

Design research to support ongoingness

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Abstract: This article details the development of a live design research project working with people who are bereaved, people who are living with dementia and people who are approaching end of life. The project aims to support people to continue bonds with others in anticipation of and following death. It centres on the idea of ongoingness and using art, design and digital technologies in gentle, personally meaningful ways.

Keywords: continuing bonds, bereavement, design, digital technology, cocreation, participatory design

Ongoingness

We are using the term ongoingness to signify a forward-looking facet of continuing bonds (Silverman, Klass, & Nickman, 1996; Howarth, 2007). While continuing bonds can be enacted in a number of ways, for instance through memorialisation or reminiscence, what we are trying to do is create possibilities that go beyond 'looking back' or 'maintaining something precious as it was' in order to create newness and dynamic continuations of relationships. Ongoingness gives us the conceptual framing to think of how we can give people experiences that can be personally curated to unfold dynamically in response to future events in a person's life and to think about continuing bonds in relation to fluidity, surprise and change over time.

Digital technology

As a team of researchers from a range of backgrounds (design, occupational therapy, human-computer interaction, computing science, psychology) we've worked with digital technologies over many years, always seeking to make things that are personally meaningful for people and that support wellbeing and sense of self. Often this has meant working closely with individuals to make something with and for them that represents something very personal and often uses technology in a very poetic way. In this project we are trying to develop new ways to create and curate digital media to support ongoingness. This means seeking to understand if and how new forms of digital media curation and physical/digital objects can support people's sense of self and relationships with others in anticipation of end of

life and also in bereavement. We're taking a highly personal view on what digital technologies can be and seeking to make very individualised pieces with and for participants. Cruse Bereavement Care Tyneside, St Oswald's Hospice and Sheffcare have been fantastic support for the project and have helped us meet and work with participants who are recently bereaved, approaching the end of life or who have dementia.

Our research rationale relating to digital technology is that, simply as part of living in a more digital age, there are a growing number of people who are accruing and creating digital assets on a daily basis (for instance photographs, voice recordings, status updates, online conversations, videos, blogs) and that this is a hugely valuable resource that could be used to support sense of self and new forms of social practice – helping people as they move towards end of life as well as those who are left behind after death. However, because technology development is not as yet focused on supporting continuing bonds in ways beyond memorialisation and reminiscence we do not currently have appropriate tools to help people curate these digital assets to specifically support continuing bonds in bereavement or when approaching end of life. While death is an event, both dying and grief occur in the social sphere. As such there is a rich opportunity for research to explore the potential benefits that design and digital technologies can bring to people to offer new ways to express one's self in the present and for the future; create content that will support other people after one's death; and enable the bereaved to maintain lasting bonds with the deceased in new ways. There is also huge potential for future bereavement care and support where digital media could be used in new ways by individuals, families and bereavement counsellors in order to help people find new ways to continue bonds.

As we know from a number of fields (philosophy of dementia care, Kitwood & Bredin, 1992; bereavement studies, Klass, Silverman, & Nickman, 2014), we construct identity partly through our relationships and in combination with others. In many contexts, however, our sense of who we are can become brittle and weakened. Following the death of a loved one or living with the knowledge of approaching end of life are just two examples of when sense of self is threatened. In situations like these the digital media that we have accrued or made over time could offer new ways of reflecting back to us meaningful things about ourselves and our loved ones and give us new materials and ways to create continued bonds for the future. In this project we are thinking about digital content as far more than data – it is about human connectivity and that in turn relates to health and wellbeing; when we feel connected to things, we feel part of something and supported in that nexus of people and things that has meaning to us. At the centre of the ongoingness project is the idea that objects and interactions that have poetry are powerful tools in helping us see meaning and connections for ourselves.

Design

Similarly, through things like design, through craft and making bespoke things for people, we can support health by acknowledging the power of beauty. Beauty is often underestimated and taken to mean aesthetics or how something is styled, but it is much deeper than this and has real potential to help us when we are in pain. There is a quote from Florence Nightingale in 1859 that captures this so well:

'The effect of beautiful objects, of variety of objects and especially of brilliance of colour is hardly at all appreciated... I have seen in fevers the most acute suffering produced from the patient not being able to see out of a window and the knots in the wood being the only view. I shall never forget the rapture of fever patients over a bunch of bright coloured flowers. Little as we know about the way in which we are affected by form, by colour, and light, we do know this, that they have an actual physical effect. Variety of form and brilliancy of colour in the objects presented to patients are actual means of recovery.'

(Florence Nightingale 'notes on nursing' – 1859, quoted in the Department of Health's Report of the review of arts and health working group (Cayton, 2007)).

Florence Nightingale isn't talking about beauty as a stylistic component here, she is describing a powerful, pragmatic use of beauty as an aid in suffering. Within the ongoingness project we are working very closely with a small number of participants to make things with and for them and have the opportunity to explore what someone feels is beautiful and meaningful for them. Design flows through all our methods and we use creative means to get to know people and find a way to support them through making things. One of our design methods is to make objects that give participants different ways to reflect on their relationships with others – for example a medal asking when have they been at their bravest, or small paper houses asking them to reflect on homes they have built with loved ones (see images below). Metaphor and gentle ways to ask difficult questions are very important and it is useful to think of artefacts being something that we don't merely speak 'of' or 'about', but agents that we speak 'through' or 'with'.

From the things (stories, objects, photographs etc) that people share with us in response to these design methods we start to build together ideas of what we could make to support continued bonds for them. As the term ongoingness, and the ways that this could manifest in physical/digital things, is somewhat complex to imagine, before we started to work with participants we began by drawing on our own lives to create a series of examples



Fabric medal and paper houses made for a participant (designed and made by Jayne Wallace).

of what this could mean. Here we share pieces and storyboards from this process.

ReFind

This is an object with digital capabilities that we made using photographs from the first author's (Jayne's) mother throughout her life. We wanted to explore if and how we could create something that acted like a dialogue of sorts between someone bereaved and someone deceased using a finite archive of media (in this case photographs). Our idea was in some ways akin to a mentoring object and motivated by the desire for a loved one to connect to the deceased person and get a sense of what their advice or opinion would be in a certain situation.

Jayne tagged around 63 photographs of her mother, Betty, who died in 2015, with information about what was happening in each photograph including, and also beyond, what was visibly obvious – for instance a photograph of Betty in her kitchen was tagged to describe the year; the location; who had decorated the room; things that were made by specific people in the room; the significance of certain clothes that she was wearing; that this was the first day in a new job and that she was nervous, but also proud of herself. By adding the semantic meanings of photographs, we were able to create a multi-layered categorisation of them all and develop ways of connecting meanings together. The 63 photographs that made up Betty's archive in the piece spanned her life from a young child to the age of 81.

Using an android smartwatch, we altered the coding, disabled the watch functions and touchscreen and focused the interaction solely on the gyroscope sensor in the piece



which detects rotational movement. The watch stopped being a watch and became a circular, customisable digital screen manipulated by turning or rotating the object. The device was housed in a metal and Corian® casing to move the piece away from looking and feeling like a watch and making it more like a pebble or small object to fiddle with and turn in the hand.

The piece houses the 63 tagged photos of Betty and comes to life when a new tagged photograph of something that is happening in Jayne's life now is sent via wifi to the object. This triggers a small collection of five photographs from Betty's archive to be shown that relate to the new one of Jayne. Five began as an arbitrary number, but through living with the piece and exploring smaller and greater quantities of photos shown in response five the right number. We found that more made it difficult to draw clear personal associations or a sense of specific meaning between what is sent to the object and what it returns to you. Fewer than five images seemed to limit the scope for narratives to develop across a collection. This could be altered for each individual however to tailor the piece to what felt right for them.

The collection of photos can be seen by rotating the object forwards and backwards in your hands. Each time the



ReFind piece made from Corian®, brass and an android digital watch (designed and made by Trevor Duncan and Jayne Wallace, coding by Kyle Montague and Luis Carvalho).



By rotating ReFind new images are revealed.

screen is rotated a new image appears. Because of the tags that have been given to each photograph the connections between the new photo of Jayne and the collection of photos of Betty occur but are for the individual (in this case Jayne) to make their own sense of. We found that although Jayne knew the photos of her mum very well she hadn't seen the connections between the photos or the groupings of photographs that were triggered by the object and this brought a fresh sense of newness to them. Beyond a feeling of something new they were like a puzzle to think through and to make sense of; why were certain photos triggered in relation to new ones of her? In some cases the collection of images that were shown really made sense in relation to the new photo and gave Jayne a tangible sense of what her mum would have been saying to her. This didn't happen every time, but when it did there was something that felt personally valuable and a sense of connection to her mum and the current things that were happening in Jayne's life.

We can only speculate as to the meaningfulness of ReFind for other people as we have as yet only used it with one person. But at this early stage of the project the designs that we have been developing serve as examples of what ongoingness could look like if we use the vast array of design and digital technologies now available. Our hope with this object would be that someone would be able to feel something tangible, visceral even, in seeing the connection between a photo of them now and the collection of old photos that this triggered. Perhaps it could give someone a sense of tuning in to the idiosyncrasies of the person who they knew so well and getting a sense of what they would be saying now about what was going on in their life.

Storyboard ideas

In addition to thinking about physical/digital objects like ReFind we have also been thinking about things that happen in particular locations because a loved one was once there, or how services could be used meaningfully to create ongoing connections between the bereaved and the deceased.

For example, in one story board someone is travelling and finds herself in an airport in a foreign country – somewhere that her father used to travel through for work. Before he died he curated a future experience for her: if and when she was in the airport, she would be sent a message to say that there is a surprise waiting for her from him at his favourite café.

This second storyboard, below, shows what someone might put in place in anticipation of their own death.

Something that a widower (John) does triggers a letter from his dead wife to be delivered. The letter tells John that he needs to make the most of his life, that what they had was a very deep love and that he needs to get out of the house and embrace the good things in life again. The letter tells him to be ready for a short trip later that day and just to trust her and 'go with it'.

Later that afternoon a prepaid Uber arrives at the house. The driver has been briefed on the trip and has been selected by John's wife as someone who is gently talkative. He has been briefed to play certain songs on the car stereo during the journey. The Uber takes John to one of his and his wife's favourite places – a park with a favourite view of theirs – and the driver tells him that he will be back for him in an hour. After a few minutes a Deliveroo cyclist arrives at the bench where John is sitting and gives him a picnic – all foods chosen by his wife and prepaid by her.



Drawing by Nantia Koulidou

These storyboard examples of ideas are ways in which services and the digital trail we leave behind us could be curated purposefully into an experience that could give someone bereaved a sense of being closely connected to a deceased loved one. It is also a possible way to give agency to people approaching death to put things in place for the future. These are only beginnings of ideas of course and there are many logistical complexities within them, but services such as Uber do offer levels of customisability,

such as the ability to request certain music to be played or whether a driver engages you in conversation or not, which make them interesting in design terms in a context such as this. Equally there is the potential to trigger an experience if someone was seeming to not be coping well, or if someone was physically at a significant location – like a daughter travelling to one of her dad’s old haunts. Each of the storyboard ideas are achievable now and conceived with the services and technologies that we currently live with. There are significant challenges to find ways for technologies and services (ie Uber, Deliveroo, TaskRabbit) to work in harmony and be configurable for activities that are to happen at a point in the future dependant on the life of the bereaved person. But these challenges pose fascinating research and business opportunities and could significantly support people as they live with bereavement and as they prepare for end of life.

We made these storyboards and the ReFind piece among other designs as a way to illustrate to potential participants what could be possible and as a way to open up conversation with them about what might be valuable for them in their lives and particular relationships. We are currently working with two participants and pursuing new, remote ways to work with more people during the covid-19 pandemic. If you would like to know more about the project, or about participation please get in touch. We’ve

been very lucky to be supported by our project partner organisations and in particular Cruse Bereavement Care, Marie Curie, St Oswald’s Hospice and SheffCare. The ongoingness project runs until June 2021. If you would like to know more or talk about becoming a participant find out more at enablingongoingness.com. ■

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