



The Digital Legacy Association

What happens to your digital assets after you die?, grieving online and how do you plan for a digital legacy

Education for Scotland The Changing Face of Bereavement: Providing care and maintaining our own wellbeing during the pandemic Wednesday 24 November 2021

About me

*End of life technologist

- Digital Legacy Association
 - Digital Legacy Conference
- MyWishes
- Michael Sobell Hospice Digital Research Fellow
- Velindre Cancer Centre Honorary Design Fellow
- Law Society Digital Assets Working Group
- Former UCL lecturer (Digital & Social Media)
- Palliative Care Fellow (graduate)







Certificate

This is to certify that

James Norris has successfully completed the Fellowship in Palliative Care in the month of August 2021



DR SURESH KUMAR DR HEATHER RICHARD

DR LIBBY SALLN

CERTIFICATE NO FPM043/21





My story...

- Dad died at a time after I had just transitioned from being a Jason Donovan and Kylie Minogue fan to Guns n' Roses.
- Interested in technology, funeral playlist and music from a early age
- Inspired by Bob Monkhouse
- Setup the Digital Legacy Association & MyWishes



The Internet

The way we communicate has

changed...



Technology Mass Adoption

We might be the last generate of humans who experience life without the internet....

We might also be the only generation who lived a life with and without the internet.

It took Pokemon Go <u>19 days</u> to reach 50 million users!

Digital Legacy

Do you know what a digital legacy is?



What is our 'digital legacy'?

Our digital legacy is what remains of us digitally once we die. When we die our digital footprint helps to inform our digital legacy.

https://digitallegacyassociation.org/about/what-is-a-digital-legacy/

Why a digital legacy is important



📝 Post 🛅 Photo/Video

Write something...



Memories. X

Why digital legacy is important

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•	5	Houston's Bathtimes	Danny Meyer	Mark Rol	Amazing we should definitely have a manager of the month award you could mention last years wooden spoon winner!		
Þ	6	FC Bayern Eunuch	John Callaghan	28			
Ð.	7	Le Saux Solid Crew	Dan Quarterman				
2	8	ReallyGoOff	James Norris	Andrew k	Andrew Hadley Wow. The manager of the month award for August went to Garton, so it would be a photo of Garton and his smiley little face wearing a tux. G-Money is our poster boy!		
Þ	9	Who ate all Depays?	Steve Ramage	San C			
•	10	Fish FC	Dickie Fisher				
Þ	11	Shabba Firing Blanks	Mark Robinson				



Challenge complete

Fundraising for this challenge has ended so we're no longer accepting donations. Thanks to everyone who supported this challenge.

Total raised so far **£14,431.39**

Total plus Gift Aid: £16,753.89

Raised offline: £0.00

My story

This page has been set up to honour the memory of our son and brother, Ben Birch who died on the 22nd May 2013 of Sudden Adult Death Syndrome (S.A.D.S).

Undiagnosed heart conditions claim at least 12 young people every week in the UK and our chosen charity, Cardiac Risk in the Young, (CRY) fights to raise awareness, support bereaved families and promote heart screening, ECG testing programmes and medical research into S.A.D.S.

Our digital legacy is becoming increasingly important

If someone you care about dies, how important it is for you to be able to view all of their social media accounts?



Digital Assets

What are 'digital assets'

Digital assets are possessions that are purchased, stored or available online.

https://digitallegacyassociation.org/what-are-digital-assets/

Time to reflect: When did you last print a photograph that had you in the photo?

Time to reflect: Do you have a password on your mobile phone

Further reflection...

Following your death...

- Can someone access your phonebook (to inform people of your death and invite them to your funeral?
- Can someone retrieve the photos taken on your phone? (what about your computer, other devices with passwords)
- Can someone read the messages on your phone (do you want them to)?
- How will the person dealing with your online accounts know which photos and videos are of sentimental value to you...how will they know which ones to keep?
- How will your favourite photos and videos be shared online / offline.

"Physical assets are increasingly migrating over to digital assets"

The Digital Legacy Association

How we support professionals and the general public



The Digital Legacy Association

https://digitallegacyassociation.org/



Support for the public

https://digitallegacyassociation.org/for-the-public/

Public awareness leaflets



https://digitallegacyassociation.org/framework/free-inpatient-resource-for-hospices/

Funeral Wishes (and other third party leaflets & resources)

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www.dvingmutters.org



Freephone 0000 021 44 56
 Info Golylogmatters.org
 www.facabook.com/DyingMatters
 twitter.com/DyingMatters
 www.diyingmatters.org/domain

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Getting your funeral right can give you peace of mind and will help your friends and relatives to remember you, following their loss



Factsheet 27 Planning for your funeral

February 2021

About this factsheet

This factsheet highlights things to consider if you want to plan ahead and make financial and other arrangements for your funeral. It looks at options when deciding what type of funeral you want, ways to pay for a funeral, and information about organ donation. It may be helpful for people arranging a funeral.

If arranging a funeral in England while Covid-19 restrictions apply, you can find latest government guidance on gov.uk website. If arranging a funeral in Wales go to gov.wales website.

There is a form at the back of the factsheet to record your funeral arrangement preferences and other helpful information for family or friends.

The information in this factsheet is applicable to England and Wales. If you are in Scotland or Northern Ireland please contact Age Scotland or Age NI for their version of this factsheet. Contact details are at the back of this factsheet.

Contact details for any organisation mentioned in this factsheet can be found in *Useful organisation* section.

https://digitallegacyassociation.org/framework/free-inpatient-resource-for-hospices/

Tutorial hub for the general public

Home Free resources Training About News For the public Toolkits Support

For the public Home 1 - Aurithe pumpt



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Social Media Will (template)

Dempose who has online accounts should document what sing they use and what they would like to happen to them. should surrething happen to them. Our free Social Media Will amplitude is an exort download. Simply download the template, complete it and store it in a safe location. You may also work to email a copy of it to itomeone you trutt. To get

Language

English *

Recent news

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Information about the Digital Legacy Association

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https://digitallegacyassociation.org/for-the-public/

Facebook tutorial examples

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Home Free Resources Training About For the public News Conference 2021 Support Se

Facebook Digital Assets and Digital Legacy Tutorial

Overview

Facebook has helped changed the way in which we grieve and remember those who have died, forever. When a Facebook user dies the photos on their account and the interactions that they made converts from their 'digital footprint' to forging part of their 'digital legacy!

Facebook is often the first place where we learn of someones death. A Facebook account o friend or family member can soon become a resource of great comfort during the grieving p to the amount of time we spend on Facebook it is becoming more and more important that plans for what we would like to happen to our own Facebook account once we have died. TI information below provides all of the information and options currently available to help you which steps are most suitable for you.





Download your information

Get a copy of what you've shared on Facebook.

Start My Archive

What's included?

- Posts, photos and videos you've shared
- Your messages and chat conversations
- Info from the About section of your Profile
- And more



https://digitallegacyassociation.org/facebook-tutorial/

https://digitallegacyassociation.org/how-to-download-your-facebook-data-and-pass-it-on-to-your-next-of-kin/



Your legacy contact

A legacy contact is someone who you choose to manage your account after you pass away. They'll be able to do things such as pin a post on your timeline, respond to new friend requests and update your profile picture. They won't post as you or see your messages. Learn more.



Data Archive Permission

Allow my legacy contact to download a copy of what I've shared on Facebook. This may include posts, photos, videos and info from the About section of my Profile. Messages won't be included. Learn more

Social Media Will (template)



The Digital Legacy Association

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)				
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)	
		How do you want this account to be managed (close,	How do you want this account to be managed (close, Have you downloaded a copy of your	

*Insert Extra cells when required

http://digitallegacyassociation.org/social-media-will-template/

Bereavement...

Changing norms and values

If your family and friends were unable to pay for your funeral, would it be OK if they set up a Crowdfunder to help pay for it?





Crowdfunder is



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Changing attitudes and behaviours

Have you ever watched a funeral or memorial service video stream for a close friend or family member?

If a close friend or family member were unable to attend your funeral, would you mind if it was video streamed?





- Yes I would mind. I would not want it to be video streamed
- No I would not mind. If someone is unable to attend I would be happy for them to watch a video stream
- 🛑 l don't know
- I do not want a funeral service and this would not be relevant for me

*Professional bodies and organisations need to adapt in order to better support the dying and the bereaved.

Saying Goodbye & funeral streaming

Blog BMJ Supportive & Palliative Care

Using Skype during Pandemic Isolation Posted on March 15, 2020 by BMJSPCblog

How Hospitals, Hospices & Care facilities can use Skype to reduce loneliness during the Coronavirus (COVID-19) pandemic

By James Norris, Director of the Digital Legacy Association, London @JamesNorris



https://blogs.bmj.com/spcare/2020/03/15/usingskype-during-pandemic-isolation/

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Tutorial: How to arrange and video stream a funeral on Facebook during the COVID-19 pandemic

04/10/2020

https://learn.mywishes.co.uk/facebookfuneral/



Funeral Directors Must Speak About "Video Streaming" When Arranging A Funeral Published 5 October 2020

Video Streaming Best Practice Guide for Funeral Directors

- Partner with at least one self-shooter, camera person or independent filmmaker in your local area.
- Obtain a fixed costs for filming and/or streaming a funeral from at lear one supplier. A markup on the costs charged by externals should not be made or placed on the bereaved.
- Ensure that all staff are aware of the costs associated with providing a video stream.
- Ensure that all staff who arrange funerals talk about 'funeral streaming' as part of your organisation's best practice and code of conduct.
- If your organisation is does not provide a funeral streaming service make sure that 'funeral streaming' is still spoken about when arranging a funeral.
- Test, test, test. Make sure that whoever is providing the video stream visits the venue and checks the connectivity (WIFI / 4G signal) prior to the ceremony. When a stable WIFI is not available 4G should be used.
- Be open and honest with mourners about the technology provided and it's limitations prior to the event. Streaming funerals will bring a number of challenges. These include the sound quality, where camera's position, the weather (when outside) etc.
- Let friends, families and those arranging their decide whether or not they would like a funeral stream to be 'public' or 'private'. Most funerals in the UK are public events.
- Learn how to arrange and stream a funeral on Facebook. Arranging a funeral on Facebook can have a much greater reach than a newspaper advert. A large number of funerals are now streamed on Facebook.

https://digitallegacyassociation.org/video-streamfunerals/

Person-centred VR (anticipatory grief)



At the Heart The Room Where it Happens': An exploration of personalised Virtual Reality (VR) - bringing the home to the hospice during the COVID-19 pandemic Community

https://bit.ly/person-centred-VR

Dr Ros Taylor MBE, James Norris, Poppy McKay, Christine West, Katy Wade Michael Sobell Hospice & Harlington Hospice, London, United Kingdom

Virtual Reality

of our

Virtual Reality (VR) provides a way to transport someone to a different place and time.

Harlington Hospice is exploring using VR with inpatients, including the oldest old. It has taken patients back to the street where they grew up and visit tropical places on their bucket list. These experiences have been uplifting and the feedback has provoked further exploration of the use of VR.

Person-Centred Virtual Reality

1) The primary goal is to provide personalised VR content to inpatients.

2) A secondary goal is to provide family with a means to stay connected with the patient.

*Empowering people to connect virtually, may help reduce guilt and grief caused by separation.



Through play, discussion and innovation we have developed what we believe to be the first 'person-centred VR' intervention within the hospice setting.

During the advance care planning process a doctor at the hospice asks the patient 'what matters most' to them.

When it might be suitable, a 360 (GoPro) camera is offered to family or friends of the inpatient. The camera is taken away and content of home life is recorded. The content is then played in VR to the patient, immersing them back into family life. This is very different from just watching a video or a standard VR experience.

Instructions for friends and family members are provided to assist with the use of the camera.



amily and friends are able to tell stories, say their goodbyes, and the patient. The content is then transfered to the VR headset. The patient is then assisted and able to watch the content

Conclusion

The wellbeing team at Michael Sobell Hospice and Harlington Hospice will continue to develop 'personcentred VR' within the hospice and share learnings both internally and externally.

All VR documentation created is 'open access'. Documents are available in an editable format and can be used by other hospices and those providing end of life care.

The importance and adoption of virtual reality communication will continue to increase. Patients and families will soon expect to be able to communicate using Virtual Reality headsets and within 'the Metaverse'.

It is important that hospices are able to adapt and offer support when new communication technologies are made available.

Personalised VR might become an important service should COVID-19 measures limit the number of hospice guests in the winter months.

To start your own person-centred VR campaign visit, download and customise our guidance documentation and patient facing resources

https://bit.lv/person-centred-VR





1 OF THE 3

ABSTRACTS

IN THIS CATEGORY



Migrating the traditional over to the digital



https://blog.mywishes.co.uk/virtual-candles/

Collaborations: Tablets Against Loneliness

"Both Miss T and her husband have advanced dementia. They live in their own home and did not have internet access.

Since receiving a tablet they have been able to have Whatsapp communication and video calls with their daughter who lives in Canada.

Mrs T used to attend Yoga sessions but her now, advanced dementia prevents her from doing so (unable to follow movements).

The tablet provided was used in a 'case conference' (review of the support and housing provided by the council). A housing application video call will take place using Zoom (instead of face to face). This will occur from their own home with the support of her daughter."

A overview video can be watched by <u>clicking here</u>

*A low cost tablets, migrating existing services to the online space.

Black Country and West Birmingham

Your tablet is provided with a charger in the box. You might need to plug the cable into the plug provided and charge the device before using it. The cable might not be attached to the plug. If it isn't push one of the ends (the USB) into the plug. Both the cable and the lead

The tablet can be switched on by holding the power button on the edge of the device. The power button is the smaller silver button below the 'Lenovo' logo (the larger button above is an 'up and down'

rol and can be used to make the volume louder and quieter)

hat is attached to it is in the box

Support for professionals

Our Digital Asset & Digital Legacy Framework Chapter 1 - Supporting people to plan for the death on digital devices and online



The Digital Legacy Association

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

Prepared by: James Norris, Lucy Watts MBE, Elaine Kasket and Vered (Rose) Shavit of The Digital Legacy Association.

Peer reviewed by: Dr. Mark Taubert (Velindre NHS Trust Wales), Dr. Ollie Minton (St George's Healthcare NHS Trust,) & Vered (Rose) Shavit (Digital Dust Blog), Andrew Grey (National Council for Palliative Care)

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



Conversation triggers

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

Conversation triggers



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

Dr Mark Taubert, NHS Wales

The triggers for 155 conversations with patients, family members and carers when GPs discussed end of life



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.

http://digitallegacyassociation.org/framework

Training



https://digitallegacyassociation.org/training
Policy / Advising

We have advised a number of governmental, NGOs and blue chip providers about digital assets and digital legacy processes and best practices. These include:

- UK Government
- Portuguese government
- Singaporean government
- NHS England & NHS Wales
- Law Society
- Blue chips companies (Facebook etc)
- Charities, Legal firms, Universities across Europe & US

Digital legacy champion training slides



http://digitallegacyassociation.org/partners/

Digital Legacy Conference (annual)



Blog BMJ Supportive & Palliative Care

The Digital Legacy Conference 2 Posted on May 31, 2016 by BMJSP(blog By Sandy Weatherburn, Founder & Director at So management



My pledge for Dying Matters week

THE DIGITAL LEGACY CONFERENCE

The international conference exploring society's changing attitudes and behaviours in relation to death, bereavement mourning and the internet.

DigitalLegacyAssociation.or DigitalLegacyConference.co

www.DigitalLegacyConference.com

MyWishes

https://mywishes.co.uk

MyWishes mission is to "utilise technology in order to normalise end of life planning"

Making MyWishes accessible and normalising EOLc

My Wishes					ActivityLog > 🚱 James_norris	
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My Last Will & Testament		M	My Wishes		i 🔬	catherine
My Funeral Wishes	2	What name do you like to be calle	© My Profile	自投		52.8
My Advance Care Plan	1 Ci	Mr James Norris	1 My Last Will & Testament	57	Welcome to MyWishes. We address future planning in a new and innovative way. Our service is currently being shaped by you and the feedback you provide. To learn more click	
My Goodbye Messages				1.7	Precome to ingrising, the address foole planning in a real and anotable may, our so the is carriedly deing imple of you and the receases you plotter, to reall more close here	
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Anticipatory care planning



https://www.mywishes.co.uk/advance-care-plan

Saying goodbye virtually





Bring Joy!

My Vlad, family and friends...make a mission from this simple awareness: bring an authentic smile on an unknow face, as often as possible! I love you! Leti

Published on: 28th April 2019

https://www.mywishes.co.uk/digital-legacy

Live demo

www.MyWishes.co.uk

MyWishes - Learn Zone

Q



advance care

Why you should have an Advance Care Plan

Free Webinar: How to plan for death without leaving the sofa

How COVID-19 is changing funerals

COVID-19 Updates

How to keep your documents safe (and accessible)



Being bereaved at Christmas

12/22/2021

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How to assign a Lasting Power of Attorney (LPA)

09/27/2021



Design your own Coat of Arms



Video calling software can now be used when witnessing Last Will & Testament's



How to backup a complete archive of your MyWishes data.



https://learn.mywishes.co.uk/

MyWishes - Learn Zone



https://learn.mywishes.co.uk/facebook-funeral/

Things to think about...

- What plans do YOU need to put in place to safeguard your digital assets and digital legacy?
- How are the areas explored of relevance in your region and to the communities you serve?
- What do you need to learn?
- What barriers need to be overcome?

Homework (optional)

- Make plans for your digital assets and digital legacy in a Social Media Will...
- MyWishes
 <u>https://www.mywishes.co.uk/soc</u>
 <u>ial-media-will</u>
- Excel Template: <u>https://digitallegacyassociation.o</u> rg/social-media-will-template/
- Listen to Joan Bakewell's 'We Need to Talk About Death, <u>My</u> <u>Digital Legacy</u>'.





The Digital Legacy Associatio

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 & Testame

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)					

Make EOL planning normalised, make administrative tasks easier for your loved ones...



www.MyWishes.co.uk





Michael Sobell Hospice, Mount Vernon Hospital, Gate 3 Northwood HA6 2RN, United Kingdom

Thank you for your time.

www.DigitalLegacyAssociation.org www.MyWishes.co.uk



MyWishes How It Works - About - Features -

Login Register



	James Norris' Bucket List	My Goodbye Message	
	A Bucket List is a list of things someone would like to do before they die. If James Norris has created a Bucket List it will be displayed below.	My Scheduled Message My Bucket List My Funeral Playlist My Funeral Message	
James Norris Trying to make a positive with technology.	Play the guitar in public Due Date: 15th July 2018 Achieved		
 Facebook Twitter Instagram 	Visit Bali Due Date: 1st January 2023 Not Achieved	My Postural Care Plan	
Register for a free MyWishes account	Get a hair cut Due Date: 1st April 2021 Not Achieved	Share this profile f Solution Sol	
	Live in the Faroe Islands for 6 months Not Achieved Due Date: 1st January 2042 Not Achieved		
	Watch Guns n Roses perform Achieved Due Date: 1gth June 2019 Achieved		

https://www.MyWishes.co.uk/jamesnorris/bucketlist