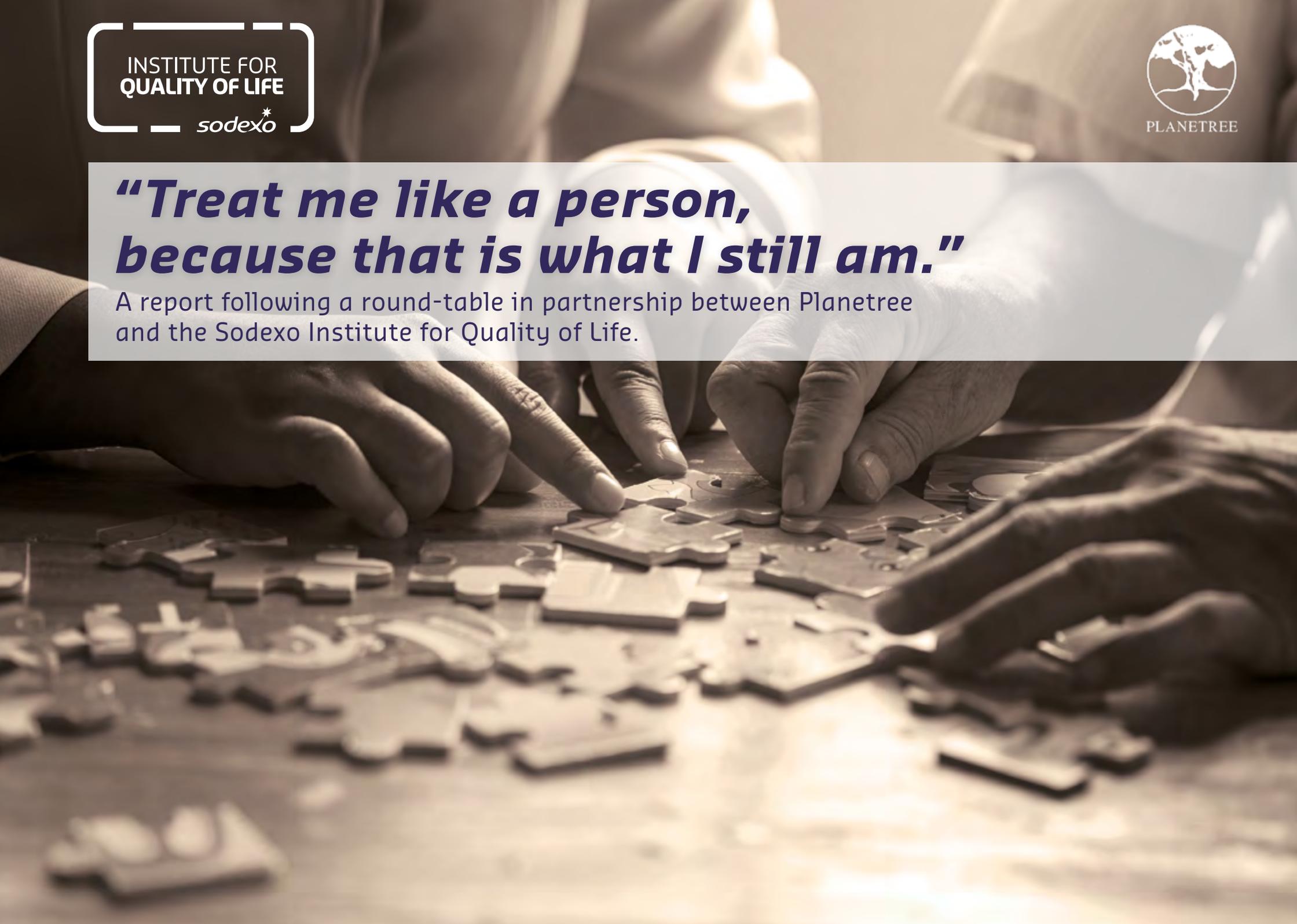


***“Treat me like a person,
because that is what I still am.”***

A report following a round-table in partnership between Planetree and the Sodexo Institute for Quality of Life.



As an in-house 'think-tank', the Sodexo Institute for Quality of Life is inspired by Sodexo's deeply held conviction that improving Quality of Life leads to the progress of individuals and contributes to the performance of organisations. Its role is to gather and develop insight to help Sodexo understand better what are the levers of Quality of Life.

This report is inspired by the Planetree and Sodexo Institute for Quality of Life 'Dialogue' that took place in Washington D.C. on 18 May 2016 and whose participants were:

Aging 2.0

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Brian LeBlanc, 2015 National Early-Stage Advisory Committee

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What should we prioritise from a Quality of Life perspective for those living with dementia, their relatives and carers?

Introduction

“The kind of society we are will be measured in the years ahead by how well (or how poorly) we care for those elderly persons who cannot care for themselves; by whether we support caregivers who devote themselves to this noble task; and by whether we sustain a social world in which people age and die in humanly fitting ways - always cared for until the end, never abandoned in their days of greatest need.”¹

How starkly these lines, penned in 2005, contrast with the well-known picture of old-age, hopelessness and indignity painted by William Shakespeare four centuries ago:

*“... old-age - a second childishness and mere oblivion...
Without teeth, without eyes, without taste, without... everything...”²*

To bridge these two quotations, to understand and position ourselves firmly in the context of the contemporary care imperative, the Dialogue that inspired this report considered the following questions:

- what is ‘dementia’?
- how are different stages of dementia characterised and what are their impacts on Quality of Life?
- what are the factors and range of responses to dementia by those living with it, their relatives and carers?
- which aspects of Quality of Life can mediate responses to dementia by those living with it, their relatives and carers?
- what should we prioritise from a Quality of Life perspective for those living with dementia, their relatives and carers?

This report reflects the broad range of responses to these questions by participants with relevant knowledge, experience and insight, from academia, civil society, and business.

What is 'dementia'?

For all its wondrous complexity, dementia has been described as '*a constellation of signs and sources*'³. Importantly for people living with dementia, their relatives and carers, "'dementia' is a word and words change"⁴. The words we use to describe health conditions evolve with time, progress and our understanding, and with them the way we think, feel and behave. Today, use of the word 'dementia' is particularly vexed. To the despair of some, dementia - a group of symptoms that exists in different forms (e.g. 'vascular' or 'with Lewy bodies') - is used interchangeably by others with Alzheimer's disease, a heterogeneous set of conditions that causes dementia. To many, the word is so much more.

For some, including many French speakers, the word 'dementia' carries more stigma than the term 'Alzheimer's disease' and retains connotations of madness. It still conjures in some older adults the image of a parent 'locked away', stripped of all autonomy, in a psychiatric hospital because they were 'mad' or 'demented'. This is perhaps not surprising as the Latin origins of the word 'dementia' mean 'out of one's mind'. In other quarters, there is anecdotal evidence that people living with the various causes of dementia are 'reclaiming' the word and speaking of 'living well with dementia', or at least of striving to do so, neither being defined by the condition nor accepting to be labelled a 'dementia patient'. How important it is, therefore, to seek and listen to the voices of those living with dementia, to understand their evolving perceptions and uses of the language that must serve, not subjugate.

In a bid to gain distance from the pejorative, in recent years use of the term 'neurocognitive disorder' (whether mild, moderate or severe) has become part of attempts to change the medical vocabulary. This development nevertheless comes with its own challenges as some patients and their relatives find it too difficult to understand.

There is arguably no accessible and non-stigmatising vocabulary for patients and their relatives other than 'Alzheimer's disease', a term that remains contested in the scientific community, but the challenges encountered with words cannot be glossed over. Some clinicians hesitate to give a diagnosis or communicate it to their patient; they may consider that the costs of potential stigmatisation outweigh the benefits of diagnosis. Use of a diagnostic 'label' can sometimes lead relatives, clinicians or professional carers, to over-estimate a person's challenges, for example forgetting to take a prescribed medicine on occasion, something that is common to all patients.

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The benefits derived from communication of a diagnosis vary. It often helps relatives to understand altered, sometimes confrontational or violent behaviour, in cases of vascular and fronto-temporal dementia which frequently lead to personality changes as the part of the brain that regulates behaviour is affected. A diagnosis usually informs interventions but the options for treatment can remain limited, especially in cases of vascular dementia where managing disturbing behaviour is a priority. Whether or not the diagnosis is communicated to a person's relatives, it is important that they and the person directly concerned should understand that it is normal to experience certain behaviours (such as frequent repetition) that can be expected. The challenge is to strike the right balance between reassurance and practical information on the one hand, and the pitfalls of potential stigmatisation on the other.

The issue of stigma attached to the word 'dementia' remains important. It can even lead some people to refuse to consult a clinician out of fear of the diagnosis. Despite challenges and fears, detection of symptoms and diagnosis allows non-dementia causes of perceived symptoms to be ruled in or ruled out, and this in turn points towards the right care. It also allows individuals and their relatives to seek and identify appropriate home and community-based support services as early as possible. With dementia, the full range of decision-making takes time and should start as early as possible as it involves learning, evaluating, consulting, and implementing legal, financial, medical / healthcare, interpersonal and spiritual possibilities.

One of the great difficulties in understanding what it is like to live with dementia is that the person with symptoms finds it increasingly difficult to talk about them as they progress. When points of reference for deeper understanding are scarce, it is easy to be judgmental about behaviour that falls outside our common frame of reference. Arguably, diagnosis defuses stigma by allowing people to speak and be heard in their own voice, to become advocates for themselves and others with similar experiences, to do and say as many of the things that matter to them as possible, even to participate in clinical research. Beyond the individual and their immediate circle, timely detection of symptoms and diagnosis creates a more accurate epidemiological and population health picture for governmental and other decision-makers while providing a demand-side incentive for clinicians, other medical and non-medical carers.

The challenge around vocabulary is far from simple and highly emotive. It brings many closer to personal fears of a particular type of death, perhaps more precisely to perceptions of loss of quality of life at the end of life.

Stigma or not, over or under-estimation of functional reality, the words we use and how they are defined matter. Words create worlds and, in our world, policy demands definition, so it is inescapable. Whether we speak of a 'cognitive impairment that is significant enough to make a person dependant', a 'cognitive syndrome', a 'persistent loss of brain power bad enough to impact on daily activities' a 'physiological disorder', a 'loss of function', a 'major neurocognitive disorder', 'ageing-associated cognitive challenges' or a 'continuum of change'⁵, nomenclature drives the healthcare system's response even as some are left in the dark.

Words are about expectation, they are symbolic, and they are embedded in narrative. When there are mismatches between the intended and perceived meaning of words, the path to conflict is laid. We use words to impart values, goals and expectations that need to be inclusive; we must use them wisely in the context of our cultures and attitudes to avoid creating barriers between genuine needs and our ability to fulfil them. Failure to do so will hinder our ability to tackle a social challenge that has no known 'cure'. First of all, we must listen early, often, thoroughly and sincerely to the words of those who live with dementia so that our language evolves in ways that ensure they are not stigmatised, but instead engaged in decision-making as fully as possible for as long as possible.

How are different stages of dementia characterised and what are their impacts on Quality of Life?

For a long time, dementia was commonly considered a 'mental' illness but it is more accurately described in far broader terms though it is difficult to dissociate the different elements from each other, for example behavioural challenges and mobility issues. Similarly, while dementia affects the cognitive and executive function of the individual, it also impacts their immediate community and it is hard to dissociate the impacts when considering the whole.

Over a period of years, the spectrum of symptoms linked to dementia has been likened to human development from birth to the age of 30, but in reverse. The thinking is that, as with infancy,

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childhood, adolescence and early adulthood, the symptoms develop in different ways and at different rates in different people, despite similarities. At any point in time, they depend on the individual's immediate environment. However, to think of dementia as a sort of 'reverse' childhood is simplistic. It accounts neither for early onset symptoms in adults who are decades away from the higher risk 85+ years age group, nor for the reality of adult personhood and the complexity of family and other close relationships established over years and decades.

To some extent, we all experience normal age-related deterioration of memory but this is clearly distinguished from the dramatically different memory, perception, and decision-making impairments commonly associated with various forms of dementia. The different stages of dementia can be described in aggregate as a '*continuum of change*'. Throughout, symptoms can be more or less in evidence depending on the environment and the level of functional support available, with different quality of life implications for the individual, their relatives and carers. Asked to draw a timeline, 'pre-diagnosis' is a common starting point, but the proper end point, post mortem, is easy to lose sight of despite being so important. It is about how a person is remembered, and that is a function of the perceived quality of life of the individual, that of their relatives and carers. The variability of symptoms depending on the environment and functional support plus the importance of how individuals are remembered opens the door for people and organisations beyond relatives and carers to think hard about what they can do to make sure that stigma is banished and quality of life valued.

What are the factors and range of responses to dementia by those living with it, their relatives and carers?

We have just noted that the immediate environment and the level of functional support available have an impact on symptoms, autonomy and quality of life. Accordingly, relatives and carers need to adapt the environment to meet the individual 'where they are', to suit the individual. There has to be a shift towards thinking in terms of 'responses to environments' rather than 'behavioural issues'. We should also consider that quality of life depends on factors such as the social and spiritual environment beyond the physical environment and the bio-psycho-medical framework that is commonly used to make sense of symptoms.

Common responses to dementia include feelings of frustration by the person living with symptoms, their relatives and carers. In all, they can be exacerbated by a perceived lack of access to support or services. Over time, frustration may develop into depression, isolation (to avoid frustration), anger or aggression. Slowing down and focusing on the person behind the symptoms are two approaches to managing frustration that are open to relatives and carers. The essence of this is familiar: it is about adapting to the individual, valuing the different elements of their identity, likes and dislikes, to find the 'person' rather than the 'label', condition or symptoms. These steps are not only about improving the quality of life of the individual living with symptoms. If those around them can learn to adapt their communication with empathy, there is fulfilment and reward to be gained from seeing a person 'light up'.

By treating individuals with symptoms of dementia (and older people more generally) as 'people', others address their own fears of becoming *'like that'* and progress beyond ignoring or avoiding them, even if communication and engagement require effort and empathy. The impact of stigma and misperception from a lack of awareness is clear from a simple example: the friend who turns to ask a spouse *'How is s/he?'* instead of taking steps to ascertain whether it really is a moment when 'the fog' has rolled in or one of brightness and clarity.

Many people living with mild or moderate symptoms of dementia still have awareness of themselves as a complete individual with a distinct personality, a preserved sense of self and dignity, a sense of purpose, a desire to contribute to and satisfy needs, to form and develop social relations, to try new things and grow, even if words are sometimes out of grasp or what is happening is difficult to understand. To ignore this is, at best, to miss chances to learn, to miss opportunities to help. At worst, it is to deny an individual's wish to be treated as a person, because that is what they still are. The easiest and most obvious way to avoid these pitfalls is to hold fast to seeking and listening to the voice of individuals.

For some, symptoms of dementia are only one aspect of how they are perceived and treated. The degree to which a person shows other devalued characteristics can inform harsher restrictions. Labelling someone as having 'dementia' can intersect with other aspects of their identity such as race, socio-economic background, gender, sexuality or religion among others. Like 'old', the label of 'dementia' is not experienced consistently and attitudes vary across cultures.

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In significant respects, dementia is therefore about '*us*', '*our*' abilities and perceptions rather than about '*them*' and '*theirs*'. As we think about our abilities that are challenged by the tasks of daily routine for others who are often affected by cognitive and physical impairment - such as personal hygiene and dressing - we are called on to remember the relationship between individuals, its purpose, the identities and expectations involved. The nature of the relationship can lead to progress and thriving, also to collapse and grief if it is inadequately supported. It may include 'tasks' but should not be solely task-based on the one hand, nor romanticized on the other as it comes with a personal cost for the carer.

Which aspects of Quality of Life can mediate responses to dementia by those living with it, their relatives and carers?

Questions of autonomy are central to instances of impaired cognitive or physical function where people and organisations are responsible for ensuring safety and security in the context of care.

In essence, autonomy is about the possibility of making progress as an agent with free will, a person who is responsible for actions. It is related to individuals' sense of identity as developed through past and present values-laden actions. As such, autonomy is closely related to the ability to fulfil one's potential. Seen in this way, autonomy requires an element of control over decisions and actions, also the ability to moderate passions, to exercise discernment and judgment.

Autonomy is related to the exercise of free will in pursuit of 'the good life', a life that is infused with moral purpose and meaning leading to self-actualisation.

On its own, autonomy is not a guarantee of quality of life; so much depends on the social context in which it is exercised. Is it one in which the nature of relationships is such that they contribute to meaning and purpose in the lives of individuals, for example by helping to maintain or increase access to outdoor amenities, to cultural resources, by providing meeting places and engaging with volunteers? Autonomy can also be framed as a relational concept: relationships inform how individuals understand and experience autonomy, how organisations and the community respond to its exercise. Similarly, social influence from role models, mentors or coaches shapes our development and behaviour.

In self-determination theory⁶ - a psychological framework for the study of human motivation and personality⁷ - autonomy is defined as behaviour that is regulated by the individual and therefore consistent with their values and interests. It has been linked to enablers of progress such as:

- more creative learning and engagement
- greater energy and vitality
- lower stress
- higher wellbeing
- better relationships

Higher levels of autonomy have also been associated with increased interpersonal closeness, including with people thought to be 'different', so it is linked to a greater openness to diversity.

Key aspects of autonomy include:

- **authorship** - behaviour that is based on the individual's values, needs and interests
- **interest-taking** - an individual with autonomy continually learns about themselves and uses this knowledge in order to act
- **control** - autonomy is characterised by the absence of control or pressure, external or internal

Even where personal autonomy is limited by cognitive or physical impairment, individuals may still be able to satisfy this higher order need. Part of the challenge lies in navigating questions of distributive justice and risk tolerance.

Distributive justice requires us to manage the trade-offs that come with finite resources. How can an organisation release someone to accompany an individual for a person-centred walk outdoors with individualised attention when staffing pressures are relentless and continually loom large over the ability to fulfil lower order needs? How can risk management and meaningful activity be reconciled to make room for the 'dignity of risk'?

In some circumstances, our willingness and the ability to provide technological adaptation can mean the difference that makes it possible for a person to engage in meaningful activities while managing risks. For example, the installation of a device that switches electric cookers off automatically after a set period of time. However, despite growing sophistication, technological

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advances are no substitute to human flexibility and adaptability in the face of changing or increasing needs with varied risk profiles. For now, many carers bear some responsibility both for determining the point when technological adaptation becomes necessary and for managing it afterwards.

Risk tolerance varies between individuals and across contexts, it changes over time and with age there is a tendency to be less anxious or worried about loss. This is noted in people with symptoms of dementia who might be unaware of risks or accept them and insist on autonomy despite the misgivings of others who would rather discount it in favour of safety and security. This discounting may be the quid pro quo of willingness to be responsible for others over a long period of time. It may also arise when people or organisations are far removed from the practical experience of memory care. Accordingly, there is a call for accountability to meet needs to rest much further down the hierarchy of care delivery than is common today, far closer to those who have the clearest and best visibility of physical and psychological risk factors, but currently the least authority. This call recognises the place of kindness rather than charity, dedication to quality of life not custody, and care over treatment.

When living in communal settings, a person's ability to live autonomously depends on the professional carers involved and their methods are informed by regulation, consumer concern about safety and abuse, and the threat of litigation. Carers need to have organisational structures, leadership support and emotional support to provide an enhanced quality of life through self-determination. The philosophy of the organisation should be examined to determine the congruence between its philosophy of care and actions of care; any disconnect will create confusion for carers and impact the individual's quality of life.

What should we prioritise from a Quality of Life perspective for those living with dementia, their relatives and carers?

- While we have a myriad concerns, hopes and opportunities to choose from, the language we use will play a role in whether, how well and how soon we take action to improve Quality of Life for those living with dementia, their relatives and carers. This language must be informed by the words and meaning of individuals who live with dementia.
- As we saw in the first part of this report, language is a priority for many reasons, including the need for care to benefit from a new narrative to underpin a renewed shared sense of purpose. This narrative should reflect that within 'memory care' there is not 'just' a loss of memory but a broad range of challenges that could be better addressed with greater understanding of symptoms. An aim of a renewed shared sense of purpose should be to integrate care in our communities rather than concentrate it in isolated 'facilities'. It should also shape our philosophy so that we grow beyond the ritual of 'programmes'. What would this look like? Suggestions based on experience of multi-generational and community engagement include mutually beneficial sharing, as a matter of course, of cherished activities that can be meaningful at very different levels of cognitive and physical ability such as music, exercise, story-telling, gardening and cooking. The place of this mutually beneficial sharing is easily undervalued in discourse that is framed in terms of one-way care and support.
- With a common language and narrative befitting a modern philosophy of care, we stand a better chance of being able to exchange and replicate success stories, of developing and following standards. We may also find it easier to reverse predictions of a large deficit of professional care by making memory care more attractive and accessible to people from a wide range of occupational backgrounds. Arguably, this is not just about organic growth in the number of people working in care-related jobs, an evolutionary adaptation to demographic necessity, or iterative role development. It is about purposefully rising up to address a fundamental societal challenge that will need a complex multi-disciplinary, policy-level response, but which is already stimulating technological innovation. A snap-shot of the range of quality of life-enhancing products and services already available gives an indication of progress:

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- a smartphone app that combines a visual diary with images and background information, contact details and automatic reminders to help people maintain their autonomy,
 - eye movement-based early diagnostics of cognitive decline,
 - an app that helps carers to manage medication and appointment information by storing it and enabling sharing with others, which can also help them to keep track of and interact with professional carers,
 - virtual reality systems that can help to relieve chronic pain, change behaviour or confront fears by helping individuals draw on their own inner resources,
 - wearable protective devices that deploy cushioning airbags in the event of a fall.

Some of these technological advances are consistent with the call to broaden our ambitions made by those who challenge us to consider the full range of engagement and contribution to care that is possible through enriching artistic, musical, gardening or cooking activity. If we fail to identify and consider advances, we risk presenting decision-makers with nothing more than a resources problem even if technological innovation is in its relative infancy and needs to be tested at scale while issues of cost, usability, privacy, care-substitution, ethics and regulation remain.

- In the context of policy and funding, there is concern that the ‘gold-standard’ of scientific research, the randomised controlled trial, prevents actions that are not measured or studied but may nevertheless contribute to psycho-social and spiritual wellbeing. An epistemological challenge has been set and it needs to be addressed to bridge a chasm between diverse approaches.
- At the heart of empathy and how we think of autonomy is getting people to understand what the experience of dementia is like for all involved. This should come through continuous listening and engagement rather than from opinions formed out of context. Understanding is the precursor to unlocking the first priority for the Quality of Life of those living with dementia and by extension their relatives and carers: not to be stigmatised, but to be treated as a person. In this, the delicate balance between safety and autonomy, managing risks while promoting engagement in meaningful activity, is essential.

“Treat me like a person, because that is what I still am.”

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