Creating the conditions for Better Endings:

Some possible ways forward

MAY 2018

Better Endings

Creating new solutions for
end of life care and support.

Innovation
Unit
New solutions
for thriving societies

GUY'S &
ST THOMAS'
CHARITY

"Most of what we most value in life – love, friendship, respect, recognition, care – comes from relationships … People die well when they are supported by relationships with people who care for them and provide their lives with a sense of meaning."

Jake Garber and Charles Leadbeater, Dying for Change (2010).
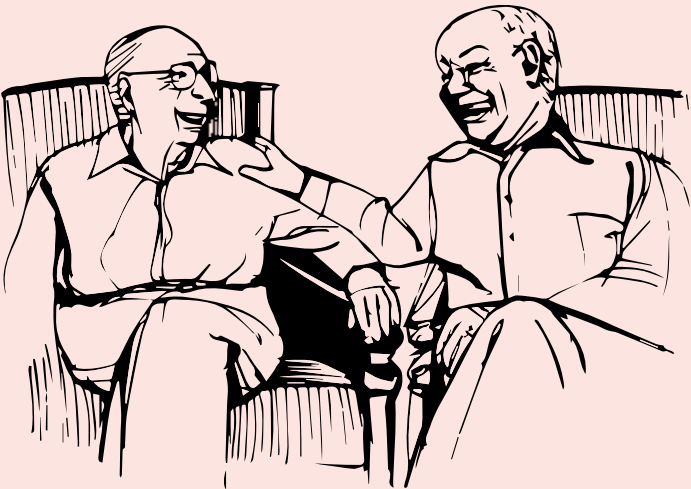
Contents

Introduction

Everybody deserves great support for themselves and their families at the end of their lives. We know this doesn't always happen.

There is no shortage of initiatives to improve care and support for people at the end of life, but very few of them aim to create the fundamental change we really need.

The world has changed. The way we live has changed. The ways we are likely to die have changed. But the basic assumptions that guide our approach to end of life care have not.

Better Endings has been a programme from Innovation Unit, supported by Guy's and St Thomas' Charity, running in Southwark and Lambeth through 2017. We set out to rethink some of our most basic assumptions about how dying people (and their friends and families) are supported, with the aim of designing some radically better alternatives and testing these on the ground. We brought together a diverse group of experts for creative and deliberative work,

involving over 200 people: clinical and care professionals, commissioners and policy-makers, voluntary and community organisations and people with experience of living and dying in Southwark and Lambeth.

We started by listening closely to personal stories of dying, caring and grieving, using these as a springboard for thinking differently about how we might better address people's aspirations and needs. Working together, we exposed some basic assumptions underpinning our current approaches to care and support, and noticed problems, limitations and opportunities continually missed. We also generated new possibilities; creating a vision for how things might work differently and more powerfully for people.

This publication shares thinking from Better Endings. You'll find here our key insights into the nature of our current system and some of the things we thought about as we strove to imagine better ways of doing things.

You'll also find three new propositions for end of life care and support – Neighbourhood Care, Coach4Care and Ripples. Developed as part of the programme, these

prototypes explore different ways of thinking and working to better support people at the end of life. Our aim was to learn about what works, and to demonstrate some new possibilities.

We certainly don't have all the answers, but we firmly believe there are better ways to support people when they are dying. Strong cultural and systemic forces keep current ways of thinking and working in place, so it remains important for us to challenge ourselves to imagine new possibilities, and to inspire and encourage others to do the same.

We hope you enjoy reading about Better Endings, and that you'll use this book to inspire and support your own conversations about how to create radically better experiences for people at the end of life.

Better Endings Team

Why we need Better Endings

By Heather Richardson, Joint-CEO St Christopher's Hospice.

Seven years ago, Charlie Leadbeater and Jake Garber authored *Dying for Change*, a publication that called for radical change to improve the experience of people who were dying in the UK. It made a strong case for transformation for a variety of reasons – to better meet people's preferences at the end of life, in anticipation of increasing demand for palliative care, and as a means of using limited resources in a more efficient and effective way. The book was received with great interest and has been widely read. Indeed a national commission into the future of hospice care was established in its wake to explore and describe how its recommendations might be implemented by the hospice sector. There is evidence that many hospices in the UK have taken the recommendations of the Commission seriously and some changes have happened as a result.

However, the innovation around end of life that Leadbeater and Garber call for – that would focus on new models of care, delivered by a different set of players and focus on societal change and system wide improvement alongside better local services – is largely absent from the picture of end of life care today.

As a result, health and social care systems are creaking in the light of growing levels of demand for end of life care, the increasing complexity of needs with which individuals present, and the chronicity of their conditions that demands help over sustained periods of time. The consequence of this situation is one of unacceptable inequities related to access and effectiveness of care, and deplorable experiences of help and support at a time when people most need it. For individuals, these inadequacies result in late diagnosis of advanced disease, poor communication, failures in symptom control and uncoordinated care. Even where policy

makers, commissioners and providers have recognised the need to improve the quality of provision and have made efforts to do so, their efforts and impact are often inadequate as a result of limited resources available to them. In particular new monies and elements of the traditional palliative care workforce are in scarce supply.

For all these reasons we believe that the time is right for catalysing and scaling innovations in end of life care. We need new models of care that address changing needs, preferences and expectations; that can be delivered by a different workforce and which can achieve higher quality across the board without recourse to significant new funds. Most importantly these innovations must reflect the priorities of those who require these services; they must also draw on the capabilities and capacity of a wider range of individuals, groups and organisations with a stake in high quality end of life care.

This aspiration is not pie in the sky. There is early evidence of innovation in end of life care in the UK being led by skilled service designers, academic institutions and hospices. Funders are interested too in supporting the upscale of innovations proven to be effective. Evidence also exists of an interest on the part of the public to become involved in end of life. A recent public survey of UK adults found majorities of people both disagreeing that dying is only a matter for professional health and social care services, and agreeing that they would be willing to offer practical help and support people who are dying.

The challenge now is to galvanise this interest, identify relevant methodologies and approaches, support new efforts to innovate and share learning so that others can replicate and build on them. Innovation in end of life care cannot afford to be fleeting in nature or undertaken only by a few players. It must be widespread and sustained.

92,000

people who died in England in 2013 did not receive any palliative care.[1]

+17% by 2030

predicted increase in the demand for end of life care support in Lambeth and Southwark by 2030.[2]

54% of **all** complaints in the NHS relate to end of life.[3]

1 Equity in the Provision of Palliative Care in the UK: Review of Evidence, Josie Dixson, Derek King, Tihanah Matosevic, Michael Clark, Martin Knapp (April 2015).
2 Need for End of Life Care in Lambeth and Southwark, Dr Alison Furie, Lambeth and Southwark Public Health Department.
3 Health Care Commission, 2008.

Key features of our current system

Better Endings brought together a diverse group of experts in end of life care. We worked to develop a shared perspective on our current system of support for the dying, and to imagine how things might be radically improved.

Here we share 10 key features of our current system that emerged as important through our work together. These features are both powerful and controversial. They expose entrenched assumptions about how things 'should work' and realities (structural, cultural, political) that feel difficult to influence. This was an important step in our work to imagine better ways of working to support the dying.
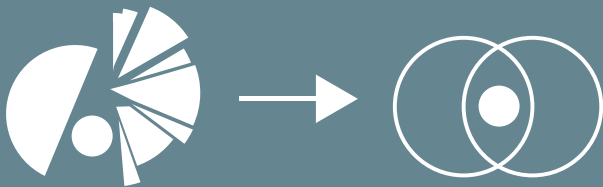
1. The professional health and social care system is small relative to the level of need and is continually overwhelmed. Many people die without access to any end of life care services.

" There is a desire to give good care, but that's often crowded out by the pressures and competing demands [on your time]."

GP and Clinical Commissioner.
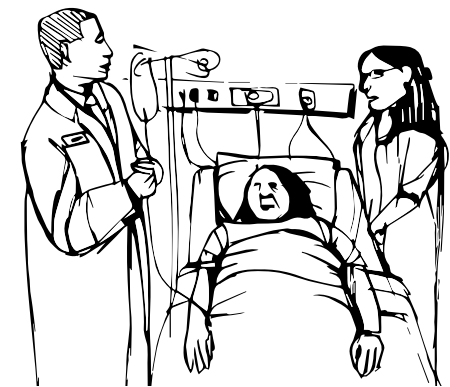
2. There are great end of life care practices and practitioners in the UK, but not everyone can access these.

3. VCS organisations with reach into different communities often provide support to people at end of life. They may not be connected into the clinical system and their role is not widely acknowledged.

4. People would like to volunteer more time to support and care for others who are dying, but don't always know how to help.

" The people who come to our hospice get great care. It's the majority of people who are dying alone and unsupported, far away from any formal care, that keeps me awake at night."

CEO Hospice.

"I have no one around I can count on. I don't trust any services to give the help I'll need. Nothing really helps me now."

Woman, late 80s.

" We think everybody dies in the NHS, but that's just not true. Professionals just don't see those who do the caring."

CEO Hospice.

"[Care-giving services are] generally very isolated from health services. They see what people are going through but they're not very empowered to come forward."

GP and Clinical Commissioner.

" I don't think that good end of life care demands specialist knowledge always. It requires courage, empathy and human kindness.

CEO Hospice.

"The key thing needed is not necessarily a professional - it's about people who can give their time and really get to know someone."

Priest.

5. We don't share responsibilities with non-professionals because we see it as risky. But the risk of people not having any support at end of life is one we are prepared to take.

> We have seen that social action is completely disempowered when it touches the system. Professionals just don't trust volunteers to make things happen."
>
> *CEO Hospice.*

"Their deaths really upset me. I think, 'If only I'd done more.'"
Manager, service for homeless people.

"It is interesting that faith groups, churches, feel empowered to support people who are dying. What can we learn from their attitudes to risk and safeguarding? What are the boundaries and where is the safety"
CEO Hospice.

6. Professionals feel ultimately responsibility for the quality of care provided and assume authority over care decisions.

> The biggest problem we've got is that death and dying have become the business and the responsibility of professionals, and society and the public don't recognise their role or their opportunities to influence it in the way that they might have done historically."
>
> *CEO Hospice.*

7. The professional system is primarily focussed on managing physical symptoms and risk, rather than our wider emotional needs, wishes or aspirations.

> I am going through a very rough, depressive patch. I feel such a sense of shame over not being able to cope better. It is as though all my former competent-enough years never happened. I have collapsed into a helpless, crying baby again."
>
> *Woman, late 80s.*

"If you are being treated for a terminal illness, a lot of the sense of making meaning of life and who I am can get lost."
Priest.

"By the time you get to 80 or 90 your network has died. Are we asking, are you still seeing your friends like you used to? We need a series of questions that attend to social and emotional wellbeing."
CEO Hospice.

8. People and their families, and family carers sometimes feel blocked or constrained by professionals and institutions in their efforts. Their wishes, knowledge and judgements are not central to decision-making

> " All these practical things take up so much time, time we could be spending with each other."
> *Family carer.*
>
> "They sent my mom and sister to the hospital. It took an hour to take her out the house. It took ages to get her there. They said they would be there for tests for most of the day. But then all they did it take her blood pressure. I went mad! Stuff like this has happened a few times. To tell you the truth, there's no point in taking her. They should come to the house if there really is something that needs to be done."
> *Family carer.*
>
> "We really do know better the support that she needs."
>
> *Family carer.*

9. The system puts too much pressure on family carers and does not offer enough support for their own health and well-being.

> " The system is designed to make the carer do everything until they break down."
> *Family carer.*
>
> "What people are crying out for is good quality ordinary care. In the middle of the night. Care where people want to be looked after with their family."
> *CEO Hospice.*
>
> "Coping with someone who is dying is more than most families can bear. We will meet people's aspirations to die at home only if people are provided with proper support."
> *Garber and Leadbeater, Dying for Change*

10. Assessments and decisions come from many different parts of the system and many different people might be involved in someone's care. People experience a fragmented system with glaring gaps.

> " One thing that struck both my father and me was that he didn't really see the same person twice ... Nobody was around to notice what was different from one day to the next."
> *Bereaved daughter.*
>
> "There was a lack of humanity really in the process right from the start. There didn't seem to be anybody that [my father] felt he could ask questions to. It was a medical process that he just had to wait for and in the meantime there didn't seem to be ... anybody to talk to or to give him advice."
> *Bereaved daughter.*
>
> "The challenge I find is that everyone's working in isolation. There's not a point where everybody's talking about the same person."
> *GP and Clinical Commissioner.*

Key themes and questions

As we considered the features of our current system of support for the dying, the following themes and questions emerged as important.

Discussing these themes, we arrived at a shared sense of how things might work differently for people at the end of life.

You might bring these questions into your own conversations with colleagues in reflection on the systems of care and support of which you are a part.

POWER

Who is 'allowed' to care for the dying? Who 'knows' best?

Who owns and defines the space where end of life care happens?

How are inequalities of power played out at end of life?

How do we help those with power to share their power?

CAPABILITY & EXPERTISE

Who has the skills and knowledge to care for the dying?

How can different skills and perspectives be integrated?

What capabilities are we missing?

Where are the capabilities that we are currently not seeing or not fully utilising?

PAIN & DISCOMFORT

What needs to happen for physical symptoms to be managed in more places and by more people?

How might we acknowledge and respond to emotional pain as well as physical pain?

How do we understand what frightens people the most and what their preferences might be?

How do we deal with long-term suffering, frailty and less predictable illnesses?

MEANING

Who defines the meaning of end of life? Who defines what is important and 'what matters' to us at the end?

In what ways (both explicit and implicit) is the meaning of end of life defined?

Where are the opportunities for exploring meaning and sharing meaning?

RISK & UNCERTAINTY

How do we deal with the fact that end of life is unpredictable?

How do we deal with the increasing unpredictability of the way we die?

Who or what determines how we approach risk?

What information, experience and judgements are necessary to navigate risks at end of life?
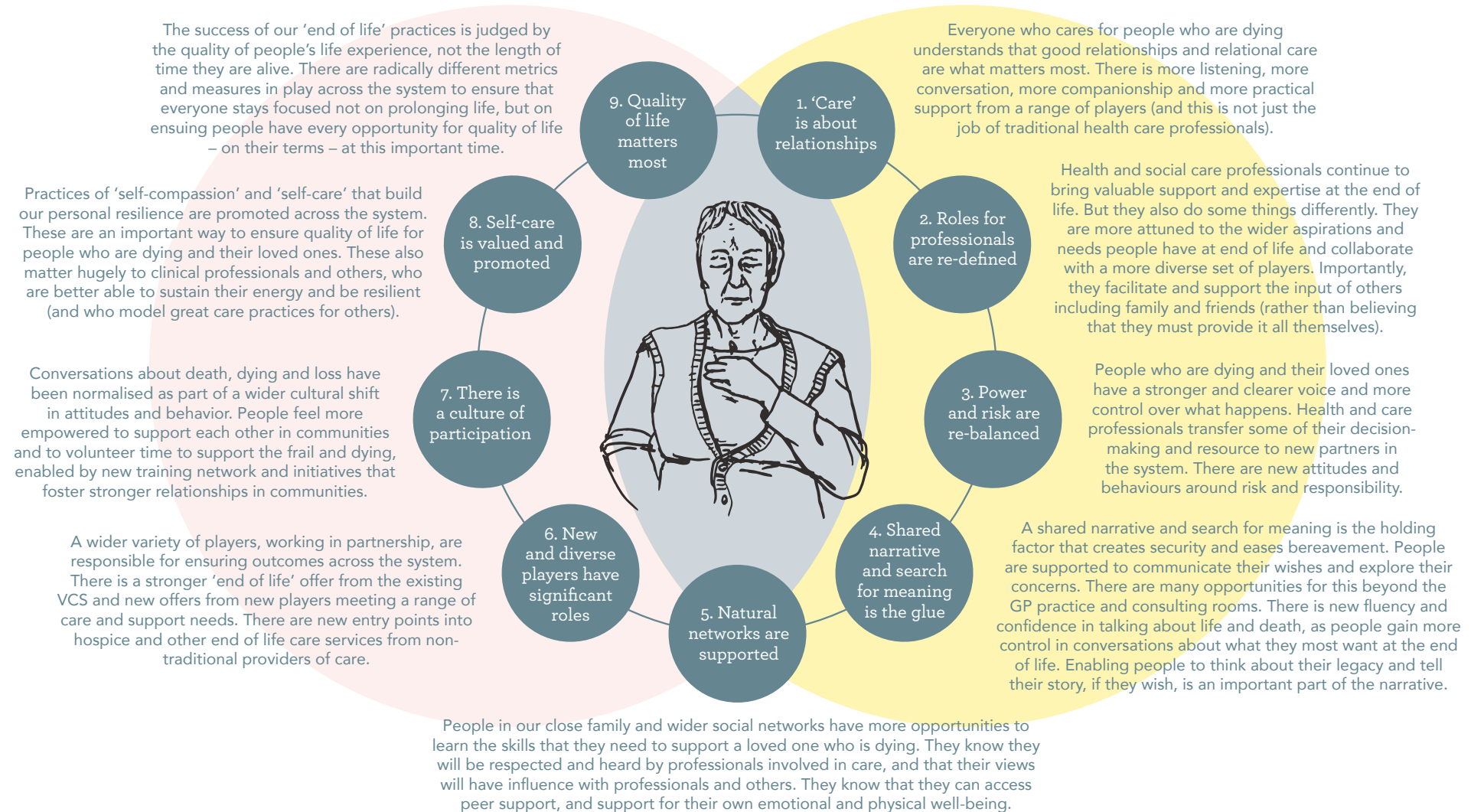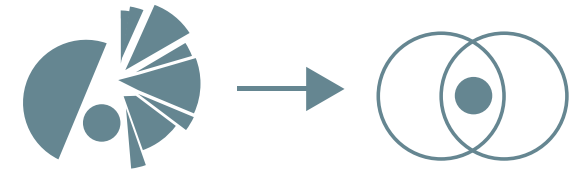
COLLECTIVE GROWTH

What are the opportunities in care of the dying that allow individuals to grow and learn?
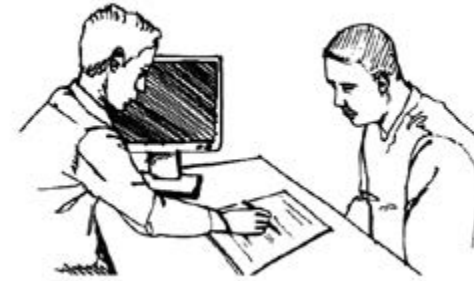
How might a sense of our own mortality and experiences of caring become a universal point of connection between people and communities?

How can the 500,000 people who die every year in Britain help the rest of us learn what is important about being human in the world today?

A system for better endings

The following shares our thinking about the features of a stronger system of support for people at the end of life. It spells out how we think things could work more powerfully, and suggests some of the different ways we might all be working to ensure better experiences for people. These features were identified through deeply reflective and collaborative work in the programme.

The success of our 'end of life' practices is judged by the quality of people's life experience, not the length of time they are alive. There are radically different metrics and measures in play across the system to ensure that everyone stays focused not on prolonging life, but on ensuing people have every opportunity for quality of life – on their terms – at this important time.

Practices of 'self-compassion' and 'self-care' that build our personal resilience are promoted across the system. These are an important way to ensure quality of life for people who are dying and their loved ones. These also matter hugely to clinical professionals and others, who are better able to sustain their energy and be resilient (and who model great care practices for others).

Conversations about death, dying and loss have been normalised as part of a wider cultural shift in attitudes and behavior. People feel more empowered to support each other in communities and to volunteer time to support the frail and dying, enabled by new training network and initiatives that foster stronger relationships in communities.

A wider variety of players, working in partnership, are responsible for ensuring outcomes across the system. There is a stronger 'end of life' offer from the existing VCS and new offers from new players meeting a range of care and support needs. There are new entry points into hospice and other end of life care services from non-traditional providers of care.

Everyone who cares for people who are dying understands that good relationships and relational care are what matters most. There is more listening, more conversation, more companionship and more practical support from a range of players (and this is not just the job of traditional health care professionals).

Health and social care professionals continue to bring valuable support and expertise at the end of life. But they also do some things differently. They are more attuned to the wider aspirations and needs people have at end of life and collaborate with a more diverse set of players. Importantly, they facilitate and support the input of others including family and friends (rather than believing that they must provide it all themselves).

People who are dying and their loved ones have a stronger and clearer voice and more control over what happens. Health and care professionals transfer some of their decision-making and resource to new partners in the system. There are new attitudes and behaviours around risk and responsibility.

A shared narrative and search for meaning is the holding factor that creates security and eases bereavement. People are supported to communicate their wishes and explore their concerns. There are many opportunities for this beyond the GP practice and consulting rooms. There is new fluency and confidence in talking about life and death, as people gain more control in conversations about what they most want at the end of life. Enabling people to think about their legacy and tell their story, if they wish, is an important part of the narrative.

People in our close family and wider social networks have more opportunities to learn the skills that they need to support a loved one who is dying. They know they will be respected and heard by professionals involved in care, and that their views will have influence with professionals and others. They know that they can access peer support, and support for their own emotional and physical well-being.

9. Quality of life matters most

1. 'Care' is about relationships

8. Self-care is valued and promoted

2. Roles for professionals are re-defined

7. There is a culture of participation

3. Power and risk are re-balanced

6. New and diverse players have significant roles

4. Shared narrative and search for meaning is the glue

5. Natural networks are supported

First steps

Improve existing touchpoints
Create new entry points into the system
Encourage and make room for new players
Create new connections
Create a new narrative
Start building a movement

Five years

New ways of working
New roles
New structures
New training approaches
New organisational strategies
New interfaces between organisations

Ten years

New national policies
New organisations
New professions
New community movements

Demonstrating new possibilities:
3 Prototypes

After we had agreed some of the features of a new system vision, we began to imagine how things could work in practice. We mobilised three small-scale projects to explore and to test how things could work.

Having engaged in collaborative work to reflect on our current system and and imagine a better system, we then identified three ideas for prototyping – Neighbourhood Care, Coach4Care and Ripples. Each of these ideas responded to compelling insights from our research and was strongly supported by our diverse community of programme participants. Each also responded to immediate opportunities in Southwark and Lambeth – we had people and places ready and enthusiastic to work with us to mobilise activity and run things in real contexts.

Though each had a different focus, our prototypes shared several features and characteristics. In each we aimed to create and demonstrate an approach where:

1. 'Care' is about relationships

2. Roles for professionals are re-defined

3. Power and risk are re-balanced

4. Shared narrative and search for meaning is the glue

5. Natural networks are supported

6. New and diverse players have significant roles

7. There is a culture of participation

8. Self-care is valued and promoted

9. Quality of life matters most

Each of the prototypes has been developed and tested in some form, and both Coach4Care and Ripples are being taken forward in different settings and with different partners in Southwark and Lambeth and beyond.

These prototypes do not provide a 'whole-system' answer. But they do seek to model aspects of our new system vision, while also showing energy and enthusiasm for different ways of working and trying something new.
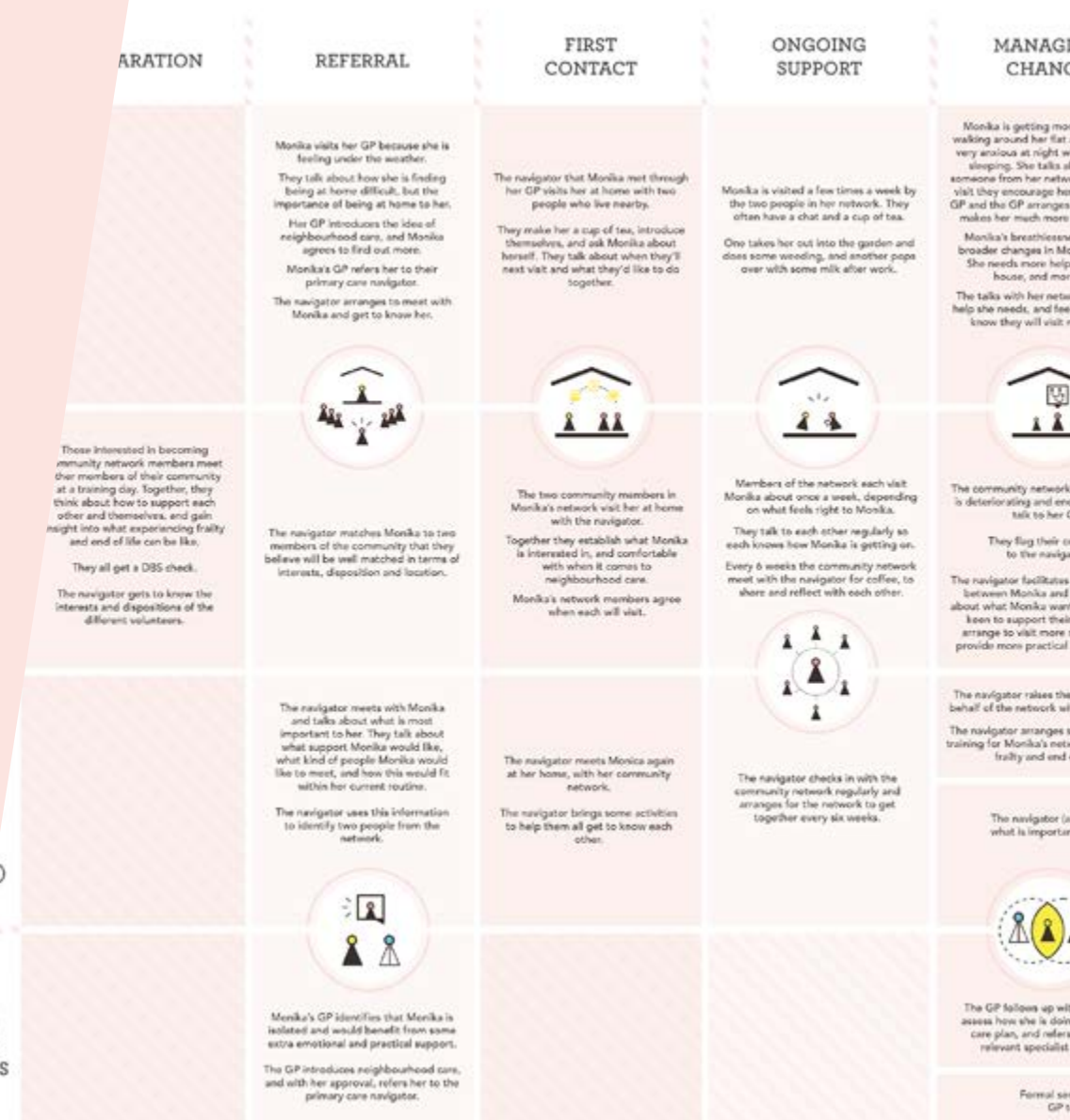
The following section describes each of the three Better Endings prototypes.

NEIGHBOURHOOD CARE

Building neighbourhood volunteer networks around isolated people, so that no one who is dying is left without practical and emotional support.

...ARATION

Those interested in becoming
ommunity network members meet
their members of their community
at a training day. Together, they
think about how to support each
other and themselves, and gain
nsight into what experiencing frailty
and end of life can be like.

They all get a DBS check.

The navigator gets to know the
interests and dispositions of the
different volunteers.

...)

...R
...ND
...ARE
...NALS

REFERRAL

Monika visits her GP because she is
feeling under the weather.

They talk about how she is finding
being at home difficult, but the
importance of being at home to her.

Her GP introduces the idea of
neighbourhood care, and Monika
agrees to find out more.

Monika's GP refers her to their
primary care navigator.

The navigator arranges to meet with
Monika and get to know her.

The navigator matches Monika to two
members of the community that they
believe will be well matched in terms of
interests, disposition and location.

The navigator meets with Monika
and talks about what is most
important to her. They talk about
what support Monika would like,
what kind of people Monika would
like to meet, and how this would fit
within her current routine.

The navigator uses this information
to identify two people from the
network.

Monika's GP identifies that Monika is
isolated and would benefit from some
extra emotional and practical support.

The GP introduces neighbourhood care,
and with her approval, refers her to the
primary care navigator.

FIRST CONTACT

The navigator that Monika met through
her GP visits her at home with two
people who live nearby.

They make her a cup of tea, introduce
themselves, and ask Monika about
herself. They talk about when they'll
next visit and what they'd like to do
together.

The two community members in
Monika's network visit her at home
with the navigator.

Together they establish what Monika
is interested in, and comfortable
with when it comes to
neighbourhood care.

Monika's network members agree
when each will visit.

The navigator meets Monica again
at her home, with her community
network.

The navigator brings some activities
to help them all get to know each
other.

ONGOING SUPPORT

Monika is visited a few times a week by
the two people in her network. They
often have a chat and a cup of tea.

One takes her out into the garden and
does some weeding, and another pops
over with some milk after work.

Members of the network each visit
Monika about once a week, depending
on what feels right to Monika.

They talk to each other regularly so
each knows how Monika is getting on.

Every 6 weeks the community network
meet with the navigator for coffee, to
share and reflect with each other.

The navigator checks in with the
community network regularly and
arranges for the network to get
together every six weeks.

MANAGI... CHANG...

Monika is getting mo...
walking around her flat...
very anxious at night w...
sleeping. She talks a...
someone from her netw...
visit they encourage h...
GP and the GP arranges...
makes her much more...

Monika's breathlessn...
broader changes in Mo...
She needs more help...
house, and mor...

The talks with her netw...
help she needs, and fee...
know they will visit...

The community network...
is deteriorating and can...
talk to her G...

They flag their c...
to the navigato...

The navigator facilitates...
between Monika and...
about what Monika wan...
keen to support their...
arrange to visit more...
provide more practical...

The navigator raises the...
behalf of the network w...

The navigator arranges...
training for Monika's net...
frailty and end...

The navigator (a...
what is importan...

The GP follows up wi...
assess how she is doin...
care plan, and refers...
relevant specialist...

Formal s...
GP...

"There are a lot of people who need help in this country. In Nigeria we work with the community - your problem is my problem. I know the United Kingdom, they are very good. They do everything in humanity, 'A' for effort. But loneliness! Loneliness is here."

THE NEED:

People have practical and emotional needs at the end of life that professional care does not address. Without strong support from family and friends, the last months and weeks of life can be lonely and distressing. It helps hugely to have people around to do domestic tasks, liaise with services and just to talk.

KEY QUESTION FOR THE PROTOTYPE:

How can we create informal networks around isolated people, so that no one who is dying is left without practical and emotional support?

I feel such a sense of shame too over not being able to cope better. It has become so that all my former competent-enough years never happened. I have collapsed into a helpless, crying baby again. One of the greatest terrors I have now – this is why I wish I were dead – is having a fall and a fracture, and then there not being sufficient services to help me."

FEATURES:

- Identifying people who may need additional practical and social support through GPs and other services

- Building volunteer support around people (ideally from the person's immediate neighbourhood) and creating strong, authentic and reciprocal relationships. The volunteers are formally networked and professionally trained

- Staged training, which is focused on building confidence, and familiarity with end of life needs, that allows volunteers to stay with the individual as they approach the end of life

- Linking volunteers closely with formal health services

- Exploring partnerships with Housing Associations and others who could help host and deliver Neighbourhood Care schemes.

BENEFITS:

- Enabling people to live independently and lead the lives they want to lead, up until the end

- Helping to reduce and avoid moments of crisis and greater intervention

- Creating communities in which people feel more confident to reach out to each other and support each other, connected by stronger relationships.
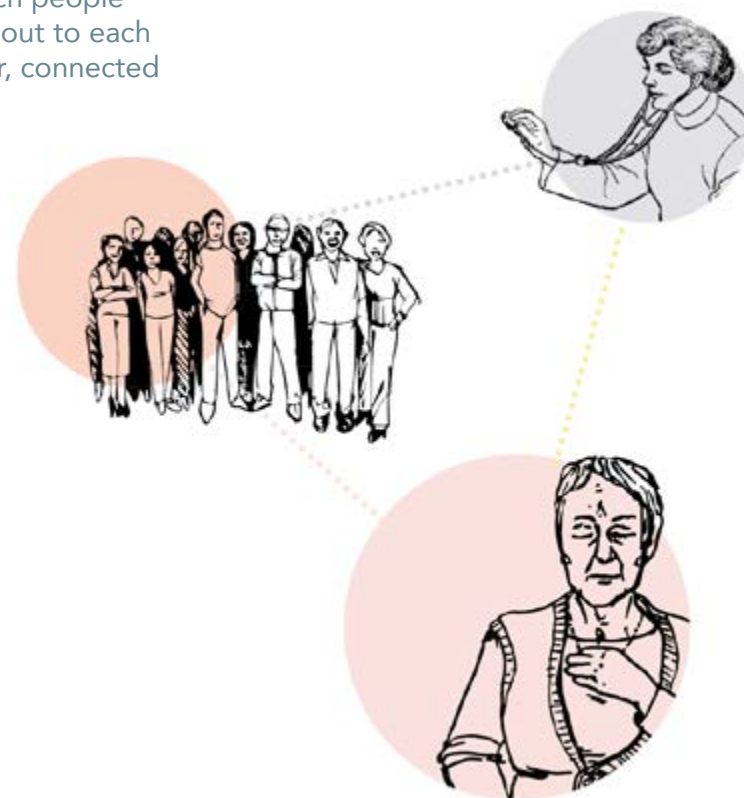
WHAT DID WE DO?

We worked with a variety of different people to develop Neighbourhood Care: GPs, Members of GP Patient Participation Groups, palliative care specialists, volunteers for existing third sector community services, informal neighbourhood volunteers, community groups providing services for older people, and Housing Associations.

Running discussion groups and more structured co-design sessions, we aimed to deepen our understanding of the needs of frail people in the last year of life; explore how to unlock community capacity for care and support at end of life; and develop a working model for community support for those in the last year of life.

WHAT NEXT?

There was lots of interest in this idea from formal services, and from VCS organisations. Many could see its potential. But questions about risk and safe-guarding and differing views of what is possible between formal and informal services blocked our progress.

The prototype has two key outputs: an early version of a service model; a set of insights and provocations about community capacity in end of life care. We remain compelled by the concept of building more community and voluntary capacity around GP services and are keen to explore the model further.

COACH4CARE

Peer-led coaching to help people sustain their love, energy and well-being when they are caring for a loved one who is dying.

I joined Coach4Carers because

It helped me find more love and energy to give to my wife.

" It is so hard to think about my own needs when she is in such a worse condition."

THE NEED:

Family and friends often play a crucial role in the support and care of someone who is dying. This can be a rich and precious experience for everyone, but also one of the hardest things we might do and can have a profound and lasting impact on so many different aspects of our lives. We need to take care of ourselves, as we take care of others.

KEY QUESTION FOR THE PROTOTYPE:

What helps us to look after ourselves as we take care of others?

" It can be very overwhelming sometimes. You are dealing with situations that are new and hard. It can be frightening. Sometimes I feel ashamed because I know I am not handling things as well as I could be. The fact that I am mostly on my own, that makes it worse."

" It is a full-time job. I don't feel like the person I used to be. I hardly see my friends and I can only work part time now. The only time I have for me is a coffee morning I go to once a week. Even going there I feel guilty."

FEATURES:

- Supporting people to process experiences and take care of their own health and well-being while they care for a dying loved one

- Offering one-to-one coaching with a specifically trained peer coach (with lived experience of supporting someone at the end of life)

- Putting people who are dying and their loved ones in genuine partnership with professionals and with peer coaches

- Referring people through GPs, social services and hospices. Hosted by hospices or other community agents.

BENEFITS:

- Enabling people who are dying to live independently and surrounded by loved ones, until the end

- Helping to reduce and avoid moments of crisis and greater intervention

- Protecting family and friends from fatigue and burnout and sustain their own health and well-being as they care for a loved one

- Creating ways for people who have cared for dying loved ones to find new meaning and value in the experience through giving support to others.

WHAT DID WE DO?

Coach4care addresses the emotional needs we have when caring for a loved one who is dying, and supports us to look after ourselves as well as possible through the experience.

Based on a one-to-one coaching methodology, Coach4care matches people with a specifically trained peer coach (with lived experience of supporting someone at the end of life). The coaches help to create a space in people's lives for reflection and for taking small but important actions to sustain energy and improve well-being.

We mobilised an energetic, diverse and committed group of people to explore the needs of those who are caring for a dying loved one, and to develop Coach4care. This included: 12 people with lived experience as family carers, 3 organisations that support carers, 14 voluntary and community organisations, 15 health professionals and 20 professional coaches.

During the development of the prototype, we ran several co-design workshops through which we developed a full service specification, along with a coaching handbook and resources.

WHAT NEXT?

We are continuing to work with St Christopher's Hospice and other key partners to develop Coach4care with a view to implementation at the Hospice later in 2018.

The full set of Coach4care resources is available for anyone to use via the Innovation Unit website.

PROTOTYPE 3:

RIPPLES

Using dialogue and story-telling to help people to explore the value of their lives and experiences for themselves and to others.
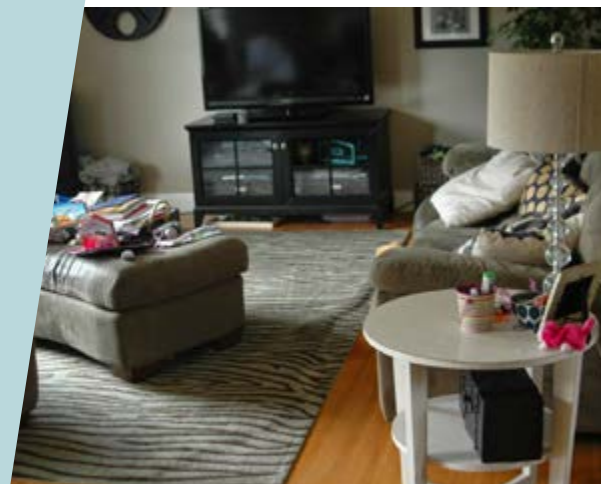
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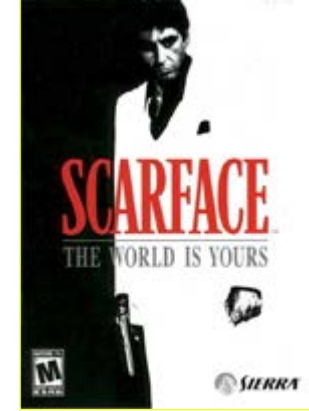
Choose a movie or a song
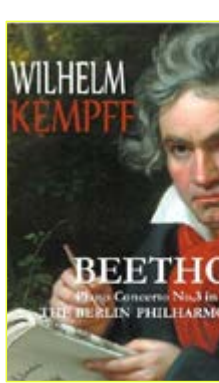
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"I'm not happy it's coming to an end... I feel like I haven't done enough with my life. Never really figured out what I was good at."

THE NEED:

It can often be hard for us to recognise what's valuable about our life experiences, and the kind of mark we've left on the world. Making sense of things and finding meaning can be important, and there might not always be someone around to help you do that.

KEY QUESTION FOR THE PROTOTYPE:

How could we support people to explore and see value and meaning in their lives?

"I'll remember the ripples I've caused in my life. This helps me when I'm feeling hopeless about the state of the world, and that I had no impact on improving it."

"Many of our members lost their partner and don't have any connections left with their family. Giving them the opportunity to find value in their often challenging lives can be very important." "Life is short term for these guys. When someone doesn't come back, they're easily forgotten. No one asks for them anymore. It's assumed they are either in the hospital, in prison or dead. They become a rumour."

FEATURES:

- Enhancing the experiences of people without a solid network of loved ones around them who might help them to make sense of things

- Training listeners to feel confident to lead people through a visual and engaging process of conversation and self-reflection

- Offering easy-to-use resources and light-touch training to support conversation. The aim is to empower a range of organisations to lead conversations with people who are dying

- Sharing inspiring messages of people who would have otherwise been left unheard.

BENEFITS:

- People to feel heard, and valued for who they are and what they experienced

- People to feel empowered at the end of life, and feel motivated to make life altering decisions

- To improve the quality of our conversations with people who are dying through creative and personal activities

- To utilise the great wisdom from people who would otherwise have been left unheard. These messages can teach us how to live more meaningfully and be more aware of how we participate in and contribute to the world.

WHAT DID WE DO?

Ripples specifically aims to enhance the experiences of people who may not have a solid network of loved ones around them to help them talk about their experiences and make sense of things.

We developed and tested the approach in three different settings with three participants: a 95 year-old woman in a nursing home; a 65 year old gay man and recovering alcoholic who lives by himself; and a 50 year old woman with MS who attends a homeless shelter. We chose to work with these people so that we could explore different contexts in which Ripples might have impact. We also worked with colleagues in each setting to explore how Ripples could work, and how it might be delivered: a volunteer for Opening Doors (a charity for older members of the LGBT community), the manager of a homeless shelter, and the manager of a nursing home.

WHAT NEXT?

While testing the model, we also ran workshops for a wider set of partners to share what we were learning. There was strong enthusiasm for Ripples from charities that support homeless and vulnerable people, and we started to work closely with Groundswell, St Mungo's and Ace of Clubs. We are currently working on a training offer for each of these charities.

The Ripples messages we have been capturing will also be hosted on the website www.passingboxes.com, amongst other places.

We have also recently learned that City and Hackney Mind are interested in running Ripples and we have offered them our support and training materials.

What Next?

Better Endings concluded as an official programme in December 2017, but the work here continues in several ways. The programme brought together a brilliant group of people who were open and creative in their thinking, deeply experienced in their practice and impatient for radical change in the way we support the dying.

We will continue to push for Better Endings as part of a movement that is growing momentum locally and on a global scale.

Please get in touch with us if you'd like to know more, or if you have great ideas for improving our experiences at end of life.

We also encourage you to look more closely at our prototypes by visiting our website, and where many more resources might be found and put to use in your community.

Acknowledgements

Over 200 people contributed thoughts and energy to the Better Endings programme. There are too many organisations and individuals to name but they include colleagues from hospices, hospitals, care homes, GP surgeries, emergency services, community and voluntary groups and organisations, faith groups and so many more. We are grateful to everyone who shared stories and views and rolled up their sleeves to create new things in pursuit of Better Endings.

Special thanks to St Christopher's Hospice, Pembroke House, Ace of Clubs, Blackfriars Settlement, St Mungo's, Groundswell and Opening Doors.

Original illustrations by Sonia Kneepkens.

ABOUT INNOVATION UNIT

Innovation Unit is a not for profit social enterprise. We create new solutions that enable more people to belong and contribute to thriving societies. We develop alliances for change with places, organisations and systems, to ensure that innovation has lasting impact at scale.

ABOUT GUY'S & ST THOMAS' CHARITY

Guy's and St Thomas' Charity is an independent, place-based foundation. It works with Guy's and St Thomas' NHS Foundation Trust and others to improve the health of people in the London boroughs of Lambeth and Southwark, and to tackle the major health challenges affecting people living in urban, diverse and deprived areas.

Better Endings
Creating new solutions for end of life care and support.

Innovation Unit
New solutions for thriving societies

GUY'S & ST THOMAS' CHARITY