Understanding suicide and assisted dying – why "design for death" is tricky?

By Lorraine Gamman & Pras Gunasekera

"A girl calls and asks, 'does it hurt very much to die?'
'Well, sweetheart', I tell her, 'yes, but it hurts a lot more to keep living'."

— **Chuck Palahniuk**, **Survivor, (1999)**

We cannot escape the reality of dying, it will happen to all of us. At least 0.8% of the planet's population (55m people) are estimated to die each year (De Sousa, 2015). But how to design for death is very tricky considering that 'assisted dying' (a system that allows a person the choice to get help to control their death if they decide their suffering is unbearable) is a taboo subject and 'suicide' (taking one's own life) even more so. In daily life, most people don't often talk about *suffering* (men find this particularly difficult, see Galdas, Cheater and Marshall, 2005) nor about death, suicide or assisted dying because of cultural customs and other repressive mechanisms that prevent open discussion. In the global context, death is usually connected with the sacred rather than profane material issues and suicide transgresses assumptions about the sanctity of life. So, policy, concerning how to dispose of our bodies in new ways when we don't need them and how to design the end of ourselves, don't happen that often. The subject of death is sacrosanct, particularly if the person concerned chooses to commit suicide. Also the differences between lonely 'do-it-yourself' suicide compared to assisted/accompanied dying (as in the Swiss 'assisted dying' model) are rarely the subject of open discussion.

Designing is acknowledged as inherent to human beings (Dilnot, 2014; Fry *et al.,* 2015). It shapes power relations, it can (re)write pasts, reconfigure presents, and prefigure futures (Prado de O. Martins, and Vieira de Oliveira, 2016). It has the potential to be a catalyst for intentional material and philosophical change, but outside specialist design education circles the world talks about design as much as it talks about death, i.e. not that often (with a few notable exceptions!). So, this chapter will try to address the gap in knowledge of how 'design', which is about pragmatic arrangements that can be envisioned and created, can be a space that can facilitate autonomy for end-of-life and assisted dying decisions in the context of 'sanctity of life' discourses. Of course, legally binding advanced health care

directives (to refuse treatment) are not per se ‘assisted dying’, even if it is an end-of-life decision that is legal in the UK. It is also one that can leave some individuals with no other choice, when medical treatment is stopped, than to starve to death.

The context of our discussion therefore, is that developments in medicine and our lifestyles have meant that humans are living longer, some with poor health conditions they would prefer not to experience long term. In fact some research indicates that increasing longevity for many people over the age of 65 could mean adding poor quality not good quality years to their lives (Crimmins, Zhang and Saito, 2016). An earlier European Court of Human Rights ruling (2002) in the case of Pretty v. the UK (paragraph 65) went further and pointed out: "In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflicts with strongly held ideas of self and personal identity."

Of course the human desire to control death, even in difficult scenarios, raises all sorts of ethical and political questions about the ‘right to die’ and also about ‘abnormal’ mental health conditions. For example, Cavanagh, Carson, Sharpe and Lawrie (2003) have argued that the majority of people who die by suicide suffer from mental disorders. Many other writers following Durkheim (1897) describe diverse causal factors including weak social ties and social isolation issues that inform suicide or requests to assist suicide, and inevitably these accounts have informed protective social policies. With assisted dying, however, the evidence is such that the individuals being helped have nothing in common with people suffering from mental disorders. The data from the US-State of Oregon, for example, shows that it is not the weak and vulnerable that opt for assisted dying, but rather the health-insured, and the above averagely educated (Public Health Division, 2017).

In a 2014 debate for MA Communication Design students at Central Saint Martins, UK, Baroness Mary Warnock recognized the diverse reasons and factors for suicide, when she spoke *for* changing policy to support assisted dying. Baroness Ilora Finlay spoke *against* this position, explaining why so many disability groups oppose ‘assisted dying’. Speakers at the same debate from the Samaritans, the British Humanist Association, and Survivors of

Bereavement by Suicide and other social innovation networks (documented at www.macdextendingempathy.wordpress.com) demonstrated that the issues raised by suicide and policies about it, are equivalent to a 'wicked' design problem (defined and outlined by Rittel & Webber, 1973; Buchanan, 1992). No agreement or easy discussion regarding the issues raised by suicide, appears to be available that suit all actors in the political and social landscape. Consequently, this chapter considers discourses that have informed this existential debate by first reviewing 'design against suicide' initiatives and secondly, reviewing issues raised by designing for assisted dying and voluntary euthanasia. The final section of our chapter will consider why it is important to open up agonistic discussion on this topic in the way Chantal Mouffe (2013) describes when thinking about the world politically. Ultimately this paper will look beyond the design of existing humanist anti-suicide policies, to consider broad questions about how more design engagement regarding end-of- life rituals could aid the development of pragmatic ways to make new suicide policies work by design to better serve democratic purpose.

1. Design Against Suicide

To understand why we often speak about suicide in hushed tones, the cultural taboos that surround death along with its euphemistic language like 'passed away' needs to be examined and understood. Elsewhere we have discussed how future visions of death care design, generated by a 2013 *Designboom* competition, offer important new ways of thinking about how to design for death (Gamman and Gunasekera, 2015). In a similar way the social design research team in Hong Kong led by Yanki Lee, the *Fine Dying* Project used participatory/critical design methods to engage communities to codesign dying matters (Lee, 2015). This included new ways to dispose of their own bodies or to commemorate or remember those who have died by introducing the concept of a Death Jewellery Collection; designed to hold synthetic diamonds made from human ashes.

Fig 1 The Light of the Death Jewelry Collection (design research by Yanki Lee of HKDI DESIS Lab/ concept designed by Pascal Anson), 2015.

In seeking to identify new forms of human body disposal, the *Fine Dying Project* has worked with community groups, including groups of senior citizens, to create sustainable strategies and possible new futures for cities. Hong Kong, like other cities struggles to find space for people to live as well as to die. Yet neither the *Fine Dying Project* nor the *Designboom* competition addressed design for suicide or assisted dying, perhaps because these concerns (despite the dominance of neo liberal economies) are difficult to discuss. With a few global exceptions, such as Hollywood portrayals of Japanese Samurai (or their wives) committing 'seppuku' (also called 'hara-kiri' in English) for honorable purposes in films like *The 47 Ronin* (1941) *The Last Samurai* (2003) and James Clavell's TV mini-series, *Shōgun* (1980) suicide is rarely represented as a form of death that design could engage with. Nor is it taken to be a way of dying that deserves positive commemoration, not least because of concerns about suicide "contagion" and "copycat" suicides.

Whilst there are websites that promote suicide and discuss details of best suicide methods including the most painless ways to die, most search engines are designed to display prevention discourses associated with the Samaritans when the word 'suicide' is used as a search term. This may be because in 2012 suicide accounted for 1.4% of all deaths worldwide, making it the 15th leading cause of death (Preventing Suicide: A Global Imperative, 2014, p. 22). In 1998, suicide constituted 1.8% of the total disease burden; this is estimated to rise to 2.4% by 2020 (Bertolote, 2009). It is now one of the three leading causes of death among young people (both male and female) aged 15-44, (Public Health Action for the Prevention of Sucide, 2012, p. 4). Suicide is traumatic for those left, affecting parents and families dealing with the loss of children to suicide as well as communities when suicide occurs in social spaces. Bridgend in Wales unfortunately became known for its attempts to makes sense of teen suicides when between January 2007 and December 2008, 26 people committed suicide in their homes, many of whom were aged between 13 and 17. 'Suicide clusters' and ideas about 'suicide contagion' have been investigated in a number of other geographical regions, including Palo Alto High School in Silicon Valley, with inconclusive results.

Suicide attempts are up to 20 times more frequent than successful suicides (Preventing Suicide: A Global Imperative, 2014, p. 26). The World Health Organization (WHO) identifies that almost 800,000 deaths by suicide occurred in 2015, making it the second leading cause of death by injury after road traffic injuries (World Health Statistics, 2017, p.

32). Prevention discourses are paramount in discussion with the WHO Mental Health Action Plan 2013−2020 aiming for a 10% reduction in the suicide rate in countries guided by this (Preventing Suicide: A Global Imperative, 2014, p. 09). However, the cultural sensitivities that surround suicide mean attempts to design against it in the built environment often have to be covertly implemented. Even at suicide hotspots, we don't want to be reminded of suicide or death by any means. Consequently, discourses that promote safety and protective designs to prevent suicide attempts usually contain hidden target hardening metaphors, rather than operating as part of an open discussion about suicide, mental health or social isolation issues.

In most countries suicide is no longer a crime, but an ethical issue. In the UK, the Suicide Act of 1961 decriminalized the act of suicide in England and Wales so that those who failed in an attempt to kill themselves would no longer be prosecuted. Given the criminological context associated with the history of suicide, it is not surprising that some of the measures from the Design Out Crime (DOC) movement were taken on board by those who promoted suicide prevention because agenda setting promotions by the UK Home Office were influential and connected both approaches. In 1988 crimiminologists Clarke & Mayhew, employed by the Home Office, showed that gas suicides in Britain in the 1960s and 1970s (literally putting your head in the oven to die) were reduced when the carbon monoxide content of domestic gas changed. When coal gas was replaced by natural gas from the North Sea, suicides by cookers virtually stopped altogether. By the 1990s, such accidental 'designs' against suicide inspired the DOC movement (see Clarke, 1983; 1992). Clarke made a strong case that physical design can provide opportunities to commit suicide, or make them more difficult. See also Gamman & Thorpe (2017) on issues raised by design for behaviour change.

The idea underlying this work that suicide and death needs to be prevented, that public places need to be safe, can be extended to humanistic and empathic design understandings (Gamman & Thorpe, 2016). As well as protecting those who may feel suicidal from harming themselves, preventive design protects the relatives and operatives who have to live with the impact of successful suicide events. Public Health England (2016) puts this bluntly, noting that when "a suicidal act takes place outside the deceased's or another's private

home or in a public location, it offers potential for the act to be witnessed by members of the public, or for the body to be found by someone unknown to the deceased". The secondary impacts of suicide not only involve financial clean up costs as highlighted in the DIGNITAS inquiry (2017, p. 11) but can cause immense emotional suffering, not just to the loved ones of the suicide victim, but also to the workers and bystanders, such as the drivers of trains that hit suicides.

Harm to others clearly can't be ignored by those designing *against* suicide even if this focus, might result in the sort of target hardening design that often adversely affects the aesthetic of the built environment (as Minton 2009 describes). Design for suicide prevention has not yet delivered the sort of empathic designs associated with healing places like the Maggie's Centers (drawing on nature to reduce alienation) because often suicide prevention design is an "add on" or retrofitted to pre-existing built environments. The designers of spaces/places that become suicide hotspots will not have anticipated such spaces/places would aid or facilitate people killing themselves. One positive side-effect of retrofitting such spaces to make them less convenient for suicides, is that anti-suicide design strategies raise issues about the need for human agency as well as physical design. In locating telephone helplines at such hot spots, or designing in human inspections, there is recognition of the need for human contact to aid prevention. A recognition that reliance on physical barriers or remote and distant crime prevention strategies such as CCTV (or worse, surveillance of spaces via drone activities) is not enough.

The Samaritans, a UK charity that supports troubled and suicidal individuals, has delivered some excellent anti suicide campaigns including the "We Listen" campaign, designed by MullenLowe in 2016. They point out that, despite best practice prevention design strategies, more lives are lost in public space to suicide than to road traffic accidents. They recently brought together over 50 stakeholder organizations to try and address this problem. Amongst the actions they reviewed, was the need to regulate internet sites used by high risk networks and individuals. These sites contain statements such as: '*You may be reading this looking for information on methods to commit suicide. They are here*.' (lostallhope.com) and '*planning ahead greatly improves your chances of a good death*.' (finalexodus.org) which could be seen as promoting suicide. This example of the ethical consequences of digital public space is a particular instance of broader, tricky dilemmas about how best to design or regulate it, given a broadly liberal desire for freedom of information that seeks to tolerate

diverse and controversial views.

2. Is it possible to ethically assist dying by design?

Debates around ‘assisted dying’ and ‘voluntary ‘euthanasia’ remain more controversial than designing against suicide. ‘Euthanasia’, which is prohibited all over the world, and ‘voluntary euthanasia’ which is possible in the Netherlands, Belgium, Luxembourg and to some extent in Canada (where it is defined as Medical Assistance in Dying or MAID), are of course very different approaches. Assisted dying and voluntary euthanasia *always* require the explicit wish/consent of the patient (and acceptance in law of this process), without which, the doctor administering the drug would be commiting euthanasia which is a criminal offence of murder/manslaughter.

Those who are in pain, and want to put their affairs in order by managing their own ‘end of life’ and/or designing their own merciful death, are rarely allowed to do so legally. These are very different situations to people who attempt or commit suicide, whilst the balance of their mind is/was ‘disturbed’, as Barraclough and Shepherd (1976) point out. Even when mental illness is not the main reason for suicide, dealing with the aftermath of suicide is very distressing to the families left behind, for moral, emotional and religious reasons. Yet this distress also constrains open discussion about assisted dying for fear of offending those who have already lost loved ones to suicide or are worried about this happening. There is also concern, about whether or not the design of systems for assisted dying can avoid criminal mis-use and abuse, and manage the potential for an individual to be influenced by others to commit ‘voluntary’ suicide. However, this focus on the potential ‘misuse’ of law, is not always helpful because concerns about murder of the vulnerable, rather than design of systems that could prevent this, tend to block open discussion. For example, living wills (also called ‘advanced directives’ or ‘advanced decisions’) with clear, actionable parameters (such as “I only want to be given a lethal injection if I can no longer consistently recognize any members of my family when consulted over a specified period”) could be implemented by carefully designed strategies, that include checks by medical and other professionals. At a future date, if the law changes, advance directives made by individuals when ‘compos mentis’ might mean those of us who do not wish to experience

advanced stage dementia, for example (where we cannot recognize loved ones) can have our wishes to end life at this point, heard and implemented.

Of course, design could be used in many ways to assist dying or prevent suicide. Yet discussion of design and suicide is limited perhaps because the capacity of design is poorly understood outside of design circles. Designers are rarely invited to discuss how to prevent suicide in terms of service provision where radical social innovation is needed. Here, empathy with the potential distress of those whose lives have already been harmed by suicide may repress truly agonistic debate or social innovation benchmarks by design being developed. Paul Bloom's *Against Empathy* (2016) suggests democratic debate can be hijacked or blocked by stigmatized interest groups. Such as those with disabllities who are worried changes to the law on suicide (and the design opportunities this could bring) will eventually impact on them in negative ways, possibly in worse case scenarios, linked to eugenic narratives.

Open discussion is also compromised by the fact that suicide attempts are viewed as a 'cry for help' and actual suicides are often understood by the therapeutic community as 'missed opportunities' to provide that help or social contact. Consequently, the debate about suicide and, by extension assisted dying and voluntary euthanasia, run into a number of powerful and tricky ideological conflations about preserving life at all costs, that even a legal order to allow someone to die cannot override. Cathy Rentzenbrink's brother existed in a vegetative state for over eight years, and when his family decided the last act of love would be to let him die, they obtained a court order that agreed to the withdrawal of life support, as a form of passive euthanasia. There then ensued an ordeal for the family as withdrawal of life support did not provide assistance with death. As Rentzenbrink observes: "There are kinder ways to end life than starving someone to death" (Rentzenbrink 2015). This merciless situation occurs (and reoccurs) in the UK because our medical practice primarily aims to 'save lives, not tend to their demise' (Gawande, 2014) and Cathy Rentzenbrink and her family had to prove her brother's prior mental disposition to refuse life support rather than accept palliative care.

At the time of writing, voluntary euthanasia is legal in the Netherlands, Belgium, Colombia,

and Luxembourg. Assisted dying is legal in Switzerland, Germany[1], Canada, and in the US states of Washington, Oregon, Colorado, Vermont, Montana, and California. In other geographical regions such as the UK, requests to seek assistance with dying are not supported by policy and are deemed 'criminal' (linked to manslaughter or murder charges).

2.1 Designing for autonomous dying and against youth suicide

Many of the themes and issues we have introduced so far in relation to suicide and assisted dying were explored in 2014 by a group of Communication Design postgraduates at Central Saint Martins, University of the Arts London. Their brief gave them two choices: to design a campaign *against* suicide, aimed at preventing harm to the young or to work on a policy campaign *for assisted dying* aimed at individuals with only 6 months' life expectancy. Although the cohort that engaged with the project were nearer in age to the target group for the brief against suicide, the majority chose to design campaigns that were 'pro' or in support of assisted dying.

Fig. 2: 'Living Wills' project, MA Communication Design, Central Saint Martins, 2014.

Overall students hotly debated ways of creating 'safeguards' in systems to support assisted dying that would preclude abuse. At the moment all living wills/advanced directives can do is outline an individual's wishes to refuse treatment (or not to be revived) by medical practitioners. But even this request is not always assured: in 2017 a UK stroke patient (Brenda Grant) who made a living will was found to have been kept alive and fed through a stomach peg for 2 years, despite her wishes, because her living will/advanced directive was 'mis-filed'. Future designs of living wills by our students anticipated building in more sophisticated options than just the choice of not being revived or refusing treatment but also with firm constraints to prevent abuse. For example, not going ahead with broader options for assisted dying or voluntary euthanasia until certain conditions are met. The students also produced communication campaigns to support assisted dying organizations who help individuals live and die with dignity and to help the public understand why some people demand the 'right to die'.

[1] Since November 2015 with some restrictions, namely that only a one-off assisted suicide would be legal. Professional help is therefore restricted from repeated acts by Section 217 of the German Criminal code.

The low key visual responses from our students, such as that shown in figure. 2 took place in a context where there is not only a need for designs of new campaigns but also demand for the design of new *policy*. But shortly after this student project was completed (in September 2015) UK MPs rejected Lord Falconer's assisted dying bill in England and Wales, which was based on the Oregon model that has been in place, and scrutinized to have been effective since 1997 (see Sullivan, Hadberg and Fleming, 2000, for a full review). This was the UK's first vote on the issue in almost 20 years (Gallagher & Roxby, 2015) and it failed, despite polling evidence conducted by Populas for Dignity in Dying recording that 82% of publics they canvassed supported the bill! The parlimentary debate heard impassioned views and personal experiences from both sides and the bill was rejected with 330 votes against and 118 votes in favour.

A clear distinction can be made between 'euthanasia' and 'assisted dying'. Legal ethics expert Penney Lewis reviewed the law in a number of countries in 2015 for the BBC. She showed that euthanasia is defined as an intervention undertaken with the intention of ending a life to relieve suffering - for example a lethal injection administered by a doctor. Whereas 'assisted dying', the more commonly used term in the US and UK, (mainly used by the organisation Dignity in Dying. They are pushing for the US-Oregon model to become legal in the UK and so almost copy its wording) about to a terminally ill, mentally competent adult, who makes the choice to die of their own free will (at an earlier time to avoid what they would consider an undignified death) after meeting strict legal safeguards, in the way security design is familiar. This could occur through the individual, taking prescribed medication which will end their life (www.dignityindying.org.uk/assisted-dying) or arranging for an appointed medical practitioner or other representative to administer it. (Organisations in the UK, such as MDMD https://www.mydeath-mydecision.org.uk tend to prefer this latter approach.

The key difference between the two is that in assisted dying, the individual, rather than medical professionals, makes the decision to end their life. We should clarify **we are for choice and for assisted dying/voluntary euthanasia** but *against* euthanasia. We support those who who want and need varying types of end of life care and we value their democratic decisions, but we also want choice.

The UK is surrounded by countries that take different, arguably more rational, views on end of life choices. In Europe, the Netherlands was the first country to legalize voluntary euthanasia and assisted dying, in 2002 after nearly 30 years of parliamentary debate. Belgium and Luxembourg have followed and also implemented end-of-life choices. In October 2016, the Dutch government have gone further and announced plans to draft new laws to extend assisted dying to those who feel their **'life is complete'** (Sterling, 2016). The health and justice minister advised that the extension should only be made available to the elderly who have met 'strict and careful criteria' (Sterling, 2016) and that their choices should dominate. This provision includes developing systems that design out potential abuse or mis-use to ensure that vulnerable patients who claim the right to die are adequately protected from those who might wish to inherit property or assets.

The Swiss member society, DIGNITAS - To live with dignity - To die with dignity (in short: DIGNITAS), provides a space and designed means to end one's life in the frame of legal doctor-supported accompanied suicide. It is the only legal option available for UK citizens wishing to end their life via assisted dying, and involves travel to Switzerland. The process itself requires membership to DIGNITAS, and a formal request including medical evidence to be reviewed by DIGNITAS and by Swiss doctors (independent of DIGNITAS). It also involves follow-on payments to cover running costs (although there is a sliding scale and possible exemption for those who do not have the financial means). Also two consultations before a lethal dose of powdered Pentobarbital, provided by the doctor and dissolved in water is provided for the patient to ingest. In Switzerland, assisted dying is legal and generally takes place in the home of the individual. When this is not possible (for example regarding patients who live in care homes that would not allow this assistance to take place), and for people from abroad, DIGNITAS provides a room in a house for this purpose. Due to complaints from residents (about undertakers and hearses), the space provided by DIGNITAS has been moved from an inner-city location to the city's edge. This move may be a failure of design from the point of view of the experience of the clients involved and the stakeholder associations who support it, but it became a necessity. It has also raised broad questions about who would rather die where – in the familiar comfort of one's own home, or far away.

Fig 3. Garden with pond in front of the Dignitas-house, 2013.

Design interventions to assist dying in the UK, could develop future visions of spaces that could offer a service like DIGNITAS, creating scenarios about how things could work pragmatically. Linking such designs to the use of *ritual* could make a difference by helping the public to explore their pre-death wishes through increased cultural understanding of, and participation in, such processes .

Rituals have a long cultural history. Durkheim (1957, pp. 225-6) showed that religious rituals unite individuals into collective groups serving to 'strengthen the bonds attaching the individual to the society of which s/he is a member'. We seek to make the case not just for the design of new policies but also for ritualistic end of life systems using design. This is because, ritual enables enduring patterns of social organisation and cultural symbolic systems to be brought to bear on real events, that are assessed and negotiated in ways that can transform these traditional patterns or structures (Bell,1997, p. 77).

Every religion has a structured approach to dealing with death. The Jewish community has communal activities as well as clearly defined periods of mourning (Parkes, Laungani and Young, 1997, p. 112). In Buddhist Japan, there are prescribed measures as to how a body should be laid out and with what objects in preparation for the soul to transcend to the next life (Grimes, 2000). As Catherine Bell outlines rites of passage known as 'samskaras' within Hinduism, are intended not only to purify but also to 'make over or transform' (Bell, 1997, p. 99). These ceremonies denote a series of actions that progressively refine and prepare the inner and outer person for the ultimate goal in Hinduism of 'better rebirth and final release from the cycle of life and death in this world' (Bell, 1997, p. 99). Such rituals provide important ways to make sense of death, making tangible the stages that we encounter throughout life and offering the potential to explore the stages pre-death for those that wish to die, perhaps to aid better decision making.

Fig 4. Futuristic service tools to create predeath rituals. Pras Gunasekera (MA Industrial Design, Central Saint Martins), 2012.

The events leading up to death and the recognition that someone has died can be traumatic and often produce ambiguous moments. Mary Douglas (1999, p. 111) has pointed out that many societies regard death as a stage of meaning that is polluted by ambiguity. Fear about ambiguity, and a lack of control, produces all sorts of effects for those left behind. Consequently, rituals used within rites of passage to mark death could help people make sense of the trauma death often causes particularly in the context of assisted dying. Innovative design might usefully draw upon ritual in the implementation of assisted suicide policy, achieving better social understandings about managing the threshold of the end of life.

3. Designing for death and the future …what role for design?

In our view design that is plural, responsive, political, delivering ideas that may not find affinity with market-led strategies, has a place in 'design for death' that supports humanist accounts. There can be no single solution to end-of-life management that suits everyone and this fact is accentuated in the wicked and distressing problem of suicide, particularly of young, vulnerable people. As we have already identified suicide as a subject is linked to stigmatization and any new policy or pragmatic design for assisted dying and voluntary euthanasia must address fears that policy could lead to decisions being made that "creep" towards practices that were not intended. Design's ability to envision possible new futures, including those that concern assisted dying, can therefore have a positive role. By offering pragmatic options and visualizing them, design can make a difference by engaging publics in democratic debate about those options and solutions. Perhaps design activism and even user-centered design for new future users has a role to play, not least because given the rising trends of agnosticism, atheism and those who are not affiliated with religion (Bullard, 2016), means there are new social needs to be served.

Such 'user needs' are not being addressed and prevailing taboos, about death, suicide and assisted dying indicate that religion continues to influence many of our "choices". Debates,

such as that over capital punishment, for example, draw upon some of the same ethical principles. The humanist golden rule of 'treat others how you wish to be treated' is hard to make real in design terms when not everyone in the world agrees on what 'appropriate' treatment actually is! Amnesty International's view that the death penalty is 'the absolute irreversible denial of human rights' (2013), is not shared by fifty-eight countries in the world who retain capital punishment[2]. Yet it is possible in those countries, with marked differences resulting from their democratic systems, to make arguments against the death penalty to demand change, to be part of what Chantal Mouffe (2013) proposes as the space for positive contestation and 'agonistic democracy' to occur. So why are accounts of assisted suicide in the UK still compromised by cultural taboos?

By making marginal voices heard and visible, presenting choice scenarios, designs for death and assisted dying can be delivered as ethical design. Such community engagement discussion that uses design skills to offer better visions of the future and solutions about how to deal with end-of-life choices is currently absent. There is no engagement with how to make assisted dying easier, or to protect vulnerable individuals at risk from suicide. Designers could be involved in making that debate heard and visible; we are skilled future visionaries, strong at making future scenarios understandable through design prototyping and visualization. Such envisioning of how assisted suicide could work could have an important role to play in democratizing innovation regarding end of life choices. Also answering the challenge of achieving the communities' engagement with the complexities of legal debates on this subject.

When faced with life or death decisions, all designers recognize how small we really are, and how different contexts raise different issues. After the death of his father, IDEO's Chief Creative Officer, Paul Bennett, wrote an article in September 2014 titled 'can death be designed?'. Bennett's experience made him realize that his father was trying to take control of his last moments and ultimately, to design his death, to make it acceptable. But Bennett found this difficult to bear, as have those of us who have powerlessly witnessed parents

[2] in 2016 102 countries have completely abolished the death penalty for all crimes, six have abolished it for ordinary crimes (while maintaining it for special circumstances such as war crimes), and 32 are abolitionist in practice. Consequently, almost 60% of human beings live in democracies like the USA, India, China, Indonesia which experience the death penalty as a reality.

dying (from dementia, for example) who could not take control of their last years. Dementia leaves many families and friends with little to do except watch loved ones living and dying in ways we know they would not have wanted when they were their full selves. Such lived experiences have inspired many of us to look our own death in the face and to try to figure out how best to design for it in the future. Some of us want to use living wills/advanced directives and other methods, to allow us as individuals more democratic choice and agency, if, and when, we as citizens are not capable of making those final decisions.

'Reinventing death for the twenty-first century' is such an agenda, promoted by Marie Curie's Design to Care Programme. It asks tough questions that highlight a tension between humanist and laissez faire neo liberal discourses that often make people uneasy. James Pallister has reviewed the Marie Curie programme and highlights a range of further start-ups, corporations, venture capitalists and health providers who see designing for death as a positive thing, linked to different approaches. Together many involved in design are trying to devise new and more meaningful ways of dying, including for assisted dying, by suggesting *design* should have a role in the arrangements for death. A role that is socially responsive to human suffering, participatory and collaborative linked to democratizing innovation and choice (Lee, Y. et al 2015) rather than simply a logical extension of economic concerns. The articles by Bennett and Pallister both emphasise our current medicalized view towards death and suggest that we need to move beyond this. Given design is employed readily to create the nuances of our *living*, it is argued that the same opportunities for design should be sought and applied to our inevitable *dying* (Pallister, 2015).

Conclusion

It may seem cynical to see death or assisted dying as a design opportunity, but many social design innovation groups are making strong arguments about the need to help society see different future visions and design *for* death. Groups like Modern Loss (www.modernloss.com) and the Death Cafés (www.deathcafe.com) have been growing across the globe. The audience at a Southbank Death Café, (March 2017) were told that over 4,000 café events have already happened and that Death Café events have occurred in 26 countries across the globe. Understanding these conversations about death may be a key factor in improving how society deals with end of life decisions including issues

raised by assisted dying (and also voluntary euthanasia), discussions that are central to Death Café group activities.

Speculative and critical designers have also joined the design for death debate and are trying to present new possibilities too. Unfortunately, most of the examples from critical design such as 'Afterlife' by Auger Loizeau (October 2009), the 'After Life Euthanasia Device' by Dunne and Raby (March 2011) and the 'Euthanasia Coaster' by Julijonas Urbonas (2010) (See Fig 5) sit in publicly inaccessible spaces such as art galleries. Also they do not present 'preferable futures' or the sort of strategic future thinking that accounts of socially responsive design (Gamman and Thorpe 2011) or design activism (Guy Julier 2013) offer. Instead, they engage with death as a spectacle, presenting uncomfortable mysterious technologies designed to disgust and shock audiences through their uncanniness (Di Salvo, 2012; Tonkinwise, 2014; Prado de O. Martins and Vieira de Oliveira, 2016). If such critical design approaches are able to start public debate it appears to be delivered with little pragmatism, in terms of broad community engagement, or any account of further actions that might be needed.

Fig 5. Euthanisia Coaster by Julijonas Urbonas (Royal College of Art), 2010.

We think design can do better. We must use design visioning, including speculative and critical design faculties, in proleptic or positive ways to address death. Instead of generating self-indulgent as well as self-contained narratives exhibited in a gallery space (accessible only to a few who may already support liberal, pro end of life choices), we need to open up conversations about death, beyond cynical economic arguments, so that broad audiences and publics as well as multiple stories can be involved, revealed and followed (Prado de O. Martins and Vieira de Oliveira, 2016). We argue that the diverse possibilities for death and assisted dying in the future can be reimagined, by design, discussed and conceived, as new choice. If the contemporary moment of 'difficult and dangerous times' (Manzini and Margolin, 2017) has taught us anything, it is that designers need to be able to visualize in material ways objects, systems and services that address *conflicts* regarding our understanding of human rights and values that characterize our times (not just the values we support). We need to use design to design different things

not just to ‘solve’ problems, but to speak disparate truths that will support real democratic debate, and help us to understand wicked problem scenarios. Well-designed technology is not only for living moments but technical and design skills can also be drawn upon and stepped up, to greet our inevitable death. Of course, thinking about how to prevent or aid suicide may be painful and never less than tricky, but designers should have the courage to invent and visualize new possibilities and help to design new policies and ways of pragmatically implementing them in the real world. All this, to paraphrase the lyric to Johnny Mandel’s and Mike Altman’s *Suicide is Painless* (1970), is aimed at allowing us to ‘take or leave them, as we please’.

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