



A good life
with dementia

> About this report

ESRO

Leading the fight
against dementia
**Alzheimer's
Society**



This report was written by ESRO – a multiple award-winning, independent research agency, with expertise in innovation, social policy research and hard-to-reach audiences. It was inspired by a number of projects we have conducted studying dementia in partnership with Red & Yellow Care. These studies have included over 200 hours of ethnographic observation in care homes and with individuals living at home. They have taken into account the views of more than 80 people with dementia, around 50 carers, and numerous frontline practitioners working in different clinical, care or support roles both in and beyond dementia care settings.

In preparing these reflections, we have spoken to a range of dementia experts and leading thinkers on happiness and wellbeing, and also conducted a wide-ranging literature review covering policy, academic and mainstream publications. Findings from a February 2014 YouGov survey, capturing the views of a UK adult audience (n=2,347), have also been incorporated throughout.

This report was funded by Red & Yellow Care and published in association with Alzheimer's Society. It was written by Becky Rowe, Tom Brown and Jenny Holland from ESRO, but includes the research, analysis and thinking of a far wider team of researchers including Dr Agnes Hann, Oliver Hopwood and Dr Robin Pharoah.

Any mistakes or inaccuracies are the authors' own.

'We're just people.'

Judy, person with dementia

Dementia: A stigmatised label that is compounded by being both a mental health issue and a condition associated with old age. In many ways it has come to be a byword representing the frailties and fears of ageing. This must change.

The stigma is getting in the way of people living their lives, deflated by the 'nothing can be done' attitudes of hopelessness that pervade not just public, but some professional attitudes towards the condition. The effect of this leads people to hold beliefs such as 'a diagnosis is not going to make a difference', and 'it doesn't matter because they won't remember anyway'.

Life with dementia can be very difficult; it can emotionally and physically drain the carers, and isolate the individual. Unfortunately there is no single panacea. However, we have met and worked with many people with dementia who are enjoying their lives, and who, together with their families and carers, challenge the negative perspective associated with the condition, and are overcoming the difficulties they face.

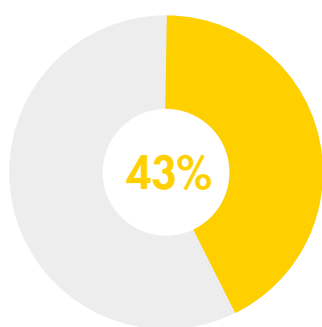
As a company we have spent five years immersed in the condition, and have built up hundreds of hours of anecdotal and researched evidence. This has reinforced our conviction that each individual experiences dementia differently, and that with the right care and support, people can live a good life, and continue to play a role in their families and communities.

Much needs to be done to help this growing population, and in some ways the greater challenge is in changing attitudes, not just towards the condition but towards old age. We commissioned this report with a view to encouraging a debate, and seeding it with a more hopeful perspective that we would like to see lead to more energy and optimism in society's approach to dementia.

I would like to thank the wonderfully gifted team at ESRO and the ongoing support and insight provided by Alzheimer's Society, who lead the way on this work. Lastly, and most importantly, many thanks to all the people with dementia, their families and carers, and the professionals who have shared their stories and expertise.

Dr Bahbak Miremadi
Founding Director, Red & Yellow Care

➤ Defining a 'good life' with dementia 'Just a different chapter'



43% of UK adults agree that they don't think it's possible to live a good life with dementia

Source: YouGov¹, February 2014, n=2,347, all UK adults

'Nearly two-thirds (63%) of people with dementia surveyed said they felt anxious or depressed. A third of people with dementia said they had lost friends and 5% said they have not told their friends about their diagnosis.'

**Martina Kane and Laura Cook,
Dementia 2013: The Hidden
Voice of Loneliness,
Alzheimer's Society, 2013**

¹ All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 2,347 adults. Fieldwork was undertaken between 26–27th February 2014. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+).

^{2&3} Source: Alzheimer's Society

A fate worse than death?

Dementia looms large over contemporary society. Radical improvements in healthcare are keeping the population alive ever longer, but the good news is overshadowed by fear of what may become of us if – some even say *when* – dementia strikes.

One in three people over 65 will develop dementia before they die², and the condition is understandably frightening. Nobody can pretend that gradually losing your faculties, becoming less able to care for yourself, and possibly even experiencing public embarrassment, are in any way positive experiences. Nor can it be anything other than deeply disturbing to witness your loved one becoming increasingly frail and undergoing sometimes radical changes in their behaviour and personality. The knowledge that dementia will ultimately kill those who have it brings the fear of death centre stage – although some people believe that the prospect of living with dementia is even worse.

What is there to fear?

Experts agree that a timely diagnosis is key in improving the experiences of those with dementia, bringing with it appropriate medication, intervention and support – and yet over half of those living with dementia do not have a formal diagnosis³. For those who do, diagnosis sometimes comes as a relief from the anxiety of not knowing what's happening, or why. But it can also be the moment at which the real fear sets in; when life swerves onto a new road, and the ultimate destination is clear.

So much is inevitable and, as we say, scary. But beyond death – which, of course, comes to us all – what else is actually certain? The kinds of symptoms and likely progression of the disease are all unknown at the point of diagnosis. And yet our fear of dementia is so all-consuming that we may feel like giving up on life altogether – assuming the worst when, in fact, we may have the faculties and the time to continue living well for a considerable while.

In coming years, increased and perhaps earlier diagnosis will mean more people living longer in the knowledge that they have dementia (often in a relatively mild form), which will in turn make the presence of people with dementia in our families and communities ever more widespread.

How prepared are we to respond to this? Do we need to re-examine how we care for and support people with dementia not just now, but in the future?

And what of our fear? Will it simply increase proportionally – meaning that all of us, at all times, live in fear of either getting dementia, having dementia, or caring for someone with dementia? Or is there, in fact, a way of living with dementia which could, over time, reduce our fear – one where people are able to achieve fulfilment, even happiness, after dementia has been diagnosed?

Six paths to a ‘good life’

This report makes the case for what this ‘good life’ with dementia looks like, and it explores the implications of that ideal for individuals, communities, and caregivers.

Our framework is rooted in universal notions of happiness and fulfilment. Specifically, we explore six areas of life, introduced on the next page, in which we believe it is the right of people with dementia to achieve the same kind of fulfilment as those without the condition. We examine each of these themes in relation to individual coping, but also with reference to relationships within families and society more broadly. We also relate each theme to the question of how service providers currently engage with people – and what more could be done to create the right conditions for a good life with dementia.

Assuming the best

The report is aimed at those who are in a position to affect the experience of people living with the condition – but we hope it also offers a ray of hope to anyone who has or fears dementia. A lot of what we discuss may seem most applicable to those in the early or middle stages of the condition, but we believe that these principles can, and should, be applied with equal rigour to those in the later stages of dementia – even if they lack powers of communication, and are dependent on others for their care.

Our sincere goal is that after reading this report people will not only be better able to articulate what a good life with dementia entails, but feel more assured in assuming the best, not the worst, from a dementia diagnosis.

What we say may be controversial in places, but we do not believe that anything here is a revelation. It is simply a reminder that a good life is possible for everyone – including those with dementia.

‘Dementia is seen by so many members of the public as being the “end of the road” – a demon to be feared – when in fact dementia is coming to be recognised as a very normal part of our ageing experience and a feature of our societal life in general. Many of us will live into old age experiencing some of the symptoms identified within the “dementia spectrum”.’

Professor David Sines, expert on nursing and community care

‘Lots of people give up, but it’s not the end. It’s just a different chapter.’

Sue, Brian’s carer

➤ Six paths to a good life with dementia

*‘People view it as something you can’t control. What they don’t realise is that you **can** control lots of things.’*

Judy, person with dementia

‘I’m not going to tell you my age. I feel about 35.’

**Milly, person with dementia
[aged 63]**

#1 Respecting identity: ‘It’s not one size fits all’

Seeing people as distinct individuals is central to having a good life with dementia. This means a genuine and determined desire to treat and respect those with dementia as unique and valuable.

- How do we reduce fear so people feel less pressure to self-identify as ‘having dementia’?
- How do we overcome the dementia label, and the stereotypes, bad habits and compromises that flow from it?
- How do we design services that allow people’s individual identities to flourish and grow?

#2 Embracing now: ‘It’s a moment-living life’

The gradual disappearance of memory brings about a strong desire to focus on the thing that is being lost. While support with ‘remembering’ can be hugely valuable to people with dementia, this should be balanced with the importance of experiences in the here and now.

- How do we empower people with dementia to make their own choices about whether to ‘consume’ memories or not?
- What more can we do to enable people to ‘live in the moment’?
- What are the implications of focusing more on what people with dementia can do, rather than what they can’t?

#3 Sustaining relationships: ‘You don’t always need words’

Dementia brings out different aspects of relationships. Some are beautiful, but others are tainted by prejudice, preconception and impatience. For those with dementia to thrive, sustaining meaningful relationships is essential – and that responsibility extends throughout society.

- How can we allow people with dementia to lead fulfilling social lives, on their own terms and without stigma?
- How do we create conditions that enable the meaningful continuation of important relationships?
- What can we do to normalise dementia, and ensure people do not feel ghettoised?

#4 Valuing contrast: 'Good days and bad days'

Happiness is complicated – a roller-coaster of highs and lows, of being able to express ourselves freely and gain contentment in whatever we choose. But this nuanced reality can be absent, or difficult to achieve, for those living with dementia.

- How do we assess what makes someone with dementia happy?
- How can we overcome the determination to eliminate unhappiness from the lives of people with dementia?
- How do we design care environments which allow people with dementia to experience and express a full range of emotions?

#5 Supporting agency: 'What's there to worry about?'

Letting a person with dementia take risks is hard to square with our desire to keep vulnerable people safe. But if the knowledge of certain death brings a sense of freedom and thirst for life, then to enable a good life we need to be clearer about what it is we are protecting people from.

- How can we promote spontaneity, choice and risk as assets in a life with dementia?
- How do we design dementia services to ensure we do not restrict individuals' freedoms by limiting them to our desired routines?
- What role can technology play in providing reassurances to carers about individuals' safety?

#6 Maintaining health: 'My priority in life'

Dementia is a serious condition which requires specialist treatment. But that focus can cause unintended disregard for other parts of an individual's health which, if neglected, may become a source of needless suffering, or limit opportunities to live well.

- How do we design services that have the flexibility to address every aspect of a person's good health, regardless of their dementia?
- What more can be done to enable people with dementia to communicate their feelings in relation to health and wellbeing?

'It is a mercy [of dementia] that there are so many bright days to be relished before winter closes in, if only people can be helped towards living rather than dying.'

Sally Magnusson,
Where Memories Go:
Why Dementia Changes
Everything, Two Roads, 2014



**ACHIEVEMENTS
PASSIONS
PERSONALITY**

#1

Respecting identity
'It's not one
size fits all'

'You change the world by being yourself.'

Yoko Ono

➤ How do we better support people to maintain their unique sense of self?

*'I've got dementia –
but I've got a life.'*

Victoria, person with dementia

*'If you've met one person with dementia . . .
you've met one person with dementia.'*

Dementia professionals' mantra

*'It's not one-size-fits-all.
Everyone has an individual
journey . . . Everyone lives
with it differently.'*

Jim, person with dementia

What makes us who we are?

The question of identity – of what defines us as human beings – is almost impossibly complex. It underpins a lot of current thinking relating to dementia and runs beneath the surface of much of this report. But for all its intricacy, it's also a question to which we all know our own answer. That answer may involve any number of factors – values, beliefs, tastes, talents, achievements, hobbies, relationships – but more often than not, we will be fairly certain about our own identity: what makes us who we are.

The first rule of dementia

Just as we all have our own individual mix of identifying traits, so all individuals with dementia have their own experience of the condition. Every person's dementia is different. No matter what symptoms may be shared, actual experiences are as unique as the individuals themselves; and even a long way through the condition, many of a person's own behavioural quirks still rise to the surface – whether it is their proficiency on a musical instrument, appetites for particular kinds of food, or eccentric personality traits. Glimpsed by carers, and supported by scientists, the truth is that people retain their own, evolving identity throughout dementia.

In our lives without dementia, we expect our identities to be respected by others and allowed to flourish, free of labels. And yet, despite considerable effort, a lot of existing care approaches – and the wider discourse around dementia – struggle to recognise and work with people's individuality. Instead, people with the condition are grouped together in a generic fashion, and important identifying characteristics are sometimes overlooked.

The dementia 'type'

Our research highlights that one problem relating to identity is that people with dementia and their carers often label and re-define themselves. For example, they start to identify themselves (as do others) with the caveat of 'having dementia', as if that is the most important thing to know about them as a person. Their own prejudice and deep-set assumptions take over about what, as a person with dementia, they will want, need, like, and dislike.

There is no good reason for this loss of selfhood. Even for those in the last phases of the condition, dementia doesn't change the fact of their individuality – the past achievements, experiences, choices, loves and losses that have made them who they are. It is therefore essential that caregivers collect and continue to use information relating to a person's history, past experiences and personality right up to the end of their experience of dementia.

Life goes on

Looking back over their experiences, one of the biggest regrets for many carers and individuals with dementia is that, after diagnosis, they simply stood still in the proverbial headlights, waiting for the impact of dementia. A potentially long and rewarding time of life went to waste by needlessly seeing everything through the prism of 'worst case' dementia – viewing diagnosis as the end, and screening out the dreams and desires they continued to have.

It is critical that people with dementia feel not only empowered to pursue their desires – whatever form they take – but recognise in themselves the potential for future growth, and for finding happiness in new things. As in life, the identity of those with dementia is never static, and people's right to keep exploring, expressing themselves and achieving things must be honoured.

'People with dementia deserve respect. They have heritage and identity which they have forged over many years. They have pride.'

**Alice Osborne, designer and
Creative Director at Spots of Time⁴**

'I feel I'm normal. I can answer the phone, and I can cook.'

Margaret, person with dementia

'A sense of achievement and pride is frequently not offered to people with dementia – even though it's something that everyone else values and works towards.'

**Dr James Warner, psychiatrist
and dementia researcher**

⁴ Spots of Time is a social enterprise which – in association with the My Home Life network – is highly active in care homes, connecting them with people in local communities who are able to provide fun, creative activities that enhance care home life.



**PAST
PRESENT
FUTURE**

#2

Embracing now 'A moment-living life'

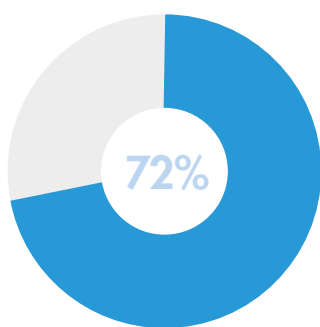
'What day is it?'

'It's today?' squeaked Piglet.

'My favourite day,' said Pooh.

A A Milne

➤ Do we have the right balance between memory-based activities and the here and now?



72% of UK adults think 'not living in the past' is important to happiness

Source: YouGov, February 2014, n=2,347, all UK adults

'It's a moment-living life with dementia.'

Sue, Brian's carer

'Listening to music isn't just about remembering; it's about experiencing being in the moment with music . . . trying to be anchored or present in what you are feeling.'

Dr Gianna Cassidy, Research Co-ordinator at Playlist for Life⁵

Living life forwards

Aside from death, the only thing virtually guaranteed in dementia is the loss of memory. So it is unsurprising that addressing memory problems is a key aspect of caring for people with dementia. Lots of energy goes into devising activities and tools for remembering, whether it is the creation of memory boxes (containing prized items and trinkets to trigger recollections), the facilitation of reminiscence groups, the focus on creating life histories, or even the design and installation of nostalgic past environments. Many of these are widely acknowledged to be very rewarding and impactful, making a significant contribution to living well with dementia through the stimulation of memory and release of positive emotions.

However, while past experiences are crucial in shaping our present selves, we do not need to continually remember them to retain our sense of identity and enable us to be happy. Leading thinkers such as the Nobel Prize-winning psychologist Daniel Kahneman argue that the 'consumption of memory' is over-rated – that we do far less of it than we think, and have a disproportionate sense of its importance. Kahneman's key distinction is between the 'remembering self' and the 'experiencing self', and he suggests that the 'experiencing self' has a greater say in how happy we are; that we would arguably feel more fulfilled, as a species, if we could suppress our 'remembering selves' a little, and focus more on momentary pleasures.

⁵ Playlist for Life is a charity dedicated to encouraging families and other caregivers to develop and assemble personal music playlists for individuals with dementia

The tyranny of memories

The implications of this for those with dementia – who can start struggling to think coherently, whether contemplating the future or the past – are striking. Indeed, one might even argue that the growing inability of people with dementia to remember – coupled with their often uninhibited approach to enjoying happenings in the moment – has something to teach those *without* dementia about the value of the experiencing self. All over the world, we thirst for and pay huge amounts of money to have amazing experiences, but many of us then miss the moment because of our desire to record the memory through photography, film or social media – all the while knowing the awkward truth that we are unlikely to revisit what we've documented, and that looking back never quite captures the thrill we would have felt had we properly engaged in the moment.

Remembering the experiencing self

By recognising the value of living in the moment, we are not underestimating the importance of memories. People must do what makes them happy. However, our research also highlights the importance of working proactively with what people still can do, as well as what they can't. When people begin to find remembering more difficult, then perhaps there's an opportunity to embrace the potential for happiness that comes from the 'experiencing self', and facilitate momentary pleasures wherever possible.

*'If I knew then what I know
now, I would have been off,
doing everything I could.
Living my life to the full.'*

Bob, person with dementia

'Forever is composed of nows.'

Emily Dickinson, poet

*'It's about what you can do, not
what you can't do.'*

Judy, person with dementia

*'You can always choose to perceive things
differently. You can focus on what's
wrong in your life, or you can focus on
what's right.'*

Marianne Williamson,



**CONNECT
APPRECIATE
BUILD**

#3

**Sustaining
relationships**
**'You don't always
need words'**

*'Lots of people want to ride with you in the limo,
but what you want is someone who will take
the bus with you when the limo breaks down.'*

Oprah Winfrey, entertainer and actress

➤ What more can we do to ensure people are able to experience meaningful human connections?

'Imperfections are not inadequacies; they are reminders that we're all in this together.'

Brené Brown, author and scholar

'It's important for people who are living with dementia to feel they are included, involved and have a purpose in life. Keeping people engaged in activities can help retain their level of functioning for longer. Without human connection and meaningful engagement, people can become isolated and withdraw into themselves.'

**Rachel Thompson,
Dementia Project Lead at the
Royal College of Nursing**

'People give you a wide berth when they find out you have dementia. Because they don't know how to act.'

Brian, person with dementia

Perfect imperfection

Meaningful relationships are critically important to all of our lives – they shape us, support us and give us a reason to keep going. We feel this especially keenly when we hear about people who are lonely or isolated from the world. Instinctively, we want to help them – to bring them out of the 'cold', and into the 'warmth' provided by social interactions.

When we think of the friendships we most value, we intuitively think of what we love about people. But there are shades of grey to even the most durable human relationships. Just as we may be able to see redeeming features in our fiercest enemy, we learn to accept imperfections in those we love – and, in so doing, learn to accept them in ourselves.

Our research has shown that dementia has a tendency to accentuate revealing aspects of relationships, in a way that it is directly comparable to other important life transitions. Just as having a baby or retiring can bring us close together, they can also expose faultlines that were already present – and the same is true of dementia. Those who seem to adjust the best are those who dare to view dementia as just another one of our many human imperfections – a serious one with a sad ending, admittedly, but not one that automatically undermines a person's potential to enjoy meaningful adult interactions. Put simply, those who embrace the changes, for better or worse, seem to fare better than those who struggle to accept the reality of the condition.

Timeless friendship

One of the sad consequences of a dementia diagnosis is that it often precipitates many changes in a person's social interactions. Normal, fluid social activities – motivated by an individual's unique set of interests, sensibilities and memories – are eclipsed by old friends struggling to know 'what to say', and replaced by sometimes tenuous gatherings for people united chiefly by their label.

While family caregivers – by virtue of their closeness – are often beyond reproach in their patience, empathy and quality of care, larger care systems and society as a whole struggle to allow people with dementia to form and sustain naturally satisfying, organic relationships with others. Startled into compromise by the challenges of communication, the trend is for bringing people together for no better reason than their having dementia, while simultaneously limiting opportunities for them to create or continue to experience meaningful emotional connections with others.

Don't talk down to me

Being patronised is often a common complaint for individuals with dementia. Rather than seeing the symptoms of dementia as merely another imperfection to be worked with, the 'default interaction mode' (as James Warner calls it) switches from 'adult to adult' to 'adult to child'. To an extent, this is understandable – dementia brings with it a need to be clear, and the vulnerability felt by people with dementia naturally provokes (or revives) parental behaviours in those charged with caring. Too often, however, the 'parental mode' becomes something more than merely linguistic, encouraging us to patronise people with dementia as though they were children – an analogy which is ultimately unhelpful and deeply unfair.

Love beyond words

While it would be wrong to pretend that having dementia is necessarily a positive step in the formation of relationships, time and again in our primary research we have seen the inordinate value of those powerful emotional bonds which transcend the more superficial challenges posed by faltering speech and meaning. Dementia can teach us volumes about how much can be communicated beyond words – as well as the importance of connecting with others on your own terms, and the value of company and companionship.

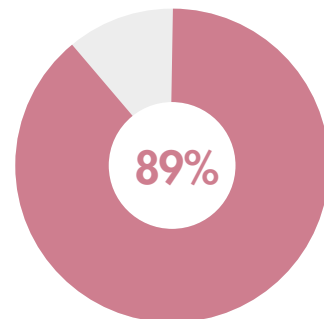
Those who are able to find the support they need describe remaining connected to the world in a meaningful way as an essential part of being human. The familiarity and sense of self-worth derived from being appreciated and loved are hugely comforting; and the confidence that comes from being accepted not only by family and friends, but also the supermarket cashier and the postman, is utterly invaluable. The challenge for the rest of the world is how to accommodate those vital needs.

'People offering care to those with dementia often treat them like children, but they are adults, with adult feelings.'

Barbara Pointon, former carer of a person with dementia

'We call it "our" diagnosis because it's our disease.'

Sarah, Mike's carer



89% of UK adults think 'feeling lonely or isolated' would be likely to make a person with dementia feel unhappy

Source: YouGov, February 2014, n=2,347, all UK adults

'Sometimes we sit together in silence. You don't always need words to know you are loved and loving back in return. Those moments are precious.'

Kate, Tony's carer



**HIGHS
LOWS
VARIETY**

#4

Valuing contrast 'Good days and bad days'

*'I pulled over and I just cried like a b***h. I cried so much. And it was beautiful. Sadness is poetic. You're lucky to live sad moments. And then I had happy feelings . . .'*

Louis CK, comedian

➤ How do we ensure people are able to experience a full range of emotions?

'We argue sometimes, just like we always have and everyone does. That's not the dementia. It's just one part of our relationship. It would be weirder if we didn't.'

Kate, Tony's carer

'Moaning... is socially therapeutic – highly effective as a facilitator of social interaction and bonding. Moaning is also highly enjoyable.'

**Kate Fox, *Watching the English*,
Hodder & Stoughton, 2004**

'Like anyone, you can have good days and bad days.'

Louise, Richard's carer

Don't force me to be happy

'Happiness' has become big business – barely a week passes without the publication of a new thought-piece or self-help guide on how to achieve, measure or encourage happiness. A strong central theme in much of this literature is that you can't have the good without the bad. If life is a balance sheet, then the happiness needs to be reconciled with the sadness. You need one to make sense of the other.

However, our research has shown that the fear provoked by a dementia diagnosis can be deeply distressing, and leads to an understandable desire – both among individuals with dementia and especially their carers – to make their 'remaining time' as contented as possible. The temptation is to do only 'happy' things and avoid those which might lead to 'sadness'. But how can we make informed decisions about something so utterly subjective as what makes us – and those we care for – happy?

What makes us happy?

In Britain, we are famous for our enjoyment of negative things. Think of the reassuring warmth we experience when complaining about the weather, or the fulfilment we feel when regaling friends about the farcical failure of a well-laid plan. The complicated truth is that sources of unhappiness, just as much as sources of happiness, can readily spark enjoyable social experiences – negativity facilitating positivity.

The difficulty of gauging happiness is compounded by our love of linguistic devices like irony, innuendo and understatement. Our talent for not saying what we really mean, or how we really feel, creates a minefield for those judging how happy we are – one which gets even more challenging when you introduce the communication challenges that may be experienced by a person with dementia.

Designing in neutrality

The nuanced reality of our emotional lives stands in stark contrast to the singular approach of a lot of current dementia care – where happiness is regarded as the sole emotional goal, and attempts are made either to design it *in* to people's lives, or conversely to design unhappiness *out*. There is a real danger that either approach, however well-meaning, leads inevitably to blandness – to environments and experiences intended to generate happiness but which, by failing to cater for a full spectrum of emotions, actually make true happiness impossible. More than once during our primary research, we encountered attempts to 'design in' happiness in a 'one size fits all' manner which had only succeeded in generating a neutral kind of contentedness, where the restricted emotional range meant people were neither happy nor sad, but simply existing.

The connection between pros and cons – ups and downs, light and shade, good days and bad days – is a profound truth which urgently needs to be reconciled in the provision of care to those with dementia. Emotion is about range. Enabling true happiness means also enabling the experience and expression of a full spectrum of other potential emotions – which in turn requires us to address difficult questions, such as how unhappy are we prepared to let people with dementia be?

'You can't keep someone happy and contented 24/7 because that's not normal for anyone.'

Louise, Richard's carer

'In life, people go through all of these experiences, positive and negative, so why should it be any different with dementia?'

Brian, person with dementia



**CHOICE
RESPONSIBILITY
FULFILMENT**

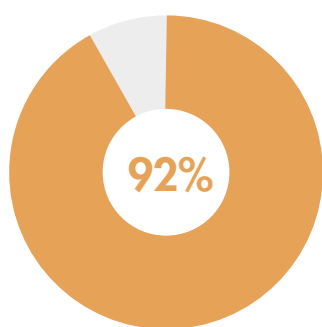
#5

Supporting agency
**‘What’s there
to worry about?’**

*‘To dare is to lose one’s footing momentarily.
Not to dare is to lose oneself.’*

Soren Kierkegaard, philosopher

➤ What are we really protecting people from?



92% of UK adults think 'being independent' is important to happiness

Source: YouGov, February 2014, n=2,347, all UK adults

'I know things could go wrong, I'm not stupid, but riding his motorbike gives him freedom, gives him independence and makes him happy.'

Sue, Brian's carer

'These risk management agents . . . have become preoccupied with their own risks, particularly in media and law-intense environments. Coupled to institutionalised assumptions and myths about the manageability of risks, there is an intensification of strategies to avoid blame when things go wrong.'

**Michael Power,
The Risk Management of
Everything, Demos, 2004**

Daring to value risk

Whether we acknowledge it or not, taking risks is an integral part of our day-to-day lives. We will engage with many of these risks unknowingly, while deliberating over others; carefully weighing up the pros and cons. Anything from choosing a new flavour of soft-drink to making a romantic advance or bungee jumping – taking responsibility and negotiating risks is not only unavoidable, but enables us to properly engage with life. It is a chance to deviate from the norm and do things differently, reminding us we are alive and masters of our own destiny.

Received wisdom states that empowerment and independence are key to delaying the decline of any illness, and dementia is no exception. A core idea of 'person-centred care' is the commitment to actively involving the patient in decisions about their own care, ensuring they remain in control. But true empowerment should involve more than just enabling people to manage their own decline, and our research suggests that even those providing high quality care may still fail to appreciate the importance of freedom, risk and, crucially, responsibility as integral parts of happiness.

The dangers of risk aversion

A 2012 report⁶ by Alison Faulkner for the Joseph Rowntree Foundation highlighted the importance of embracing risk as a positive attribute which needs to be more widely addressed in adult social care – arguing that the 'right to take risks' is such an inherent part of identity and independence that taking it away from people fundamentally restricts individual freedom. 'For many of the people I spoke to,' Faulkner wrote, 'the risk of losing their independence was of greater concern than many of the potential dangers perceived or apparent in their lives.' Yet we live in a risk-averse society, where risk management often becomes confused with blame avoidance and defensiveness – and it is people's independence that ultimately suffers.

Encouraging everyday responsibility

The thought of granting a vulnerable person permission to take a risk can feel uncomfortable, with both individuals and organisations fearing the impact on their reputation if something goes wrong. But we're not necessarily talking about skydiving, or placing people directly in harm's way. We're talking about smaller, everyday risks – going to the shops, say, rather than staying in and ordering groceries online. Many of these are simply about responsibility – doing things for oneself – and in this respect, our research suggests that the management of risk and embarrassment has become

disproportionate. Rather than taking a positive, enabling approach, risk management has a tendency to be overly negative; restricting people with dementia into collective routines which aspire to the wholesale elimination of risk and discomfort. At times, it is almost as if people with dementia are in danger of becoming the safest of what Dan Gardner calls the ‘safest humans who have ever lived’⁷.

Harm and happiness

One of the wonderful (and risky) attributes of having dementia is the loss of social inhibition, leading to an increased sense of playfulness or impulsiveness. This means that people with dementia can instinctively embrace activities that others may avoid or be embarrassed by – creating numerous (often frightening or embarrassing) challenges for those that care for them.

These behaviours feel like challenges, but in fact – taken in the right spirit – they should really be seen as opportunities. For some of those we met, indeed, the idea of a certain death and the clock ticking was seen as a liberation.

The challenge of industrialisation

Perhaps more than any other of our themes, the principle of allowing free agency exposes the challenges inherent in caring for others as individuals. In particular, it highlights the difficulty of balancing efficiency with appropriate care in an increasingly cost-constrained world. The willingness to take on responsibility and risks is an intensely personal decision, and our ability to let people do so is a powerful gauge of our actual comfort in letting them make their own decisions. Enabling the possibility of risk is therefore a key challenge for providers of dementia care if they are to make good on promises of truly individualised care.

Risk matters because the ultimate consequence of avoiding it is more than just increased safety. Minimising all risk constitutes what Charlotte Clarke *et al*⁸ call a ‘silent harm’ that can in itself do damage and prevent people from making the most of the time they have left. It would be difficult to imagine a world where we deliberately restricted the freedom of individuals with other kinds of ‘disability’. Surely we should be creating environments and communities that allow people to embrace freedom – being clear about what exactly we are preventing people from when we say we are preventing risk.

‘There’s too much health and safety rigmarole – for example, preventing people from getting hands-on in the kitchen, or using real cleaning products.’

**Alice Osborne, designer and
Creative Director of Spots of Time**

‘I used to be very cautious. I hated taking risks. Now, it’s like the diagnosis has given me the freedom to feel that I can take risks. There is death at the end of this journey, so what’s there to worry about?’

Bob, person with dementia

‘I think it’s important that I’m given responsibility . . . You’ve got to let people get as far as they can without help.’

Jim, person with dementia

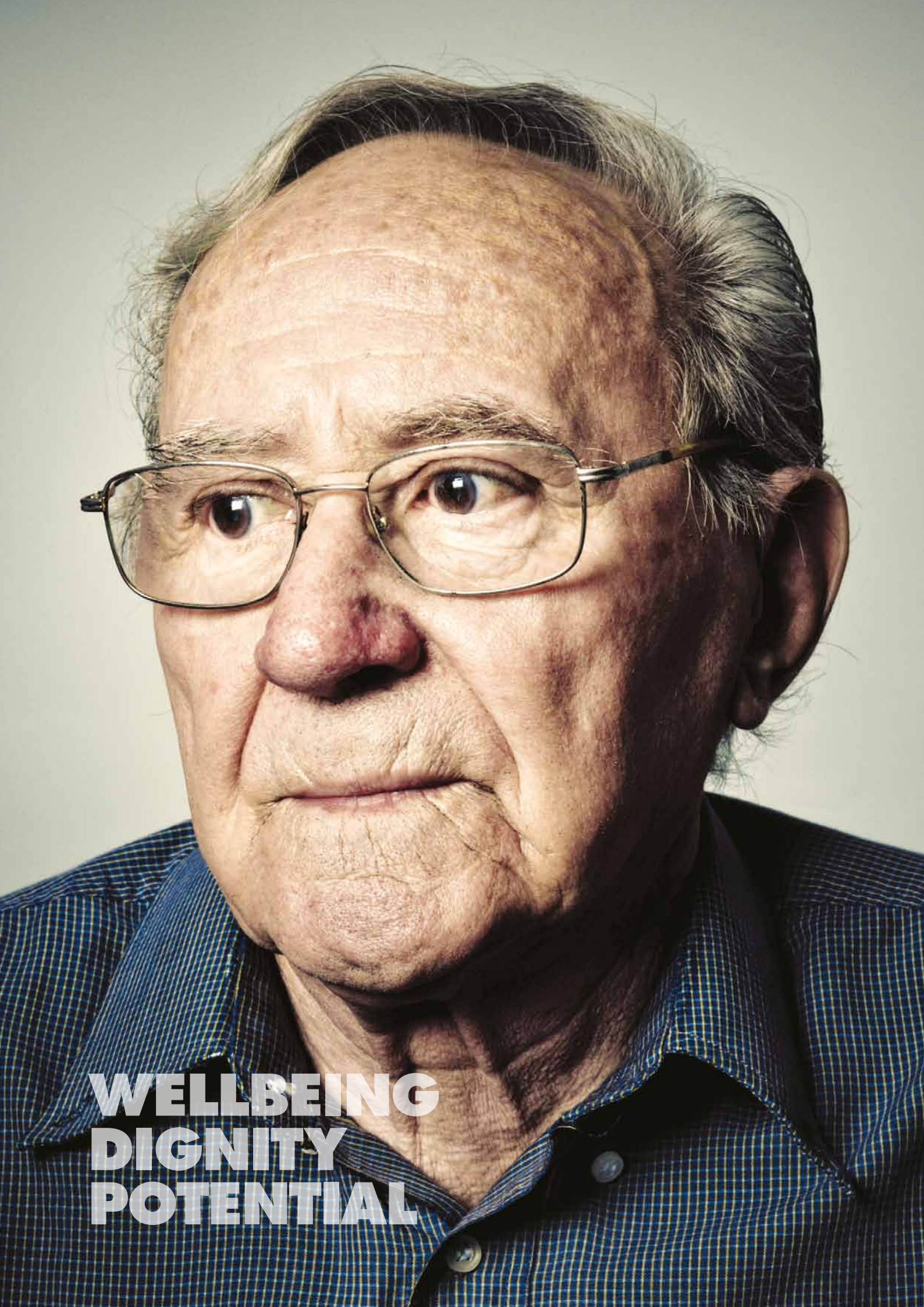
‘Independence is very important. Let us do things while we can.’

Judy, person with dementia

⁶ Alison Faulkner, *The Right to Take Risks: Service Users’ Views of Risk in Adult Social Care*, JRF, 2012

⁷ Dan Gardner, *Risk: The Science and Politics of Fear*, Virgin, 2008

⁸ Charlotte L Clarke *et al*, *Risk Assessment and Management for Living Well with Dementia (Bradford Dementia Group Good Practice Guide)*, Jessica Kingsley Publishers, 2011



**WELLBEING
DIGNITY
POTENTIAL**

#6

Maintaining health
'My priority in life'

'The greatest wealth is health.'

Virgil

➤ What more can we do to ensure people's good all-round health?

'It's important to diet right, keep your weight under control, exercise and keep smoking and alcohol under control.'

Jim, person with dementia

'There is no other illness I know of where the medical and health care providers tell you to give up.'

Kate Swaffer, advocate for dementia and the elderly,
www.kateswaffer.com

'I'm also a diabetic – but they don't judge me on the diabetic side.'

Judy, person with dementia

'Many people will also have other co-morbid conditions which can significantly impact on their experience of dementia. These need to be addressed and treated.'

Rachel Thompson,
Dementia Project Lead at the Royal College of Nursing

Holistic health

Our understanding of 'good health' is more sophisticated than ever. It is no longer satisfactory to say simply that physical wellbeing equals healthiness. Instead, we take a more rounded, holistic view – recognising the different parts of 'health' to include both the physical particulars plus all the other factors that play their part: intellectual, emotional and spiritual wellbeing. We are constantly reminded that there is no one key to a healthy lifestyle; the important thing is to look after ourselves in a balanced way.

Thanks to advances in medicine and technology, plus an abundance of accessible information, we are ever more able and attentive in monitoring each part of our wellbeing. We recognise that good health is both our right and responsibility, and if any one part of it falters, we are quick to address it.

There is no better gauge of our success than our increased life expectancy – and, in turn the ever wider prevalence of dementia. In many ways, the spread of dementia is the ultimate testament to our collective good health – and in particular to achievements in keeping all the different parts of our health functioning smoothly.

'Blame dementia'

What happens, however, when dementia is diagnosed? Our research suggests that, all too often, the health of someone with dementia is treated differently to that of someone without dementia. We have met people who experienced walking difficulties due to a problem which could easily have been remedied by simple treatment from a specialist – but which goes unaddressed because the finger is pointed at dementia instead. Similarly, we have heard regular tales of people with everyday dental problems growing increasingly frail because their struggle to eat well is blamed on their dementia.

Fear and flaws

There are several factors which seem to contribute to this. One is the fear that surrounds dementia, and the ensuing sense of futility. The certain knowledge of death can too easily cloud the fact that continued good physical and mental health – and all the different elements that contribute to it – is as much the right of someone with dementia as someone without dementia.

‘Once she was diagnosed with dementia, it was like people saw it being not worth the bother to treat. But I could see her in pain, and it was increasingly preventing her from doing the things she loved.’

Kate, Tony’s carer

And then there is the challenge of communication. Those with dementia are often less able to articulate discomfort, loneliness, or take the necessary steps to get medical complaints addressed – making it harder to diagnose specific problems, or get the necessary consent to treat them. Instead, the onus falls on the attentiveness and investigative will of those around them.

What’s more, in those instances where individuals *do* feel able to seek further support themselves, it can frequently be at the cost of further complexity – involving multiple strands of treatment, overseen by different people, all based in separate places. All too often these services may be delivered by professionals with little understanding of dementia and a wave of preconceptions that may inhibit their ability to deliver appropriate care.

The gateway to a good life

Above all, there appears to be a systemic flaw in how care services tend to be organised, with the overriding focus on ‘dementia’ leaving little room for thinking about health in a broader sense. The danger of this – of not being able to see through the fog of dementia – is twofold. Not only does it run the risk of leaving people with dementia to suffer unnecessarily, but it can also severely restrict individuals’ potential to pursue other sources of wellbeing – be they physical, emotional, spiritual or intellectual.

Maintaining good all-round health is one of the most fundamental keys to any of us living a rich and fulfilling life. That it should ever be a barrier for those with dementia is a major concern, and one which – if properly addressed – could help open the door to all the other elements of a good life with dementia.

‘It’s too hard to keep trying to pursue all these different things for yourself. Sometimes you can see it getting worse, but you’re powerless to do anything.’

Karen, Derek’s carer

‘Good health and social care for people with dementia – from before diagnosis until end of life – remains an essential aspect of good quality of life.’

**Martina Kane and Laura Cook,
Dementia 2013: The Hidden
Voice of Loneliness,
Alzheimer’s Society, 2013**

‘My priority in life is to stay fit and physically active.’

Pete, person with dementia

*‘It’s not anyone’s fault.
This is what we’ve been
dealt. We can either
make the most of it, or
we can give up. And
I’m not going to give up.’*

Brian, person with dementia

> Where next?

While we recognise the significant recent strides in the understanding and treatment of dementia – thanks especially to the *National Dementia Strategy* and *The Prime Minister's Challenge on Dementia* – our research has confirmed that there is still much to do if people with dementia are to be able to live the same kind of good life as those without the condition.

In this concluding section, we hope to go some way to demonstrating how this can be achieved. In particular, we look at three important and well-established needs which have threaded their way through each of our themes: the need for diagnosis without fear, the need for increasing public awareness of dementia, and the need for improving the flexibility of care.

We recognise that nobody is seeking actively to deny people with dementia a good life. But by working harder to address these challenges, we believe it is possible for every one of us to pave the way to a future in which a good life with dementia is not just an exception, but the norm across society.

Diagnosis without fear

Timely diagnosis has long been cited as crucial to living well with dementia, enabling individuals to receive the right treatment and open pathways to further support. Our research has confirmed that diagnosis is often drawn-out and needlessly stressful. In terms of our themes, this is most relevant in relation to the paralysing fear that too often becomes an insurmountable barrier to a good life with dementia. Whether caused by anxiety of the unknown, preconceptions about what may come next, or by a debilitating sense of shame or embarrassment, a belated or problematic diagnosis is often the focal point for the panic that frequently limits people's potential, and which can cause them prematurely to 'retreat' from their lives.

What happens after diagnosis was also highlighted as being remarkably variable. Many of our experts emphasised the need for better post-diagnostic signposting to guide people through the next stages of their journeys – and for additional support to ensure that they make the most of their lives.

If diagnosis can be made more satisfactory – more timely, yes, but also clearer about what is and is not certain, as well as more positive in addressing the possibility of a good life – then it could go a long way to enabling people to assimilate dementia into their existing identities and lead fulfilling lives for as long as possible. What's more, it could preserve meaningful relationships for longer by removing the uncertainty and stress that sometimes surround a belated diagnosis.

'I now have a fuller quality of life than before I had dementia.'

Judy, person with dementia

'To normalise dementia, we need to take heed of the recovery model used in mental health therapeutic responses – basing our approach on a clear expectation of recovery, hope and encouragement.'

Professor David Sines, expert on nursing and community care

'What was frustrating was that at the beginning, the doctor literally sat down and said "I can tell you what it's not; it's not dementia."'

Brian, diagnosed with dementia after 18 months of consultations

'Whilst increasing rates of diagnosis is important – it is crucial that this is done well and at the right time for the person and their family. What happens after diagnosis is also essential.'

Rachel Thompson, Dementia Project Lead at the Royal College of Nursing

*'Dementia care homes shouldn't be
in the middle of nowhere.
They should be in the centre of things –
off the high street, even.'*

**Alice Osborne, designer and
Creative Director of Spots of Time**

*'You've got to treat dementia
as a normal thing, and
speak about it. The best thing
anyone can ever do is love
me for who I am.'*

Victoria, person with dementia

*'My grandchildren say they
don't notice any difference.
They don't treat me any different,
which is what I want.'*

Judy, person with dementia

Increasing public awareness of dementia

Spanning all the themes in this report, arguably the single biggest barrier to achieving a good life with dementia is the acceptance and understanding of the experience of dementia in the wider community. To overcome the loneliness, alienation and segregation currently felt by many people, it is imperative that we accept dementia as a 'new normal' – just one more of the many challenges faced by people across all walks of life. We must not treat individuals with dementia as people to be feared, or try to keep them 'out of sight, out of mind'. Dementia must be placed at the centre of our society, not on its periphery.

More specifically, the community at large must be prepared to care for people who take risks of their own volition, and endeavour to maintain meaningful connections with people as their dementia progresses. Leisure providers and interest groups must do all they can not only to keep existing members who have dementia engaged, but also to open their doors to those with dementia who recognise that there's no time like the present to try something new.

In so doing, people will be able to express and develop their own identities for longer, relishing the fulfilment that comes from living in the moment, experiencing a full range of emotions, and developing new and valued relationships with other people.

This is something which is already well underway with the Alzheimer's Society's Dementia Friendly Communities Programme, as part of which over 40 communities across England have already committed to making their communities dementia-friendly. The Alzheimer's Society has also recently launched an ambitious awareness and understanding programme called Dementia Friends, which is challenging the unacceptable stigma that exists across society. We believe it is vital that both of these initiatives succeed.

Improving the flexibility of care

Unsurprisingly, there is a strong desire from individuals with dementia to remain in their own homes and to be looked after by a loved one. This is understandable: the comfort and security of remaining in your own home, coupled with a carer who you trust and who understands your values, tastes, personality and history does indeed seem to be the ideal. Yet some carers can struggle to adapt to the changing needs of their loved ones, and few have the specialist expertise to ensure that individuals receive the highest quality care at every step of their dementia journeys.

For a long time now, ‘person-centred care’ has purported to do this, but our research clearly found that many such caregivers – however hard-working and well-intentioned – were often operating within systems whose philosophies prioritised efficiency or safety ahead of people’s core human needs. Indeed, some services almost seemed designed to prevent wellbeing in other forms, with some caregivers actively discouraging people from doing the things that would make them happiest – for example, requiring an individual to spend all day at home waiting for an unscheduled care visit, or by designing care homes that literally have no walkable pathway to the outside world. As the Joseph Rowntree Foundation put it in a 2006 report, ‘[person-centred practice] is lagging well behind policy rhetoric and ideology.’⁹

For care providers to address the themes highlighted in this report, they must do all they can to avoid what the World Alzheimer Report 2013¹⁰ refers to as ‘cookie cutter’ services, and deliver care packages which are truly flexible and individualised, in which dementia and their caregivers have more choice and control over decisions regarding care and support. Ultimately, we believe that this kind of care is the only way of preserving meaningful continuity of life across all of our themes – identity, experiences, relationships, emotions, agency and health – so giving people with dementia the chance of living a good life for as long as they possibly can.

Concluding words

Timely diagnosis, increased public awareness and improved flexibility of care: none are exactly new to the professional discourse around dementia (they underpin most recent strategic thinking), but we hope that this report has cast them in a new light – illustrating why they are so important to enabling a good life with dementia, and also providing inspiration to those responsible for addressing them.

‘It’s easy to say that care should be personalised – and it’s true. One size doesn’t fit all.’

**Professor Alistair Burns,
National Clinical Director
for Dementia in England**

⁹ *Promoting Person-Centred Care at the Front Line*, JRF, 2006

¹⁰ Professor Martin Prince, Dr Matthew Prina and Dr Maëlen Guerchet, *World Alzheimer Report 2013: Journey of Caring: An Analysis of Long-Term Care for Dementia*, Alzheimer’s Disease International (ADI), 2013

Acknowledgements

Our biggest thanks go to all the individuals with dementia and the carers who gave up their time to talk about, and let us explore, their lives. There are too many people to mention, but special thanks go to the wonderful couple who made us delicious home-made soup, those who prepared a quite amazing cherry and sultana cake (thanks for the recipe!), and the individual who inspired us with his new-found love of amateur dramatics. Thanks also to everyone who made us laugh until we cried – demonstrating beyond doubt that dementia has a funny side.

Thanks also go to Bahbak and the Red & Yellow Care team for their inspiring vision, and for funding both our original research projects and this publication. Similarly, we are grateful to Alzheimer's Society (in particular George McNamara and Veronica King) for their help in shaping the report, and in helping to find people who, with the support of the Alzheimer's Society itself, are living a good life with dementia. We would also like to thank Kaori Yamamoto at YouGov for her help organising our survey.

Finally, sincere thanks to all the experts, thinkers and writers who informed and inspired the content of this report – in particular our expert interviewees:

- Professor Alistair Burns, Professor of Old Age Psychiatry and Vice Dean for the Faculty of Medical and Human Sciences at The University of Manchester, and National Clinical Director for Dementia in England
- Dr Gianna Cassidy, Music Psychologist and Lecturer in Interactive Entertainment Design at Glasgow Caledonian University, and Research Co-ordinator at Playlist for Life
- Professor Steve Iliffe, Professor of Primary Care for Older People at the UCL School of Life and Medical Sciences
- Professor Jill Manthorpe, Director of the Social Care Workforce Research Unit, King's College London
- Alice Osborne, designer and Creative Director of work in care homes for Spots of Time
- Barbara Pointon MBE, former carer, Patron of Dementia UK, Ambassador for Alzheimer's Society
- Professor David Sines CBE, Pro-Vice Chancellor and Executive Dean of the Faculty of Society & Health, Buckinghamshire New University
- Rachel Thompson, Dementia Project Lead at the Royal College of Nursing
- Dr James Warner, Reader in Psychiatry, Faculty of Medicine, Imperial College London, and Consultant Psychiatrist and Clinical Director for Older People and Healthy Ageing Services at Central North West London Foundation Trust
- Professor Bob Woods, Professor of Clinical Psychology of the Elderly, Bangor University

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Background information

ESRO

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www.esro.co.uk

Alzheimer's Society

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. It provides information and support to people with any form of dementia and their carers through its publications, National Dementia Helpline, website, and more than 2,000 local services. It campaigns for better quality of life for people with dementia and greater understanding of dementia, and also funds an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

www.alzheimers.org.uk

Red & Yellow Care

Red & Yellow Care is a group of pioneering dementia specialists who believe in providing the quality of care that we would all want for ourselves and our loved ones. It offers clinical care and support for people living with dementia, from diagnosis to end of life. By treating the whole person, not just the condition, Red & Yellow Care's team of doctors, nurses and therapists helps people with dementia and their family to enjoy life beyond diagnosis.

www.redandyellowcare.com

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