



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



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)















This is to certify that

James Norris

has successfully completed the

Fellowship in Palliative Care

in the month of August 2021









CERTIFICATE NO: FPM043/21



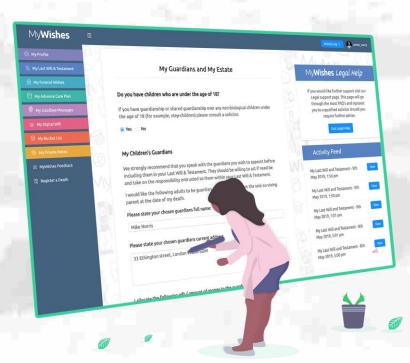
My story...

- 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

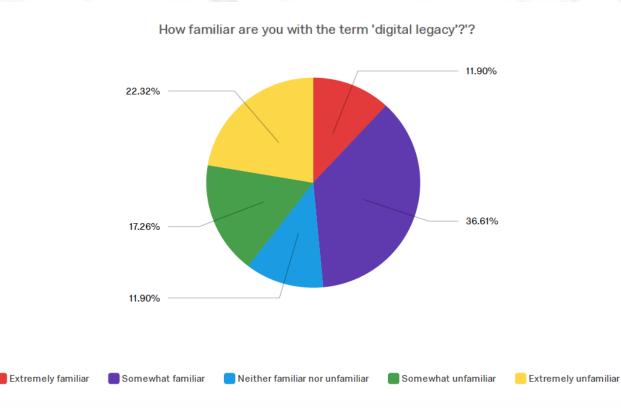
We might be the last generate of humans who experience life without the internet....

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

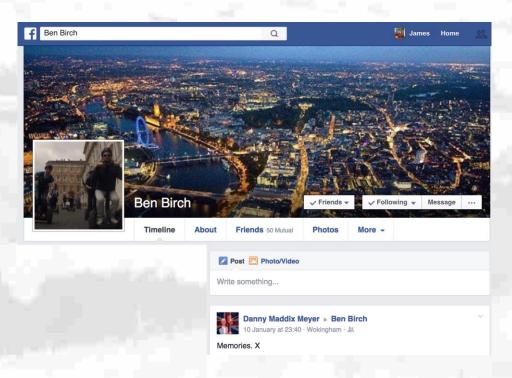
Do you know what a digital legacy is?



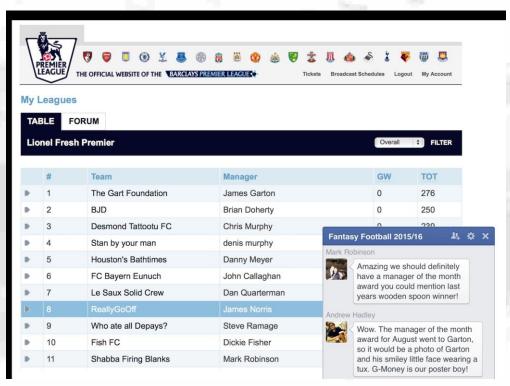
What is our 'digital legacy'?

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

Why a digital legacy is important



Why digital legacy is important





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

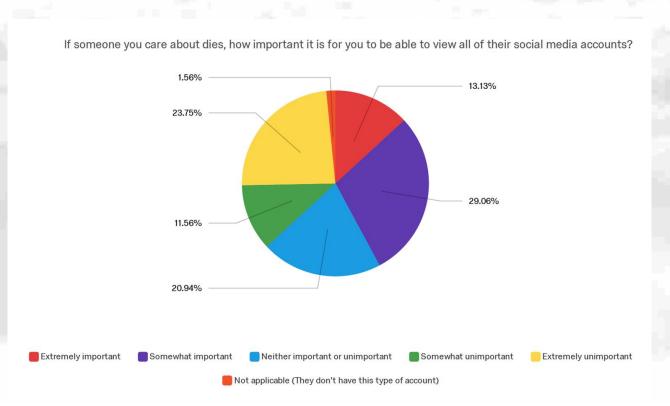
Raised offline: £0.00

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



Digital Assets

What are 'digital assets'

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

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...

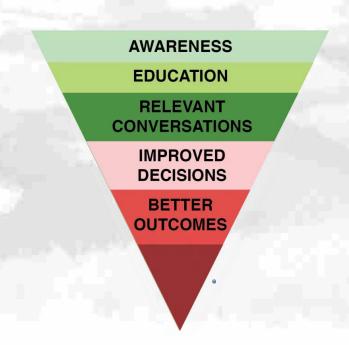
- Can someone access your phonebook (to inform people of your death and invite them to your funeral?
- Can someone retrieve the photos taken on your phone? (what about your computer, other devices with passwords)
- Can someone read the messages on your phone (do you want them to)?
- How will the person 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





https://digitallegacyassociation.org/

Support for the public

Public awareness leaflets





The Digital Legacy Association is the professional body dedicated to raising the quality of end of life care in all areas relating to digital asset and digital legacy. Our misson is to help ensure that everyone's end of life whether are met both in the real world and the digital realm. We do this by supporting the general public and by developing

WWW.DIGITALLEGACYASSOCIATION.ORG

andards, frameworks and toolkits with charities and third party organisations.

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

Funeral Wishes (and other third party leaflets & resources)





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.

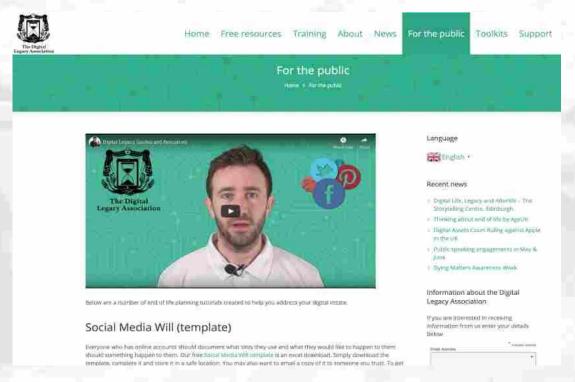
If arranging a funeral in England while Covid-19 restrictions apply, you can find latest government guidance on gov.uk website. If arranging a funeral in Wales go to gov.wales website.

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.

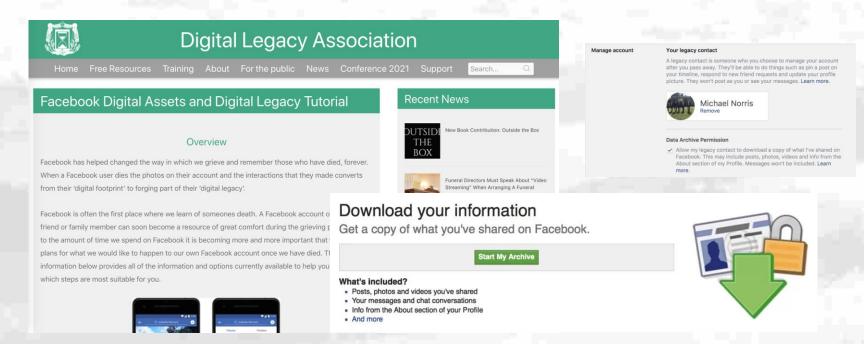
Contact details for any organisation mentioned in this factsheet can be found in *Useful organisation* section.

Tutorial hub for the general public



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

Facebook tutorial examples



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

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

Social Media Will (template)



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)

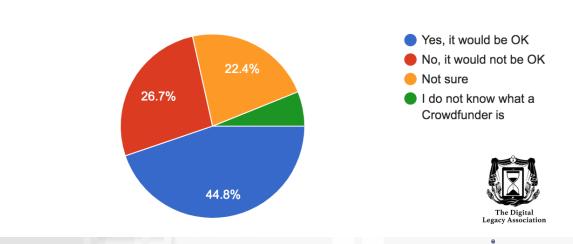
*Insert Extra cells when required

- 6

Bereavement...

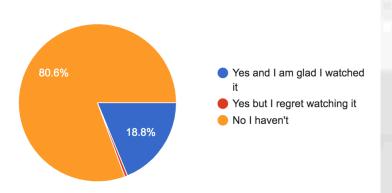
Changing norms and values

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?

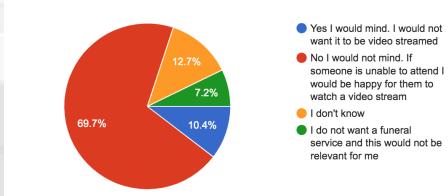


Changing attitudes and behaviours

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?



^{*}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 @James Norris



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



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

04/10/2020

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



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-stream-funerals/

Person-centred VR (anticipatory grief)



At the Heart of our Community The Room Where it Happens': An exploration of personalised Virtual Reality (VR)

- bringing the home to the hospice during the COVID-19 pandemic



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

Virtual Reality

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.

Methodology

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.

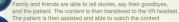
Person-Centred Virtual Reality

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









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 <u>your own</u> person-centred VR campaign visit, download and customise our guidance documentation and patient facing resources

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







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.

Support for professionals

Our Digital Asset & Digital Legacy Framework

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



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)

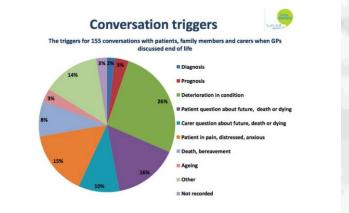
The world is changing

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.



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:

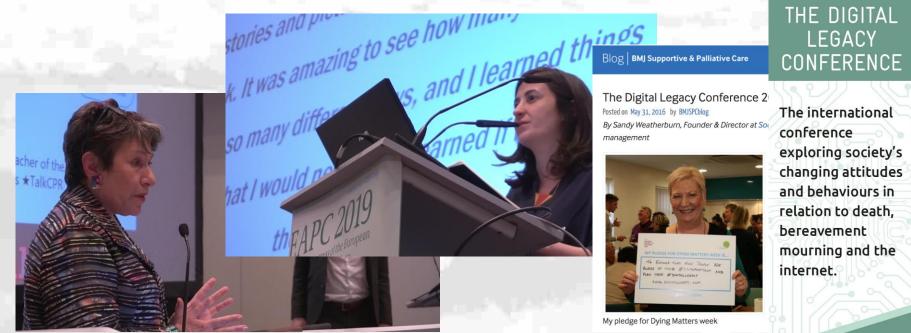
- UK Government
- Portuguese government
- Singaporean government
- NHS England & NHS Wales
- Law Society
- Blue chips companies (Facebook etc)
- Charities, Legal firms, Universities across Europe & US

Digital legacy champion training slides



http://digitallegacyassociation.org/partners/

Digital Legacy Conference (annual)



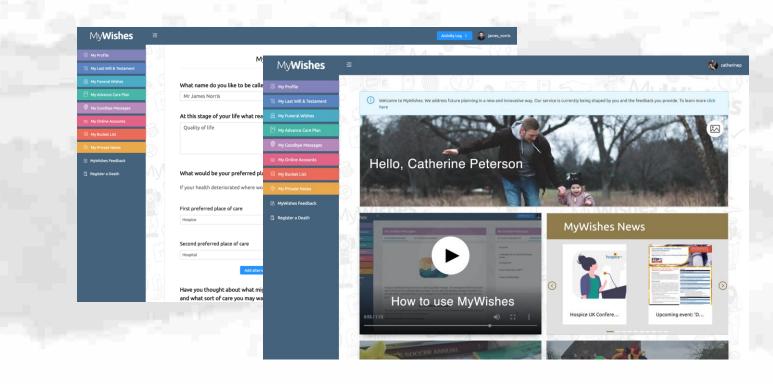
www.DigitalLegacyConference.com



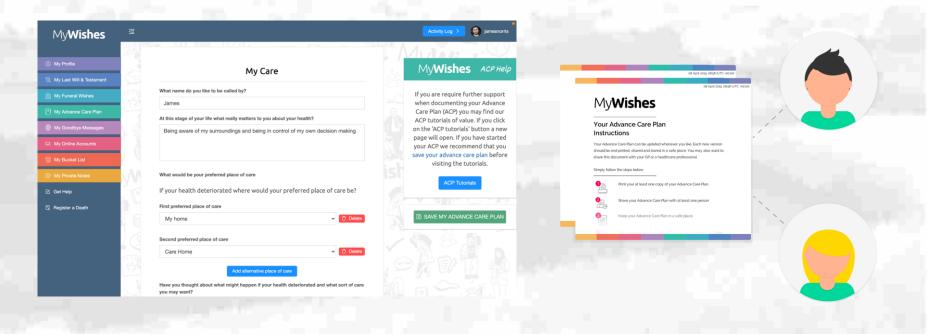
MyWishes

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

Making MyWishes accessible and normalising EOLc



Anticipatory care planning



Saying goodbye virtually





Bring Joy!

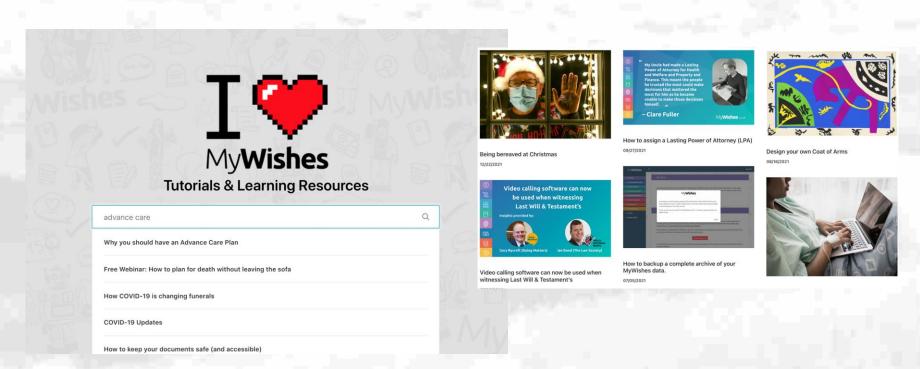
My Vlad, family and friends...make a mission from this simple awareness: bring an authentic smile on an unknow face, as often as possible! I love you! Leti

Published on: 28th April 2019

Live demo

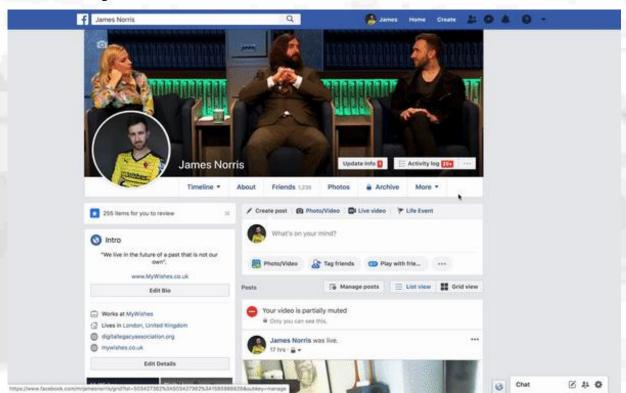
www.MyWishes.co.uk

MyWishes - Learn Zone



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?

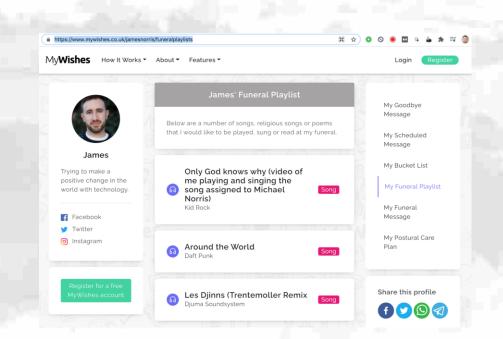
Homework (optional)

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





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





MyWishes



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

