



Digital Legacy Association

Helping healthcare professionals support the general public with digital end of life planning and digital legacy



Digital Asset & Digital End of Life Framework DRAFT Version 000.0

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&

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Overview

The research and subsequent framework outlined in this document has been created by technologists, healthcare professionals, scholars and patients. It uses public data, patient feedback, data from the Digital Death Survey (2014 & 2015) and a number of other sources to validate the framework and the proposed methodology outlined for healthcare professionals, social care staff and those providing care to people nearing the end of their lives.

*We have developed this framework using in-depth knowledge of each area to provide advice.

Contributors

We would like to thank the following for their support and contributions into the development of this framework: St Christopher's Hospice, Dying Matters, Dr. Mark Taubert and Dr. Ollie Minton.

About

The Digital Legacy Association was set up as a research and training organization supporting the end of life and hospice sector in areas relating to digital assets, digital legacy and digital bereavement. This is delivered directly to hospices, health and social care professionals.

In doing so we hope to raise awareness and knowledge and to improve the support provided to patients and the general public in these areas.

The Digital Legacy Association is a community interest company that partners with industry to help ensure improved end of life care planning across the United Kingdom.

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[www.Facebook.com/DigitalLegacyAssociation](https://www.facebook.com/DigitalLegacyAssociation)
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The Digital Legacy Association is a community interest company (CIC). It was registered on 5th October 2015 with the registration number 9810395.



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.



"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.

StChristopher's

"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 DeadSocial in 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 (Version 0.00)

Foreword

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, new healthcare opportunities and has changed the way in which society grieves and remembers the deceased into posterity.

Why this framework exists

This framework has been created for health and social care professionals, carers and the end of life sector. It will be updated on a regular basis and when changes are made by each featured website, Internet service provider (ISP) and social network in terms of how they function or in relation to their end of life policies. It provides factual information about the main online platforms and devices (like mobile phones) used in the UK today. It exists 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.

Benefits and outcomes

This framework provides guidelines and relevant information for professionals who care for people nearing the end of their lives. When hospices, healthcare and social care professionals read the framework and agree with its principles, there is the option for them to be listed on the Digital Legacy Association website as a form of association or individual. There is no cost for this service.

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 social network and various Internet platforms users.

However 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.

We will be running a series of daylong workshops across the United Kingdom from February 2016. To register your interest in attending a workshop visit: <http://digitallegacyassociation.org/training>

Who should read this framework

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

The framework is simple and currently 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 Framework – Six steps

1. 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.
2. **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.
3. 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.
4. 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.
5. Discuss whether creating a 'social media will' would be suitable. A free Social Media Will template can be [downloaded here](#) (Excel)
6. 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.
 - Submits specific questions publically using the [Digital Legacy Association's 'Question & Answers' forum](#).

A screenshot from the Digital Legacy Association’s Question & Answers forum can be viewed below:

Status: **All** **Open** Answered Resolved Closed Ask a question

Select a category View ⇅ Answer ⇅ Vote ⇅

	How can we improve the Digital Legacy Association's FRAMEWORK version 0.00 and 0.00 (1) <small>James asked 7 days ago · Category: Framework</small>	11 views	0 answer	0 vote
	What do you want from the Digital Legacy Association? <small>James asked November 13, 2015 · Category: Digital Legacy Association</small>	18 views	0 answer	1 vote
	What should I do with my mobile phone before I die <small>James asked November 13, 2015 · Category: Devices (like mobile phones, computers etc)</small>	21 views	0 answer	1 vote
	How can someone plan for death on Twitter? <small>James asked November 13, 2015 · Category: Social Networks</small>	11 views	0 answer	0 vote
	How can someone plan for death on Facebook? <small>James asked November 13, 2015 · Category: Social Networks</small>	17 views	0 answer	0 vote

Ask a question

- Contact’s the Digital Legacy Association using the email address hello@digitallegacyassociation.com. This should be recommended if the person or the patient does not want to disclose their question publically.

Being included on the Digital Legacy Association website & map

Hospices, health and social care professionals who adhere to the framework outlined above will be added to the digital legacy association website and map (at no cost).



The map and the Digital Legacy Association will help the general public find the support they require in their local region. The interactive map displayed above will be made live on the Digital Legacy Association website from the 1st January 2016.

Having Conversations. Digital Assets & Digital End of Life

The five areas below have been highlighted as being of high importance when thinking about end of life in today's digital world. The following areas of conversation may help those nearing the end of their lives and their families think about and plan for death digitally.

Evoking conversation and thought

Have a conversation with those nearing the end of their lives about their digital assets, digital footprint and digital legacy.

This conversation could be triggered when a patient is on the ward and using their mobile phone or tablet. Alternatively it would take place when addressing the patient's advanced directives or when they are receiving information about writing their will.

Example Script to refer to

We have outlined a basic script to review and use as a reference. This can be followed, expanded upon and changed based on the requirements of the individual.

Example Script

“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?”

Understanding Digital Assets, Connected Devices and Digital Legacy

The three main categories to understand in this section of the framework are:

1. **Digital assets, which** include things such as your online bank accounts, photos saved online and your social media accounts etc.
2. **Connected devices, which** include mobile phones, tablets (like iPads), computers etc.
3. **Digital legacy, which** is what you leave online once you die. This has an influence on how you are remembered.

1 Digital Assets

Your digital assets can be of sentimental, or monetary value, or both. For example, many people now use digital photography and video devices. These include mobile phones, tablets and digital cameras. Most of these photos are no longer printed. Instead they are stored and saved on devices (such as hard drives) and uploaded on platforms like Facebook, Instagram and DropBox. When you have the time to do so, it is worth learning about how you can download such content, pass accounts on and close online accounts with subscriptions.

2 Connected devices

Connected devices are basically devices that connect to the internet (also known as internet enabled devices). These include mobile phones, tablets, smart watches, eBooks, TVs etc. Many of those mentioned above connect to accounts where media can be purchased or subscribed to. These include iTunes, Amazon, Netflix, Google Play, Spotify etc. You may want to learn about each platform and think about the following:

- Who would you like each device to be given to (and would you like your media to be deleted before they receive it)?
- If you have a password on your devices how will you pass it on?
- When you 'purchase' a media file (like a song, video or eBook) you are often only 'purchasing' a one person license. This ends upon death. Therefore if you purchase media from iTunes, Amazon etc you may not legally be able to pass on your libraries like you can with CDs, printed books and DVDs. There are ways that you can address this, however it takes thought and planning. Plans may include burning media onto disks, passing on device passwords, stating what should happen to your devices within your will etc.

3 Digital legacy

We are spending more of our time online and having ever more meaningful interactions and conversations online. These take place using an increasing number of mobile phones, laptop and other devices. When we die the interactions that we made (also known as our digital footprint) often remain and help to create our digital legacy. When we die our digital footprint plays a big part in determining our digital legacy.

Digital Assets

Third party platforms containing digital assets

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). Below is a list of popular platforms used in the UK that contain digital assets. The assets that can be attained in each platform are shown 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, 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/>

- **Website and Blog**

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. Below is a list of the popular online accounts and subscriptions used within the UK.

- Online banking
- Online only saver bank account
- Online bank accounts
- Online stores (Etsy etc)
- Online store subscriptions (Amazon Prime etc)
- PayPal (especially if you keep credit located in your PayPal account / sell goods on eBay etc)
- Oyster card / travel subscriptions
- Online investment services (stock exchange, foreign currency, etc).
- Online gambling services
- Online gaming subscriptions (xBox etc)
- Online entertainment (Sky, Netflix etc)
- Newspaper subscriptions (online and offline)

Digital Assets held: Money, Crypto-currencies (Bitcoin, etc.), funeral plan, savings account, business assets, gaming avatars, financial stock.

Online bank accounts & subscriptions tutorial for the general public:

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

Digital assets stored on electronic devices

- **Electronic device / hardware general**

Digital Assets /devices (general): Photos, videos, private messages, SMS messages, in-app messages, in-app purchases (games etc.), movies, music, e-books, debit card details, crypto-currency details, access to social media accounts, business analytics, Google drive, Google sheets (formally Google docs)

Hardware / device tutorial for the general public

<http://digitallegacyassociation.org/hardware-devices-guides>

- **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), in-app 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/>

Digital Grief and mourning online

The way in which we remember and grieve is increasingly moving over from the physical to the virtual realm. This does not change the emotional perception of grief that human beings feel, but it has changed the way this is expressed or how solace is sought. The information below highlights some of the main ways in which society use digital media and digital devices to mourn the deceased in the UK.

Facebook

For many, Facebook can be the first place they visit when they hear of someone's death. It is now commonplace for a Facebook account to become a focal point to share memories, stories and celebrate a life. In short, a Facebook profile can often be the main focal point where grieving and remembrance takes place. The deceased's Facebook profile will often receive messages written by friends and family members. These are displayed publically on the deceased's Facebook

timeline. Photos and videos are also often shared on the deceased's Facebook profile soon after their death and on anniversaries.

Things to be aware of in regards to mourning on Facebook:

- Facebook may be the primary means of communication between friends and families
- It is now commonplace to hear of someone's death through Facebook
- When a Facebook account is deleted, photos and videos uploaded to the profile by the deceased can no longer be viewed. Furthermore when an account is deleted it cannot act as a memorial following the death. This may be right for some people, but can cause distress to others. The level of distress may depend on a number of factors. These include a person's relationship with the deceased, how often they use Facebook, the amount of photos and videos the deceased had previously uploaded to their Facebook account, geographical location between the mourner and the now deceased etc.
- Arranging a funeral can be facilitated by using social media contacts. Trying to do this using Facebook, for example, when trying to find contacts and addresses, is possible. But where a Facebook account has been deleted, this can no longer be done. Private messages that are shared between the deceased and their Facebook friends are deleted when the deceased's Facebook account is deleted.

Funeral Videos - Youtube, Vimeo and other video sharing sites

It is becoming increasingly common for funerals to be filmed and for photos of the ceremony to be taken. This is often influenced by what the deceased person has expressed in their advance wishes. By filming the ceremony those unable to attend due to ill health, geographical location etc. are able to view and mourn the deceased from afar. Videos recorded are not always 'made public' on video sharing sites like Youtube and Vimeo, however there is an increasing trend to do so. This is a matter of personal choice, and many have different views on this.



Things to be aware of when uploading funeral videos to Youtube:

- When a video is uploaded to Youtube, it may by default be set to 'public'. Some families may want videos to only be accessible by close relatives or friends of the person who has died. If this is the case, when uploading the video you can choose 'Unlisted' or 'Private'.



Select files to upload

Or drag and drop video files



- Unlisted videos can only be watched by people with the specific link to the video (the unique URL).
- Private mode videos will only be accessible by people with a password provided specifically for watching this video
- Private mode videos will only be accessible by people with the password for the Youtube account that the video has been uploaded to.

Other social media sites

Online 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.

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'.

The screenshot shows a JustGiving fundraising page for Stephen Sutton. At the top, there is a search bar and social sharing options for Facebook, Twitter, and Email. The main content area features a photo of Stephen Sutton, his name, and a large purple circular badge indicating that 496% of the target has been reached. The fundraising progress is shown as £4,967,453.22 raised of a £1,000,000.00 target, with 182,457 donations. A 'Donate' button is visible. Below the main content, there is a 'Story' section with a short text about Stephen's battle with cancer and a 'Raising money for' section featuring the Teenage Cancer Trust logo and name. The Teenage Cancer Trust logo includes the text 'TEENAGE CANCER TRUST' and 'We are dedicated to improving the quality of life and'.

The most prolific legacy giving account was created by Stephen Sutton. To date Stephen Sutton has raised just under £5 million for the Teenage Cancer Trust.

Digital Legacy Association Champions

We would like to speak with 'tech savvy' health and social care professionals who are currently working in hospices or palliative care settings. We are looking to develop a champion programme for HCPs wanting to develop a more indepth knowledge in this area.

If you would like to find out more information about becoming a champion, email: hello@digitallegacyassociation.org

Appendix

Free social media will template (excel download) for General Public



DeadSocial.org - Social Media Will Template

Completing this template is a quick and simple way for you to list your online accounts, websites, social media sites etc. Once it has been completed please PRINT it and keep it in a safe place or append it to your Last Will & Testament. If you plan to save a copy of your wishes online/in the cloud, you may want to read and review the 'Securely storing your Last Will & Testament (and other important documents)' tutorial below.

There are a range of free social media tutorials to help you with this process at: www.DeadSocial.org. Links to highlight relevant support material can be viewed below:

- [Writing a Social Media Will \(guide\)](#)
- [Social Media Guides \(Facebook, Twitter etc\)](#)
- [Passing on your password \(ideas\)](#)
- [Securely storing your Last Will & Testament \(and other important documents\)](#)

Social Media Will Template for (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)

Download a free 'Social Media Will Template' by [clicking here](#)

Free digital legacy guide to download and print for General Public (in English and Welsh)

DeadSocial
"Let's talk about it"
Dying Matters

Five steps to sort out your Digital Legacy today

This short guide provides the first five simple steps to help ensure that your digital end of life wishes are met. It was created by DeadSocial for Dying Matters Awareness Week (18th-24th May).

"It is important for us to think about how we will be remembered both on and offline".

"The ways in which we communicate, live, die and grieve have changed forever. This is due to the arrival of the internet and social media sites like Facebook and Twitter".

62% of us consider being able to access a deceased friend or family member's social media accounts 'important' or 'very important' - Digital Death Survey 2014.

Five First Steps...

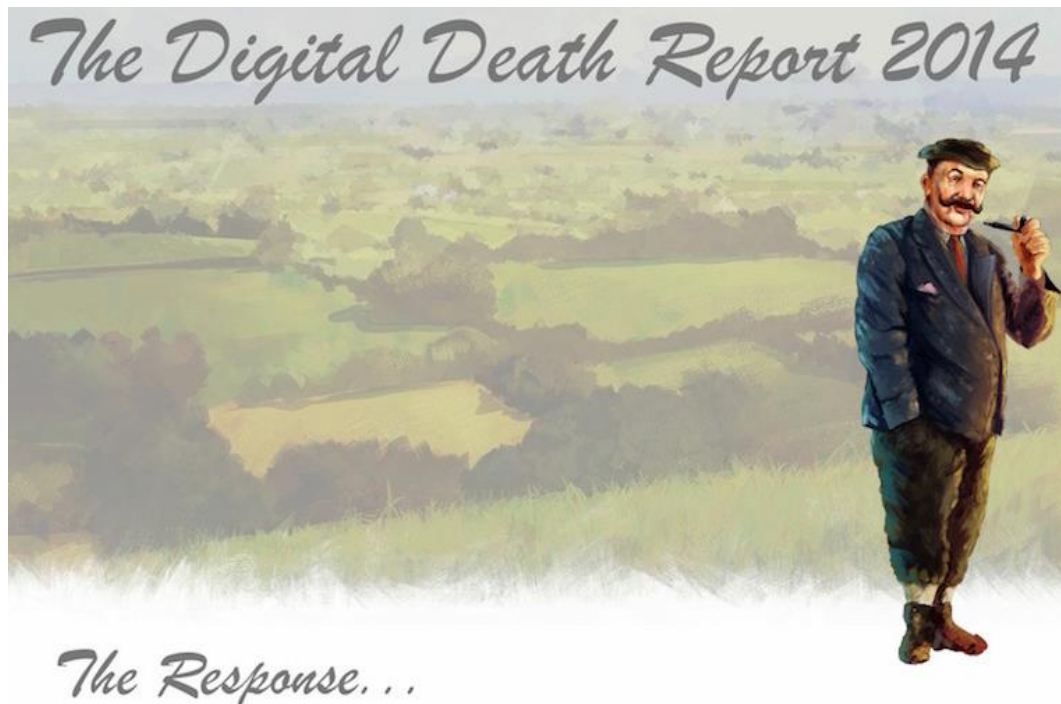
1. Write a **Social Media Will**. In your Social Media Will state what your wishes are for your online accounts as well as any digital assets not already mentioned in your will.
2. Append your social media will to your Last Will & Testament. **If you do not have a will, write one.**
3. Learn about the best ways to **pass on your passwords**. This may differ for each of your internet enabled devices as well as you email, social media, bank accounts etc.
4. **Download and share your favourite photos and videos**. In the UK most photos and videos taken are saved in a digital format. Make sure that you backup this media on a regular basis.
5. Consider **passing on your media as a gift**. You may want to pass on your photos, videos, messages etc to your next of kin. One of the easiest ways to share media is by putting it on an **external hard drive**. This can then be shared between friends and family members.

www.DeadSocial.org

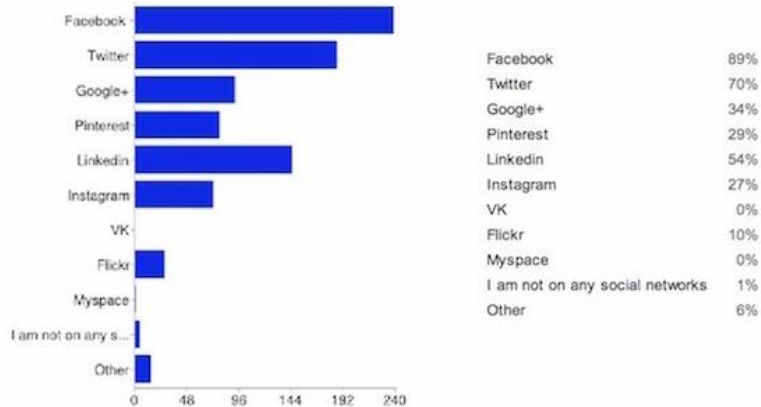
DeadSocial is the free service that helps us prepare for death in today's digital world. We provide best practice tools, tutorials and frameworks to help ensure that our digital assets are looked after, our digital memories are not lost and our digital legacy remains.

Download and share the flyer in English (PDF) by [clicking here](#) or in Welsh (PDF) by [clicking here](#)

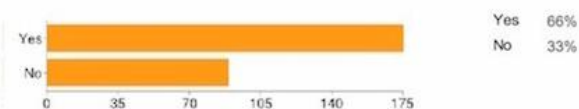
Digital Death Survey 2014(Infographic)



Which social networks have you used in the last six months? (check all that apply)



Have you thought about which song(s) you would like to be played at your funeral



View the full Infographic from 2014's data by visiting <http://digitallegacyassociation.org/about/reports>

Digital Death Survey 2015

Data is currently being obtained from the Digital Death Survey. The results will be published in the first version of the framework in January 2016. To contribute to the survey before 25th December 2015 visit <http://goo.gl/forms/rrnjS3CZTm>.

The survey can be completed anonymously. Once completed the results will be made public to help better societies understanding on death.

Digital Legacy Conference 2015/16



The photo above is from the Digital Legacy Conference 2015.

For more information visit: www.DigitalLegacyConference.com



www.DigitalLegacyAssociation.org