

Designing Dying

2013 – ongoing



Designing Dying Leaflet Cover

Brief Overview

The design aims to provide a resource to help people to plan for their own death. The general aim is to explore how permaculture design can positively influence our experience of how we approach the end of our lives and how we die.

Observations

As a nurse (specialising in palliative care), farmer and permaculture designer, with a spiritual self, deeply rooted in Earth based seasons and patterns, issues relating to death and dying are intrinsic to most aspects of my life. A core part of my experience as a permaculture designer is to ensure as good a quality of life from an EarthCare, People Care and Fair Shares perspective as possible. However, within my work and life, I frequently observe that how we die, (in the UK) is detrimental to our care of the Earth, each other and how we share resources fairly.

Client Interview

Most people in the UK die in acute hospitals, often having undergone unnecessary and resource and human energy wasteful procedures. Research consistently tells us that most people would actually like to die in their own home, away from a busy acute medical environment, which the vast majority of people do not need as they approach the end of their lives

The client interview has in fact been ongoing for several years.

The clients for this design are myself and 'people living in the UK.'

Over the past 5 years many family members, friends, neighbours, members of the permaculture community and 100's of my patients and their families have all in their different settings and situations have answered the following general questions.

“ What kind of things are important to you relating to dying and death”

“ What kind of things worry or concern you the most about dying and

death” “What would make approaching dying and death easier for you?”

My experience being and working alongside dying people and their families is that the majority of people are pleased and relieved to talk not only about their fears around death and dying, but also to make positive plans for the kind of death they would like. My own observations of dying people, and then bereaved relatives is that those who have talked openly and honestly about death and dying, and have planned for what they would like to happen tend to have more peaceful, meaningful time at the end of their life.

Obviously, we cannot all predict how, when and where we all die, but the likelihood of having the death that we want, which takes into account our needs and wishes, plus the right support for those around us improves vastly, if we make plans for it

Basemap

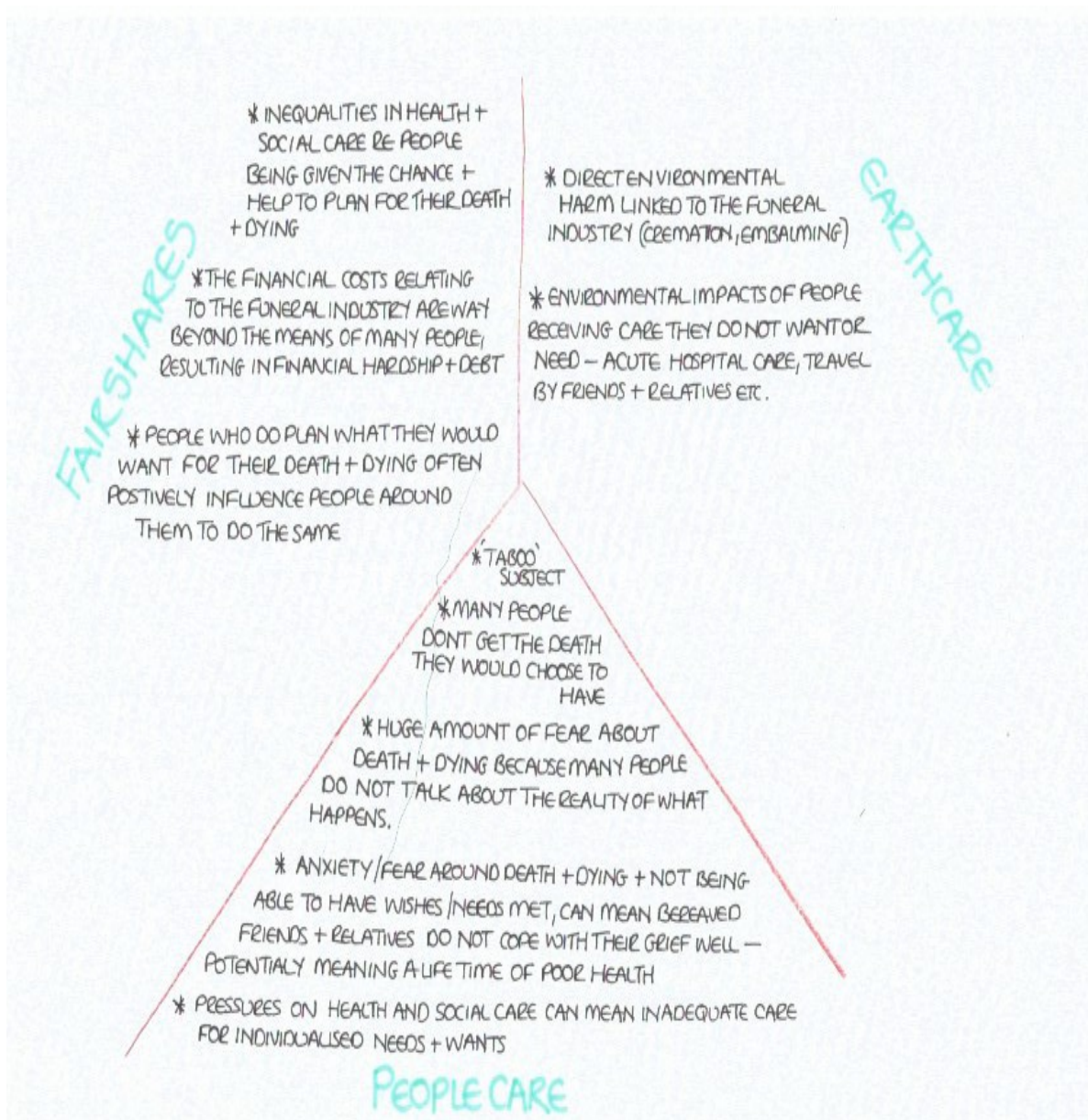


Diagram showing how the Observations made in the Client Interview impacts on permaculture ethics

Further detail on the Basemap diagram

People Care

Within British culture, death dying and bereavement are still issues that many of us feel are difficult and indeed taboo to talk and learn about. Popular media images of death and dying often portray an image of inevitable suffering, as does ongoing

media coverage highlighting the inadequacies of Health and Social services in providing good End of Life care and support.

As a result many people live in fear of death and the dying process and ultimately do not have the death they would have liked, Unspoken anxiety, misconception, lack of control and perceived 'bad death' experienced by loved ones of a dying person, can contribute towards problematic grief. Research demonstrates this can ultimately lead to a lifetime of being unable to positively address issues around any loss in life (a job, home, relationship, health), resulting in poor emotional and physical health, placing a huge burden on not only the wellbeing and happiness of the person involved, but on health and social care services and the impact of that on the economy.

Health and Social Care services in Britain are pushed beyond capacity in terms of appropriate support available to people in many areas. Also, because of the pressures on them they often do not adequately offer people individualized care they need and want. Making advanced plan for how we would want to be cared for can mean that these resources can be targeted towards appropriate care for us and others, rather than being used for care we do not need or want. In addition we might want to consider other forms of support if we need it, friends, family, SoulMidwives etc.

Fair Shares

Currently in the UK, along with many other aspects of our health and social care systems, there are huge inequalities in whether or not people with progressive serious health problems are encouraged to talk about and plan for death and dying. If people are given the space to do so, it's often at a time when they are feeling too unwell to be able to achieve what they would like to happen

Designing our own End of Life care when we are fit and well, and discussing it with friends and family, can (will, in my experience), enable others to be inspired to think about their own plans, meaning more of us will hopefully have the death we would like.

The Funeral Industry in the UK is big business and the financial cost of a typical funeral in the UK has risen by over 80% since 2004, way above inflation. And the average price of a very basic cremation, using a funeral director is about £3,400 (a burial is about well over £4000).

This puts the cost of dying beyond the financial means of many people, resulting in further distress for friends or relatives in their bereavement. A significant proportion of the monetary costs charged by some Funeral Directors are for things that are not 'essential' (as well as being environmentally harmful) Many people believe that a Funeral Director needs to be used to organize events after someone has died, but in fact its perfectly legal for our families and friends to deal with all the aspects of our after death care and ceremonies undertaken. There are of course also professionals (Funeral Directors, Celebrants etc.) who will help us to have the care after death that fits with our ethics and personal needs and wants.

Earth Care

A growing number of people within the permaculture community and beyond, are increasingly concerned about how we die is impacting on the Earth. In addition many more people do not have the awareness that this environmental harm exists within our death culture in the UK. As previously touched on, the environmental impact of death, dying and especially the Funeral 'industry', (cremation, embalming, clothing, coffins, large oil consuming cars, buildings used) can be deeply damaging to our care of the Earth. In addition in Hospitals and other official 'Health Care' resources in the rich world are very environmentally costly places in terms of equipment, power needs and location to those close to us.

Boundaries

- Talking about death and dying is generally still a taboo and challenging subject within British culture. On a personal level, past experiences of the death of others, our role as Carers, serious illness or any other kind of loss can make it a difficult subject to explore.
- There is no money available at present to fund decisions made within this design
- The time I have to deliver the decisions made within the design once completed is limited. My present role as a farmer and Carer mean that time away from home is rare, variable and often unreliable in terms of needing to cancel/change outings at short notice. However, having more time to devote to the implementation of the project in the future is a very real possibility.
- Geographical. I live in a very remote area. The costs in terms of time, environmental (diesel to drive to a venue) are significant.
- Conflict of interest. My professional role as a specialist palliative care nurse means that I would have to be very careful about how my design both impacted on my professional code of conduct, and policies set out by my employer. This is especially relating to using my professional qualification (and therefore link to my employer) in connection with information given in any format, including via social media. As I commence this design I am not working as a nurse but this will change within the next couple of years which needs to be considered

Resources

- Locally, national and globally there is a growing awareness about how our experiences of death impact on many kinds of resources: personal, health, financial, political, environmental, spiritual.

- Some of the past experiences identified as 'boundaries' may also bring a wealth of personal resources in relation to planning for Death and Dying . In addition, other people in our lives may be nearing the end of theirs and have some ideas about what they would like to happen.
- There is also a increasing wealth of resources available about various aspects of death and dying (books, websites, blogs, community events) which could be utilized to support the design. In addition there is much discussion about diverse ranges of issues relating to End of Life.
- The evident growing interest with others within the permaculture community to think about using permaculture design to explore issues around death, dying and bereavement.
- My own previous experience of project work about death and dying and also creation of websites.
- In my own geographical community there are a number of individuals and organisations who have expressed an interest in a 'workshop' type of an event to promote talking about death as a positive way to promote health.
- As mentioned in 'Boundaries' At the time of writing (just prior to the implementation of the design), there are no financial resources available. However, the nature of the subject of improving end of life care is a current political concern in national Health and Social Care systems, with resources being allocated for it. Therefore it is possible that funding could be acquired at some point.
- My depth of experience, knowledge and interest as a Specialist Palliative Care Nurse as well as extensive experience of caring for family members at the end of their lives.
- A personal experience of caring for family members at the end of their lives alongside personal history of serious, life threatening illness. I have previously written a plan for my End of Life and find it a constant support and reassurance in my day to day living and enjoyment of life.

Evaluate

SWOC Analysis of the Observations, Boundaries and Resources

Strengths

My own depth of experience, knowledge and interest about supporting people facing End of Life

Personal experience of facing death and dying

Experience of website creation,

.Workshop facilitation and project management work

Weaknesses

Time restraints Living in a remote geographical location

No funding available for physical resources

Conflict of Interest with work

Opportunities

There appears to be a keen interest from some people both within and outside the permaculture community to create positive plans for death and dying, which are based on permaculture principles.

There is a growing awareness in both community settings and via social media of the benefits of a more honest and open dialogue about death and dying. For example 'Death Cafes' and 'the 'Dying Matters' Initiative.

Constraints

The experience of death and dying for many people in the UK is not one that meets the guidance set out by the permaculture ethics of People Care, Fair Shares and Earth Care

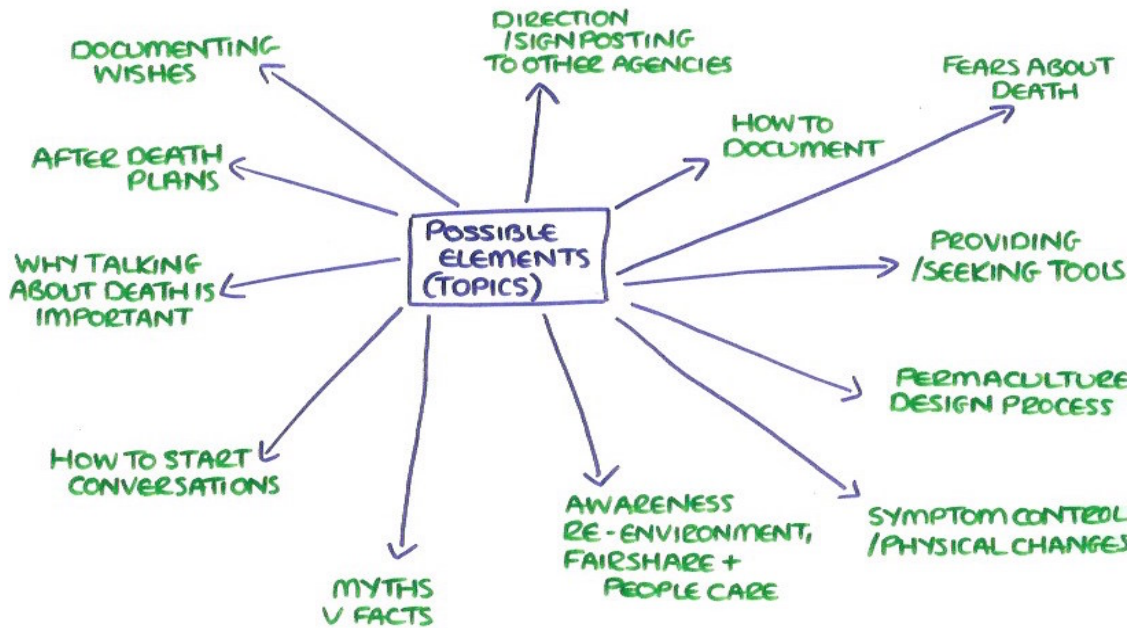
Death is a taboo subject for a lot of People in the UK. Because of fear, experience of others and the unknown, many people are reluctant to be proactive about planning for their death.

Functions

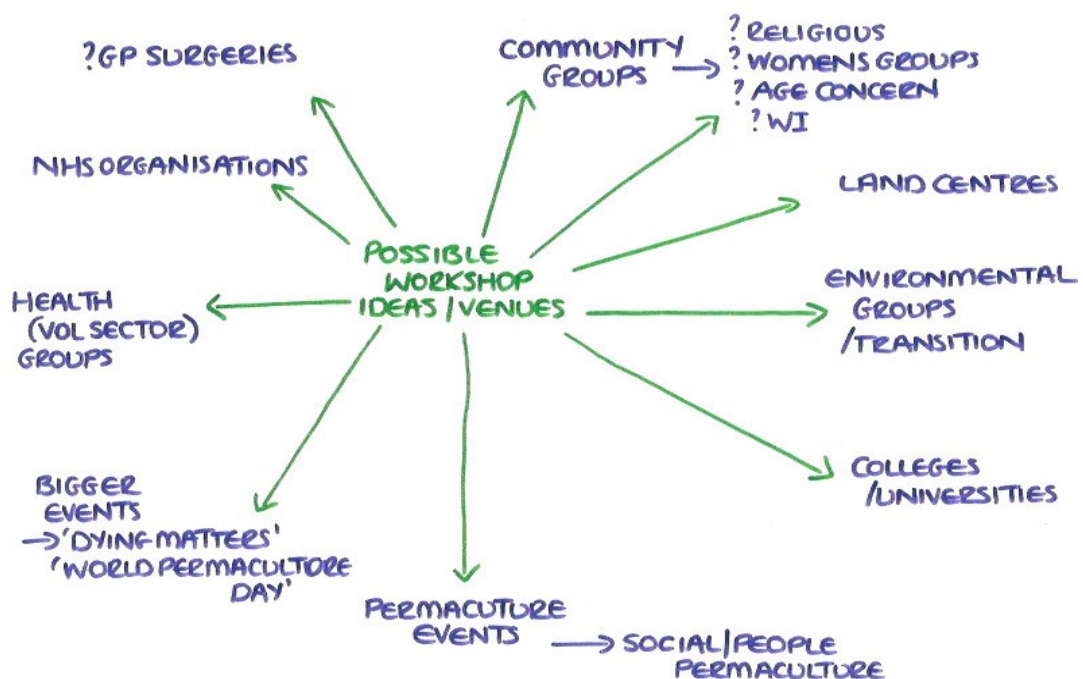
- To improve the experience of death, dying and bereavement of the public by empowering, through education and support.
- To increase equality relating to the information and support relating to

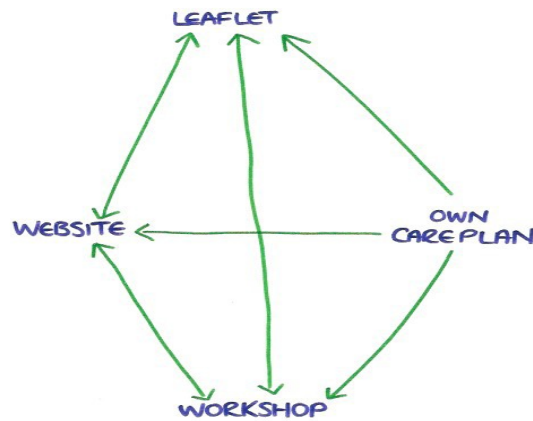
dying, death and bereavement

- To increase awareness of environmental issues relating to death and dying in the UK and to reduce the damage done to the Earth, through these destructive practices.
- To share effective use of good permaculture design in influencing our health and well being.



Mindmap of potential elements generated from the design process so far





Web of connections between the various Elements

I have identified one system for the design :

Information, support and empowerment to enable people to create design for their own death and dying

Decisions

Based on the information considered so far within the design process I have decided on 3 different elements to support the functions of the design;

1) Creation of a leaflet 'Designing Dying' (where a person can actually document their wishes, ideas and plans about their death).- I will then use the leaflet to make my own Dying Care Plan to ensure its accessibility and usefulness, and also as an example to demonstrate to others how the Design might work for them

2) Writing a short workshop (2-3 hours) to provide information, support, confidence and community building relating to Designing Dying. The workshop encourage the participants to use OBREDIMET to create a design to make positive plans for their End of Life

3) The creation of a Website that will support and further the information explored in both the leaflet and the workshop I plan to use the same written material used for the workshop as a written handout and also as the main frame of the website. This will ensure that the same information is accessible to people in different formats as well as making the most efficient use of limited time for me. I will use Weebly to create a website for the purposes of this design. I have already used Weebly to design a website for my Diploma journey in general and am happy with how it suits my way of learning and thinking. In addition the way Weebly connects easily to Social Media (Twitter and Facebook) is really beneficial and makes sharing to a wider audience very simple

My own Death and Dying Plan (using the 'Designing Dying' Leaflet)	Zone 0
'Designing Dying' Leaflet and workshop offered to close family and friends to use and complete.	Zone 1
'Designing Dying' Leaflet and workshop to the permaculture community (peer group?)	Zone 2
'Designing Dying' Website and Social Media	Zone 3
'Designing Dying' Leaflet and workshop to wider community	Zone 4
Possible Income source	Zone 5

*Table demonstrating how the decisions made can be supported by the **Zoning tool***

Implement

I decided to use small Incremental steps to allow feedback. Given the sensitivity of the subject matter and potential for upset to people caused by written and discussed material, I decided to factor in several extra 'Evaluate' and (if necessary 'Tweak' cycles to ensure as optimum people care as possible. In addition this will hopefully make the Design more robust and useful as potential changes can be made throughout the design increments as needed.



Depending on and following on from the evaluation of the initial elements, I aim to create the website/social media element to occur at the same time or just before the Public Workshop (to the wider community) . The reason for this being that having the website/social media in place would add an extra supportive element to the workshop straight away. Hopefully the prior evaluation of other elements will ensure as effective layout of the website as possible with regard to functions and accessibility. I am hoping that there will be enough feedback from the stages of implementation scheduled for November/December 2013 to be able to create a website that works well.

Maintain

The plan is that the project, once established will be fairly self maintaining. Changes that need to be made will be as a result of the evaluation progress, or changes in law, researched evidence, policy etc.

If the project develops as a more intensive one, including workshops etc., then obviously this will require further maintenance, but the details will be something that can be considered at a later date.

At this point in the design its not clear exactly what the maintenance needs will be as the incremental nature of the design with regular evaluation means that the timing and exact nature of the implementation will not be clear until the implementation progresses.

At this time (just prior to starting the implementation I anticipate that Maintenance will be needed with all the elements in the early stages of the full implementation, but then reduce as a format for the leaflet, workshops and website.

My End of life Plan Spring 2014

Before I die

If I am unable to make decisions for myself than I would like Holly Rogerson,, my partner, to make all decisions on my behalf. If she is unable to do this then I would like decisions to be made by the medical team caring for me, but taking to account my wishes in this plan.

If at all possible I would like to die at home.

If for whatever reason I can't die at home then I would like to die in a hospice.

Unless there is a very real chance that supportive and /or curative treatment/investigations is going to help prolong the length AND improve the quality of my life, then I do not wish to have these.

These treatments/investigations include:-

- *Surgery*
- *Cancer treatments*
- *IV antibiotics*
- *Artificial hydration and nutrition*
- *Invasive ventilation*
- *Scans*
- *Blood tests*
- *Oral medications*
- *Admission to hospital*

As I die

I would like Holly and any animals who live with us to be with me if possible. I would also be happy from friends to be around, particularly to support Holly. My family can visit me if they would like to but I don't want any kind of 'vigil ' keeping

In the last few days/weeks of my life I would like to be as comfortable, relaxed and as symptom free as possible, even if this means I am sleepy or sedated. I would like to have a syringe driver to deliver medications if I need them. I might like some gentle aromatherapy massage, please ask me about this.

I would like to feel the outside elements on my skin, rain, sun, wind if possible. I would like to have music I enjoy played, and lots of candles lit in the room.

After I die

*I would like to be buried as near to where 'home' is as possible
If Holly and our friends feel able, then I am really happy not to use a funeral director. I would like my body to be buried as quickly as possible and placed in the ground wrapped in a sheet only. I do not need my burial to be a big event. If the sheet option is difficult then I would like my coffin to be as a low carbon footprint as possible*

At some point after my burial, (days or weeks is fine). I would like a 'celebration of life and farewell' gathering to be held at my home or near to where I live. I have a box of poems, readings, songs etc. with my office stuff, and these can be used to give the Gathering some structure if needed.

I have no strong feelings about how the Gathering goes, but it could perhaps include food, a shared art project, drinks, ,music, tree/seed planting (or trees/seeds for people to take away to plant)

Everything I own becomes Holly's when I die. If there is enough money without causing any hardship to Holly then I would like to fund a permaculture project in my name if possible

In addition to this plan

My 'End of Life Plan' box (in my home office/art space)

Further helpful support and info can be obtained from

<https://www.finalfling.com>

<http://www.soulmidwives.co.uk>

<http://deathcafe.com>

<http://dyingmatters.org>

<http://www.naturaldeath.org.uk>

<http://www.thegroundswellproject.com>

<http://www.macmillan.org.uk>

<http://www.nhs.uk/planners/end-of-life-care/documents/planning-for-your-future-care.pdf>

<http://www.urbandeathproject.org>

Designing Dying Initial Workshop/Website Ideas and Plans

Observation

General Aims Of The Workshop/Website and Setting the Scene

An informal, relaxed workshop to ask questions, voice concerns, and generally come away with a better understanding and more confidence relating to discussing death and dying.

I aim to tailor the workshop/website material to the needs/wants of the diversity people attending/seeking information, but it will (loosely) follow some or all of this plan:-

- Why we need to talk about dying
- Getting the facts right about death and dying 'myth busting!'
- How to talk about dying and any plans you might have
- How to help someone you are close to who is elderly, or very ill
- What to say to someone who has been bereaved
- Resources; other sources of support and information which may be helpful

More specific Information and reflections can be used from the **Observations** section from this overall design.

Your own thoughts

Can be done as pairs/group work, depending on the workshop size and setting. Also depending on the confidence and motivation of the participants.

Why are you wanting to think about this now?

What are your aims for yourself and your life by creating a plan for your death?

What is your general vision about your plan?

Resources

- Experience
- Inner resources
- Other people around you
- Information and support resources as listed

Boundaries

- Personal boundaries
- Societies boundaries

Evaluation

- Functions and elements
- Permaculture Ethics and Principles

Decisions

- Is making a 'plan' the right thing for you atm?
- What things would you like in the 'Plan'

Ideas for how actually to record Plans are :

- *Online: – (via social media/website/blog?), though we need to consider that we may not all have power for Internet access in the future*
- *A scrap book /Journal /box that can be added to and changed as time goes by*
- *Statement, Letter, document (perhaps as an electronic file and printed out and kept with other personal documents?)*
- *A document designed by someone else (there is example formats in some of the links above*

I have found that breaking the design into 3 sections “What I would like to happen in the time (weeks/days hours) before I die”,

“What I would like to happen as I die” and “After I die” is a really useful way to think and plan

Several more official legal related documents are well worth looking into as part of the plan;

- *Organising a Power of Attorney (available for either financial related decisions and/or health care/treatment issues)*
- *Advanced Directives ('living will')*
- *A Will*

Implement

- Actually writing up the 'plan'.
- Alone or with a friend/partner?

Maintain (Evaluate and Tweak)

Letting others know the existence of your Plan and dating any amendments/additions can really help others to be able to implement it if you are not able to make your needs known as you approach the end of your life. In addition having a regular 'evaluation' and update of your Plan timetabled into your life, (for example, the day after your birthday?)

Useful Resources

Books

People and Permaculture by Looby Macnamara

The Dead Good Funerals Book by Sue Gill & John Fox

The Natural Death Handbook from The Natural

Death Centre The Pagan Book of Living and Dying by

Starhawk

The Tibetan Book of Living and Dying by Sogyal

Rinpoche When Parents Die by Rebecca Abrams

As Big as it Gets (supporting a child when a parent is seriously ill)
from Winstons Wish

Websites/organisations

<https://www.finalfling.com>

<http://www.soulmidwives.co.uk>

<http://deathcafe.com>

<http://dyingmatters.org>

<http://www.naturaldeath.org.uk>

<http://www.thegroundswellproject.com>

<http://www.macmillan.org.uk>

<http://www.nhs.uk/planners/end-of-life-care/documents/planning-for-your-future-care.pdf>

<http://www.urbandeathproject.org>

Blogs

<http://drkategranger.wordpress.com>

<http://lmiddletongreen.wordpress.com>

Jan Martin (one of my favorite permaculture bloggers!) created a design for her own end of life after participating in one of the workshops around the subject. Here is the link to her fantastic blog post about it.

<http://thesnailofhappiness.com/2013/12/06/terminal-scrapbooking/>

As always the Permaculture Principles are available to guide our work and I personally found Holmgrens really useful when looking at my own End of Life design

<http://permacultureprinciples.com/principles/>

Other organisations providing information and

support about death and dying

<http://dyingmatters.org>

<http://www.naturaldeath.org.uk>

<http://www.deadgoodguides.com/pages/DeadGoodFuneralsBook.html>

Evaluation Jan 2014

Elements	Ethics involved	Holgrem Principles involved
My own Designing Dying Care Plan	Earth Care People Care	Obtain a Yield Produce no waste Edge
Designing Dying Leaflet	Earth Care People Care Fair Shares	Obtain a Yield Produce no waste Edge
Designing Dying Workshop	Earth Care People Care Fair Shares	Obtain a Yield Produce no waste Accepting Feedback and Responding to Change Produce no waste
Designing Dying Website (Potential, as not implemented yet)	Earth Care People Care Fair Shares	Obtain a Yield Value the marginal Produce no waste Creatively respond to change Accept feedback Produce no waste

Table to show the different permaculture ethics and principles underpinning the design

Pluses

I used my workshop ideas and leaflet to create a new version of my own 'Death and Dying Plan' which worked really well. Undertaking this also had the added benefit of making me of the need for regular evaluation and reflection as my understanding of the permaculture Ethics and especially 'Earth Care' had influenced my needs and wants.

I facilitated 2 workshops as planned, the first with close friends and the second with other Diploma Apprentices at the National Diploma Gathering. Informal feedback from them both was more positive than I anticipated and one thing I hadn't factored in was how much my knowledge and experience of working as a nurse with people at the end of their life was utilized as many people wanted to further their knowledge about specific biological aspects of dying and care/treatment available. Nearly all people who attended

the workshops went away with firm plans to create their own Death and Dying Plan

Jan Martin (one of my favorite permaculture bloggers!) created a design for her own end of life after participating in one of the workshops around the post about it is shared below

Minuses

At this point in time, decisions relating to taking the workshop into a more public arena along with the creation of the website are on hold as I will be working in my nursing role until March 2015 (See **Boundaries**).

Time factors plus my personal experience of a close family member approaching the end of their own life also meant that at this point in time I need to take a break from the implementation of the Design

Interesting

It is possible, in the future that the leaflet/workshop combination could be used as a basis for a business venture, either within a system where money is paid for the service, or within a system of alternative currency or skills/knowledge/product swap.

There has been some interest in my local community about the workshop, from people involved in various groups. This indicates there is a very real possibility that the workshop element alone could be used with beneficial effect

Resources

The resources used to guide and influence this design are those listed in **Workshop/Website** section of this design (page 18)

Permaculture Design : A Step by Step Guide –Aranya

Designing Dying – Reflections (and ‘Tweak’ Ideas)

Design Process Used

Observe **B**oundaries **R**esources **E**valuate **D**ecisions **E**valuate (OBREDIMET)

Assessment Criteria Aims

Demonstrating design skills

Applying permaculture in your own life

Applying permaculture to your work and projects

Learning from and developing your permaculture practice

Reflections

I've used OBREDIMET several times before as a design process, but this has been the first time I have really considered how its been working for the way I design. One part of the process that in the future I would change is putting the ‘Resources’ section before the ‘Boundaries’ as I naturally tend to look at positive aspects of a situation before the challenges. In addition, I think I will also consider whether the first ‘Evaluation’ should in fact be ‘Analysis’ (of the information obtained so far)

In general the design feels quite weak in relation to the functions it set out to meet. Its weighted heavily on observations, where as I could have spent more focus on evaluating the observations, resources and boundaries. Perhaps If I had used Analysis at this point (as discussed above) it would have helped me to put more energy into this part of the design? In addition Its possible that I would have moved further within the implementation of the design with a more resilient plan, that more evaluation/analysis tools would have enabled. SMART goals could have been really beneficial.

I've never used the permaculture ethics to create structure for a ‘base map’ before but I've found that doing this really places them at the centre of my design. I really enjoyed designing a resource that itself used a design process to engage people, and this is something I would like to explore more in Edge type permaculture work Although at times undertaking the design has felt quite isolating as it has permaculture work to the edge of the Edge, Many people who have engaged with

elements of the design have fed back to me that designing for End of Life that its something they would be interested in engaging in, even after at first being wary about the whole subject. The other tools used within the design (PMI analysis, flowchart, web of connections, mindmaps) felt like they gave the design further clarity and resilience, and again I found using 'Zoning' really useful away from land based work to see where the various elements would be placed.

'Designing Dying' has also prompted and given me the confidence to use permaculture design in areas of my nursing work supporting dying people and those close to them. In recent months I have used the design process at strategic level to make positive change in major health and social care organisations

Although I'm not totally confident with how this design has gone, what it has done has enabled me create a 'base' of knowledge and design ideas to then hopefully build and expand from. Actually just getting some of my initial ideas into a format that can then be explored using tools and principles from a permaculture design approach has meant that I can demonstrate to others how this sensitive, on the 'edge' but core human topic, which challenges each of the permaculture ethics so deeply, can be a creative, positive thing. I fully intend to return to this design in the next year with the further design skill gained and take forward to a new level.

