St Christopher's are pleased to have supported the foundation of the Digital Legacy Association." - Ruth Sheridan, Director of Supportive Care, St Christopher's Hospice.

The St Christopher's Group comprises St Christopher's Hospice in Sydenham and St Christopher's Bromley in Orpington. Both care for adults from the age of 18 years upwards.

Digital Asset & Digital End of Life Framework

Foreword

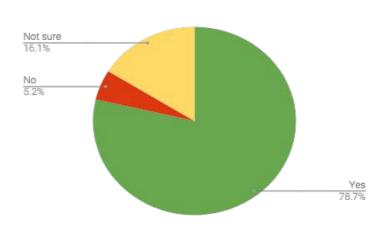
The internet is the biggest and most 'disruptive' force since the Industrial Revolution. "We are spending an ever-increasing amount of time online. This has led to a range of benefits and new healthcare opportunities. It is changing our awareness of mortality, the way in which we grieve, how we think about legacy, and the role and influence of the dead in society

Why this framework exists

This framework has been created for health and social care professionals, carers and the end-of-life sector. It was last updated in 2018. The resources it links to are updated on a regular basis.

The Digital Legacy Association was launched after it became apparent that professionals need to have support and training to better serve patients, families and the bereaved. In 2017, this was further validated through research in the Digital Legacy Association's Digital Death Survey and in West Midland Cares digital legacy research.

Would you read digital asset and digital legacy planning material if it was made available?





Benefits and outcomes

This framework has been created for all health and social care professionals and those delivering end of life care, regardless of whether or not they are themselves avid users of social network and various Internet platforms.

Health and social care professionals who use the framework and are familiar with digital platforms, social networking accounts and Internet enabled devices (like smart phones) may, however, perceive the framework as having a higher value than those who do not. This may be because those who are familiar with such services are more likely to have experienced their value during difficult periods.

Who should read this framework?

We encourage all health and social care professionals to read this framework.

This framework is simple and does not require an in depth knowledge of the internet or social media in order to understand it. Once understood, basic support can be given to patients and their families.

Applying this framework to your own practice.



This framework will not help you improve your general communication skills. This framework will not help you apply the information learned to your practice and it will not teach you enough about the internet for you to speak in depth about planning for death digitally with patients, families and the bereaved.

This framework does however provide highly relevant information for professionals about how to speak with patients about their digital footprint, their digital death and their loved ones digital remains.

After reading this framework it is the responsibility of each professional to assess how the information provided can improve their own practice and the conversations that they have with their patients and those they serve.

Although this framework has been developed for professionals, it can also be used as a resource for those who serve members of the community as they prepare for their own death, the death of a loved one, or when there has been a recent bereavement.

Chapter 1 – Supporting people to plan for the death on digital devices and online



"Providing legacy planning, including digital legacy work can be considered part of the realm of palliative care team engagement"

- Dr Mark Taubert, NHS Wales

Having conversations about someone's end of life is difficult. It is difficult if you are a doctor, nurse, someone with a serious condition or a friend or family member of another human being.

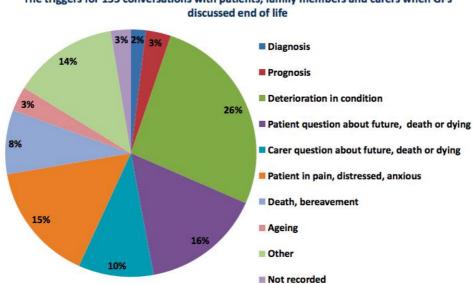
Being aware of relevant conversation triggers may help increase the quantity and quality of digital assets and digital legacy conversations.

Conversation triggers

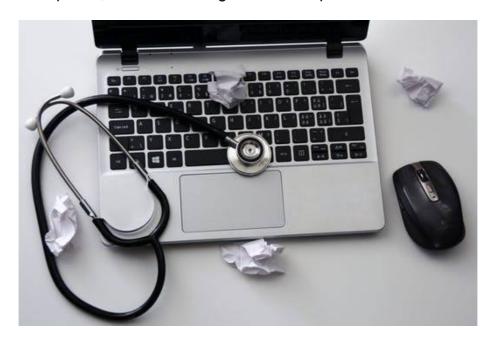
In 2011 Dying Matters mapped GPs conversation triggers for end of life with their patients.

Conversation triggers The triggers for 155 conversations with patients, family members and carers when GPs





Digital assets and digital legacy conversations open up possibilities for further conversation triggers. These could be when carrying out a ward round and a patient is using their mobile phone, tablet or working on their computer.



The trigger would be the device however the subject of the conversation may be the manufacturer, whether or not it's a Toshiba, Apple, Samsung etc. You might address whether or not it has a password on the device and if so, if anyone else has a password for it.

'Having conversations' consists of six steps. Further support is given in the following document about the terms used, the main digital platforms used in the UK, preparing for death online and grieving online. Further support material is also available to read and download at the end of this document.

Digital Asset & Digital End of Life Conversations - Six things to consider

- Start and encourage conversations about digital assets, digital footprint and digital legacy. For those under the age of 18, the conversation should take place with the presence of the person's legal guardian.
- Highlight that many people now save photos, videos, documents and important files across a number of devices and on a number of cloud based platforms.
- Discuss specific platforms that the patient / person uses (if it is appropriate to do so). It may for example be suitable to provide an overview about what happens on a specific social network when someone dies.
- Highlight why it can be important to pass over ownership of accounts and pass on passwords (for a mobile phone, Facebook account, computer etc). Reasons include being able to view media captured on a device (such as photos and videos on a smartphone), having access to the deceased person's phonebook in order to make funeral arrangements etc.
- Discuss whether creating a 'social media will' would be suitable. A free Social Media Will template can be downloaded at https://digitallegacyassociation.org/social-media-will-template
- When an answer to a question is not known, suggest that the person or the patient either:
 - Researches the question or subject matter online themselves.
 - You assist the person or patient to find the answer.

When and how to approach digital legacy conversations.

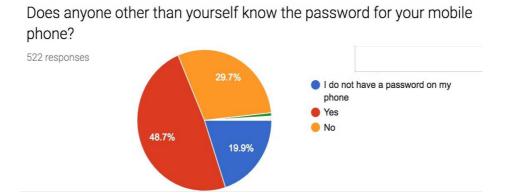
The Digital Legacy Association argue that digital legacy and digital assets conversations should be included as a holistic approach to part to all Advance Care plan conversations. In 2018 we wrote about this area in the Royal College of Physicians end of life publication. A version of the article can be read here: https://www.rcplondon.ac.uk/news/your-digital-legacy-emerging-aspect-advance-care-planning

Although advance care planning is a natural place for digital assets and digital legacy conversations to take place they may take place when someone's condition worsens or during any of the other conversation triggers (as highlighted in the Dying Matters chart above).



Example Scripts

"We talked earlier about death and dying and you were really open about what you would want. You talked about having made plans for what happens to all your belongings. I know that this may be a strange thing to speak about, but have you made advance plans about what will happen with your mobile phone, your Facebook account and all your passwords when you die?"



Data from the Digital Death Survey 2017

"What phone is that? I have now got fingerprint recognition on my phone but I haven't saved my partners fingerprint on the device should something happen to me. Does anyone else have access to your mobile phone through a saved fingerprint or password?



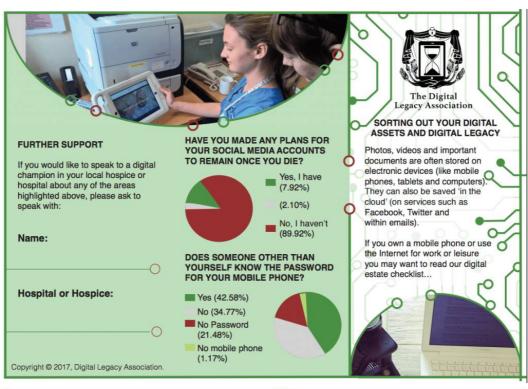
"You spend a lot of time working on your computer. Is the internet connection here of a high enough quality?...Have you also spoken to someone or made plans for your business and access to your business accounts should your condition deteriorate? For things of a business nature you may want to update your will. For things of a personal nature such as social media sites and accessing your personal photos and devices you may want to write a Social Media Will.

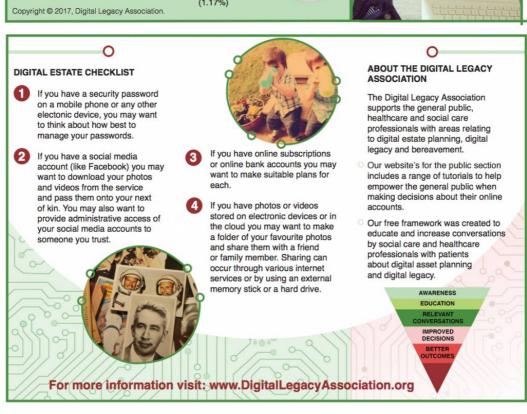


Support material

Sorting out your Digital Assets and Digital Legacy - public awareness leaflet

Our free digital legacy guide to download and print for General Public (giant font and other languages also available)





To use the public awareness resource in your hospice, hospital, practice or charity download the PDF from the link below. Once downloaded print a batch (for example 500) in your local printers and ask them to fold the leaflets as shown in the design.

- <u>Digital Legacy Association Sorting Out Your Digital Assets and Digital Legacy_GIANT</u>
 FONT
- <u>Digital Legacy Association Sorting Out Your Digital Assets and Digital Legacy</u> (for the visually impaired)

Your Digital Legacy and Digital Assets - Public Awareness Poster

This poster can be printed and used within your hospice, hospital, village hall or religious place of worship.



Click on relevant link below and either print it locally or send the file to your local printers

- <u>Digital Legacy Poster (A3)</u>
- <u>Digital Legacy Association (A3) Dying Matters Poster</u>
- <u>Digital Legacy Association (A3) Byw Nawr, Dying Matters in Wales Poster</u>

Social Media Will template

Our social media will template (excel download) was developed for for General Public. It allows each person to log the accounts that they use and make suitable plans for each service that they use. This may be a useful resource for those documenting their end of life wishes. Ideally this task would be carried out before someone writes their will or when they are starting their advance care plan journey.



The Digital Legacy Association - Social Media Will Template

Completing this template is a quick and simple way for you to list your online accounts and social media sites. Once it has been completed please PRINT it and keep it in a safe place or append it to your Last Will & Testament.

Social Media Will Template for (Enter Your Name)				
Online Accounts / Social Media Sites	Username/ Email Address	How do you want this account to be managed (close, memorialize, deactivate)?	Have you downloaded a copy of your files on this account (support)	Who would you like to manage this account (your digital executor)
		 		

This template can be downloaded at: https://digitallegacyassociation.org/social-media-will-template

Funeral Wishes leaflet



Dying Matters and the National Association of Funeral Directors produced 'My Funeral Wishes'. This is a simple form which lets you create a personal funeral plan that reflects you as an individual. It also highlights the importance of making your funeral wishes known.



This leaflet can be downloaded at: https://digitallegacyassociation.org/funeral-wishes-leaflet/

Chapter 2 - Supporting the bereaved

The more we use connected devices and interact with others online, the more meaningful our digital legacies become. When someone leaves behind a significant digital footprint, it affects the bereavement experience in many ways. On one hand, digital legacies can provide solace in mourning and can support normal grief processes. At the same time, certain features of the digital age can complicate grief and cause distress. Practitioners who work with bereaved people should be aware of both sides of this paradox.

Helpful aspects of grieving online

Continuing to feel connected with the dead is a normal part of grief, known as "continuing bonds". People throughout history have used communication technologies to connect with and remember the dead, but modern digital technologies make this particularly easy. For example, when someone leaves behind a well-developed social media presence on a site such as Facebook, mourners often return to this digital "place" to interact with the digital legacy, helping them feel connected with the person they have lost. Such platforms may also serve other purposes, such as informing people of the death, connecting mourners with one another, and serving as enduring memorials. When information about a person's life and death is digitally stored and available online, multiple mourners can access this material from anywhere, at any time.



Why someone's digital legacy may valuable to a bereaved person

There are many reasons why a digital legacy may feel especially valuable to a bereaved person. For example:

Much of our most personally meaningful information is now captured, stored, and communicated digitally: conversations, photographs, videos, music, audio recordings, and autobiographical writing. Virtually all of the memorabilia about a person's life may be in digital format.

- The digital legacy often represents and reflects a dead person far more vividly and comprehensively than the material legacy.
- Social networks often form a substantial part of the digital legacy. If the bereaved
 was a member of the deceased person's network, the digital legacy may contain an
 extensive archive of the bereaved person's history and relationship with the dead
 person. An online social network is also a ready-made community of mourners and
 can become the main location where memorialisation takes place.
- Especially when bereaved individuals have grown up with digital technologies, it is common to feel particularly connected to the dead person via online platforms, such as ongoing social networking profiles and message histories.
- The existence of digital legacies means that while the person may be physically dead, in some ways they still feel socially present.

It is important for practitioners to recognise that different aspects of the legacy may be important to different grievers. Grief is idiosyncratic, and each person experiences a loved one's digital legacy in a unique way. Continuing to interact with a digital legacy is not, in and of itself, a cause for concern. Behaviours such as sending the dead person messages, commemorating their birthday and their death anniversary, and posting photographs and videos on their social media may continue over a long period of time.

Online grieving often mirrors offline mourning behaviours, and may supplement or even supplant traditional offline rituals, such as visiting physical places of burial. In addition to utilising the dead person's own digital footprint or legacy, people may use online grief support forums or apps, search online to find offline resources, light virtual candles, post memorial videos on YouTube, or even build memorials on a virtual world such as Second Life.

Challenges

When problems do arise in grieving online, they often involve issues of access and control.

When mourners are not able to access parts of the digital legacy that are important to them, this can be highly distressing. Access can be prevented or disrupted through changes to a profile (for example, profile memorialisation); not knowing the deceased's passwords; account closure because of a platform's terms and conditions, or failure to renew; unexpected disappearance of online material by other means; or simply not being on the deceased's friends list. For information that is not online but is digitally stored, access to material can be disrupted by losing access to the devices on which it is stored, or through erasure, breakage or data corruption.



Losing access to sentimental material that one formerly had can be experienced as extremely traumatic, like a second loss; even the fear of losing access can cause significant anxiety. When one wants access but cannot get it - as may be the case for someone who was not on the deceased's friends list - that person can feel not just bereft of important sentimental material, but also excluded from the community of mourners.

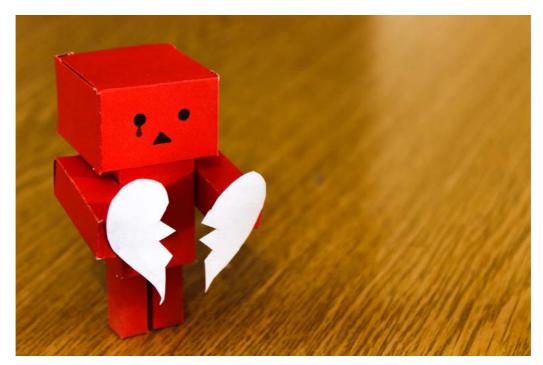


The problematic issue can also be about control. Sometimes the digital legacy can be troubling to the bereaved. It may have distressing elements, or it may not represent the dead person in a way that feels comfortable. A mourner may not be able to do anything about this; for example, the content of a social networking profile may be fixed through memorialisation, or someone else may be managing the legacy. Sometimes the terms and conditions of a platform prevent the bereaved - even the next of kin - from being able to manage a digital legacy the way they would wish.

When our legacy is digital, numerous power struggles for control and access can emerge. These can be between different groups of mourners, or between mourners and the companies that control our data. There may even be conflict between mourners' wishes and the wishes of the deceased themselves. For example, the deceased may have arranged for their digital legacy to be deleted, or for electronic messages to be sent after their death. Some mourners may be fine with such wishes being carried out, while some might find this upsetting.

Grieving online: Practical advice for practitioners

- Reflect upon your own stance towards digital technologies, and consider how your preconceptions could influence how you work with bereaved people in the context of technology.
- Be cautious about pathologising online or technologically mediated grieving. It is a normal manifestation of continuing bonds, in a new technological context.
- Remember that digital legacies can be exceptionally significant for the many bereaved people, for the reasons outlined above. Be empathic about feared or actual secondary loss, through loss of access to all or part of a digital legacy.
- Be aware that each mourner's stance towards a digital legacy will be different. This
 may be positive, negative, neutral or mixed, may vary over time, and may be
 different to other stakeholders' attitudes.
- Be aware of issues around ownership of, access to, and control over the dead person's digital legacy. This is a complex area that carries significant risk for confusion, distress, and conflict for the bereaved. They may experience helplessness, anger, and frustration.



- Help those mourners who have do control over significant parts of the digital legacy

 for example, the next of kin recognise that the legacy may be critically important
 to others. The removal of a social networking profile, for example, can be traumatic
 for many grievers.
- Be aware that a bereaved person may need help in managing their relationship and interaction with a digital legacy that continues to exist online, both practically and emotionally.

Chapter 3 – Tutorials and Resources

Online tutorials for the general public

Below is a list of platforms and social media sites that often contain 'digital assets' created, shared or purchased by their users. These include items that may have a monetary value (for example a purchased music or movie file) and/or assets that have a sentimental value (for example photos from a family occasion or private SMS messages).

*The For the Public tutorial hub can be found at: https://digitallegacyassociation.org/for-the-public/



Direct links to specific resources can be found below:

Facebook

Digital Assets held: Photos, videos, private messages, public messages, business or special interest Facebook pages, debit card details

Facebook tutorial for the general public http://digitallegacyassociation.org/facebook-tutorial/

· Google Services

Digital Assets held: Photos, videos, private messages, public messages, business or special interest Google+ pages, emails, business analytics (Google analytics) phone numbers, debit card details

Google tutorial for the general public http://digitallegacyassociation.org/google-guide/

Twitter

Digital Assets held: Photos, videos, private messages, public messages (Tweets), business or special interest Twitter accounts, debit card details

Twitter tutorial for the general public http://digitallegacyassociation.org/twitter-guide

Instagram

Digital Assets held: Photos, videos, debit card details business or special interest Instagram account

Instagram tutorial for the general public http://digitallegacyassociation.org/instagram-guide

Linkedin

Digital Assets held: Photos, videos, private messages, public messages, business or special interest Linkedin pages, business correspondence, phone numbers, debit card details, email contact list (often business centric)

Linkedin tutorial for the general public http://digitallegacyassociation.org/linkedin-guide/

Other platforms and social media sites

Online estate planning and grief can occur across a multitude of different platforms such as social media sites, forums and blogs. This will largely depend on which sites and communities the deceased participated in.

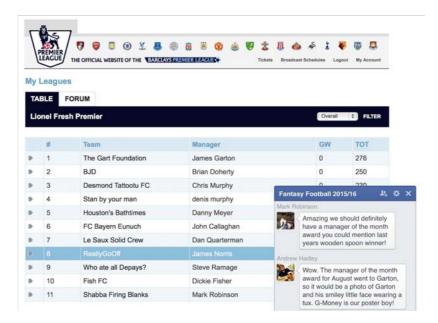


Image from Ben Birch's memorial Fantasy Football league. The league is a way for friends of Ben to remember Ben in a contextually relevant way to the person Ben was and who his friends are. As well as being a platform to remember Ben it is also used to raise funds for Cardiac Risk in the Young.

Online fundraising

There are a number of charity fundraising tools and platforms that allow for donations to be provided in memory of the deceased. The act of donating online in remembrance of the deceased is often referred to as 'online legacy giving'.



Campaigning, awareness and raising money for a charity or a specific cause can also have an impact on how the person is remembered and form part of their digital legacy.

Website and Blogs

Digital Assets held: Business website/blog, personal interest website/blog, debit card details (for domain ownership, hosting subscription), photos, videos, business emails accounts associated with the domain name) and even the URL itself.

Website and Blog tutorial for the general public: http://digitallegacyassociation.org/website-guide

Online bank accounts & subscriptions

Our finances and financial information are increasingly moving online. Shopping Gambling, online subscriptions and eCommerse sites like PayPal may all contain money or funds or a monetary value

http://digitallegacyassociation.org/online-bank-accounts-subscriptions

Electronic devices (where digital assets are often stored)

Mobile phones

Digital Assets held: Photos, videos, SMS messages, private messages (for example WhatsApp messages), in-app messages, in-app purchases (games etc.), movies, music, e-books, debit card details, crypto-currency details, business analytics details (for example Google analytics), photos taken from and saved on device, videos taken from and saved on device.

Mobile phone tutorial for the general public http://digitallegacyassociation.org/mobile-phone-guide

Tablets

Digital Assets held: Photos, videos, SMS messages, private messages (for example WhatsApp messages), in-app messages, in-app purchases (games etc.), movies, music, e-books, debit card details, crypto-currency details, business analytics details (for example Google analytics), photos taken from and saved on device, videos taken from and saved on device

Tablet (iPad, Kindle etc.) tutorial for the general public http://digitallegacyassociation.org/tablets-ipad-kindle-etc-guide

Digital Assets held: Photos, videos, SMS messages, private messages, in-app messages, in-app purchases (games etc.), movies, music,

e-books, debit card details, crypto-currency details, business analytics details (for example Google analytics) etc.

Computer & laptops

Digital Assets held: Photos, videos, private messages (for example Skype messages), inapp messages, photos, movies, music, e-books, debit card details, crypto-currency details, business analytics details (for example Google analytics), business documents, business accounts, personal financial documentation, end of life documentation, funeral plan information.

Computer and laptop tutorial for the general public http://digitallegacyassociation.org/computer-laptop-guide

Feedback

We hope that you have found this framework of value. It is important that you as the professional are able to absorb the information provided and apply it to your own practice when you feel that it is suitable to do so. If you have any ideas or feedback as to how we can improve this framework please <u>contact us</u> with your suggestions.



Further information can be found at: www.DigitalLegacyAssociation.org