ARRANGING CARE: A GUILTY PRESSURE

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Executive summary

We are a nation fuelled by guilt. The heartbreaking dilemma we all face when our loved ones grow old is well-documented but never before have we really lifted the lid on the agony behind the decisions we are compelled to make — that is, until now. In a series of qualitative, peer-reviewed interviews by Chartered Psychologists, Elder has delved into the emotions and motivations of those who are charged with deciding what type of care their loved ones should have in later life. These people, whether they are family members or close friends, face an often painful journey of decisions, and yet we see a pattern emerging; one of guilt.

This whitepaper details that pattern — we call it the Algorithm of Angst — as well as the common reasons behind those feelings. With this knowledge, we think we are finally on the right road toward the provision of robust care solutions for both the elderly and their support networks, the latter being the forgotten backbone of Britain. With so much evidence telling us that the problems facing the elderly have created an angst-ridden ripple effect for those around them, it is time to talk about our experiences openly.

At Elder, a provider of live-in care, we see these insights as invaluable because we think we can start to remove the stress from the decision-making process. If we know more about how families and loved ones feel and are likely to feel when they face these almost inevitable dilemmas, we can start to pre-empt and ease the negative emotions around decision-making.

Our findings come at a time when prominent voices across all our major political parties are calling for urgent cross-party consensus in order to solve the looming crisis of social care. Even the Government recognises more needs to be done. Only this week, it laid out four "Grand Challenges" in its new Industrial Strategy, one being to "harness the power of innovation to help meet the needs of an ageing society". Yet, despite the overwhelming evidence that the sector is in desperate need of a shake up, there was no mention of social care in the Autumn Budget.

In response to the apparent silence from the Chancellor, and this white paper, MP Liz Kendall said:

"The care crisis must be tackled as an absolute priority - we cannot leave it for yet another Parliament or yet another election. We need a cross party approach to deliver a sustainable, long lasting solution that puts the needs of older and disabled people and their families first."

Her plea is echoed by Conservative Andrew Mitchell, Liberal Democrat MP Norman Lamb, as well as Shadow Community Health Minister Julie Cooper.

None of these concerns are new. According to the Care Quality Commission's report The State of Healthcare and Adult Social Care in England[1], 'to deliver good, safe, sustainable care, more providers need to think beyond traditional boundaries to reflect the experience of the people they support.' The report calls for 'a long term sustainable solution for the future funding and quality of adult social care,' and warns that the future of care for older people and the adult care system is 'one of the greatest unresolved public policy issues of our time.' The entire system is in desperate need of innovation, with greater personalisation of care solutions, which is where we believe live-in care companies like Elder can make a difference.

But first, it is clear to us that the journey towards a solution must include greater insight around the psychological states that those involved in making decisions around care experience. We believe our research is just the beginning and provides the basis for this conversation across the care industry. In our conclusion, we have outlined five ways care providers and agencies working in and around the care industry can ease the guilt around decision-making and create better pathways to care. The debate on the future of elderly care belongs to all of us.

Pete Dowds
CEO

[1] CQC State Of Care 2016/17 Report

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Background
A broken system

The current social care system is widely regarded as broken.

This is borne out by the fact more than 2,500 hospital beds a day are taken up by patients whose release has been delayed due to problems in the social care system[2]. Shockingly for elderly care, between 2015/16-2016/17, there was a 22.9%[3] rise in the number of extra days in hospital for those experiencing a delayed transfer of care, as result of families struggling to find a residential home. And, in the most recent period, there were 245,033 delayed days attributable to patient or family choice, showing how difficult the decision to find care can be. Worryingly, government attempts to address the problem have so far seen little tangible success.

For example, the Better Care Fund, created to address emergency admissions and delayed transfers of care, according to the respected Public Accounts Committee, 'has failed to achieve any of these objectives[4]' and 'both of which have actually increased'. This exacerbates the immense strain on families desperately looking for care. Often in rushed circumstances, often in a highly emotional context.

This pressure seems to show no signs of abating, and there are growing worries about a lack of action or innovation from key policy makers. Of particular concern was the absence of elderly social care in the recent Budget. The care sector, professional bodies and influential think-tanks have responded with deep concern.

Recent research by the Nuffield Trust, the Health Foundation and The King's Fund[5] found 'social care remains on the brink of crisis' and they estimate 'there will be a £2.5 billion funding gap by 2019/20'. Researchers went on to warn that unless a solution is found 'pressures will increase for service users, their families and carers'. Pressure which, as this report highlights, may come to bear on those already struggling with an array of complex emotions.

With older people living longer than they ever have before, and an expected deficit of 42,000 care home beds in nine out of ten areas across the UK within five years[6], macro forces seem destined to condemn desperate families to a strenuous, debilitating search for care.

The macro picture means it is perhaps unsurprising that research from Which?

indicates many families struggle to find a suitable home for an elderly relative. And, even in the cases where families are lucky enough to such a solution, often the choice of the care recipient is subordinated. Some 97% of people say they do not want to move into a care home in their old age, yet it is a choice many are forced to make on behalf of their loved ones.

To find an innovative, long-term solution to this growing crisis it is crucial that we gain an understanding of the emotional and psychological implications for those looking for care. Uniquely, this report looks at the emotional journey of these overwhelmed decision-makers, relatives hoping to find the best solution for their loved one, in the most trying of circumstances.

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[2] http://www.bbc.co.uk/news/uk-england-39258606

[3] researchbriefings.files.parliament.uk/documents/CBP-7415/CBP-7415.pdf

[4] https://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/news-parliament-2015/integrating-health-social-care-report-published-16-17/

[5] https://www.kingsfund.org.uk/publications/autumn-budget-2017

[6] http://www.telegraph.co.uk/news/2017/10/04/nine-ten-areas-have-shortage-care-home-places-within-five-years/

7 OnePoll Survey July 2014

Methodology

Our qualitative research used innovative psycho-analytic reflective projective questioning to lift the lid on how people engaging in live-in care and care home services really feel. This type of questioning, unlike traditional research, allows us to look beyond what people say to identify what they actually think, and includes the use impersonal questioning patterns to navigate through embarrassment, ego threat and projected social standing. The research was undertaken with four groups of South East-dwelling respondents:

— Experienced decision-makers involved in live-in care
— Experienced decision-makers involved in care home services
— First-time care decision-makers – considering care home services only
— First-time care decision-makers – considering in-home and care home services

The insights from these groups were compared with two additional sources of data:
— Depth interviews with four Elder care recipients
— Depth interviews with three Elder carers

These insights are based on a detailed and peer-reviewed analysis by Chartered Psychologists of the various data generated. What they revealed is a psychological landscape that is complex, and that this complexity manifests itself in a range of ways.

The study was designed primarily to explore the customer journey when choosing a care home. Specifically, it looked at what aspects of provision of care the decision-maker prioritised, how the decision-maker made their choice, the challenges they faced, and how they felt in each stage of the process.

Part one

The algorithm of angst

Our research shows that buyers of care (typically relatives) face three key stages before coming to a decision: procrastination, then guilt, then the decision. These three stages are outlined below.

1. Procrastination

Procrastination is the first stage of the journey. When they are faced with the need to find a solution, decision-makers try to put off the decision in order to avoid negative feelings arising. Unless care is immediately required, feelings of overwhelm compound feelings of sadness. When humans feel overwhelmed or believe that a task is too big, the brain goes into 'flight mode', offence, or paralysis. In this instance, decision-makers, seem to avoid the unpreventable event and 'flee' until a compelling event takes place and a decision can no longer be avoided.

2. Guilt

Guilt is the second stage – and the desire to reduce guilt is a significant behavioural driver. Preexisting perceptions around care homes and/or live-in care influence how guilty the decision-maker feels and therefore drive the final decision. It's likely that these perceptions are fused with what they believe their loved one perceives about the different options (although again this is a secondary factor). During the research, respondents described how they searched, arranged and prepared a solution before 'presenting a solution' to their relative. This very much indicates that, despite claiming that 'I want the best for them', there is a higher-order psychological need for wanting the best solution for themselves first. They need to juggle their lives and relationships while managing the life of their loved ones.

3. Decision

Although price is secondary, there does seem to be an additional cognitive block in how to pay for care. Most respondents understood the most convenient payment route for care homes, which is to simply sell the recipient's property to pay for the care home, however, respondents were not aware of alternative ideas, such as releasing equity, and that this could be used to fund live-in care too. Most assumed that savings or a spare pot of money would be required. This 'ease' of payment is important in a situation where the decision-maker's needs come first.

In terms of sourcing solutions, word-of-mouth is perhaps unsurprisingly the most powerful source of insight and endorsement. Finding the right answer for their loved ones is a very sensitive topic for decision-makers, and peers present the strongest way to obtain reassurance. Online searching is used only as a supporting step to find out more information and confirm and reassure decision-makers about the choices they are making. It is only at the end stage of the process that the actual care recipient becomes influential – i.e. once relatives have done the first filtering of options and come to a preferred solution. This holds true for recipients with and without dementia.

Part two

Six psychological states in the algorithm of angst

1. Worries about permanence

"Live-in care is a stop gap"

When questioned about live-in care, decision-makers said they felt that live-in care was a temporary step in care solution rather than a permanent one, and, as a result, many felt they wanted to avoid it.

One respondent, said that "it's stressful enough organising support and care... It's bad enough doing it once, but doing it twice [moving them from live-in care to a care home] is just too much [in terms of effort, lack of consistency, heightened guilt, stress, administration]."

This is unsurprising from a psychological perspective, as in general people find inconsistency stressful. While change is evidently the fear of the recipients of the care (i.e. learning to deal with new faces, a new home and so on), it is also a strong (if not actually greater) fear for their family members who had to make the care decision. Relatives seemed more adverse to change than the care recipients.

2. Fears over consistency

"The carers Mum has had at home don't care at all"

In many instances after being hospitalised recipients were offered carers by social services. Unfortunately, the care home selector groups appeared to have had largely negative experience of local authority carers. They felt these people 'came and went' as they wanted to, with no concern for their loved one. Because of the perceived poor training and attitudes ("they just come and go, get on with the job mechanically"), live-in care was perceived negatively and with distrust ("How can I know what they're doing while I'm not there?").

Psychologically, the brain pays more attention (by way of a roughly five times greater weighting) to negative information than positive – as negative information is linked to threats to survival. This is called 'negativity bias'. So people are likely to remember more readily and for longer durations examples of negative care in the home than they do positive examples of it. These negative perceptions also highly influence the way that such buyers view carers that are not from the local authority. There also appears to be no salient perceptual differentiation between public and private sources of in-home care.

The 'availability cascade' might partly explain the pervasive negative perception about in-home care. This is a self-reinforcing process in which a collective belief gains more and more plausibility through its increasing repetition in public discourse (in effect, "repeat something long enough and it will become true"). Many of the participants talked about friends, contacts and peers who had endured bad experiences with social services – so this reputation gains strength as it gets more and more exposure.

3. Safety in numbers

“Dad’s better off with lots of carers around”

Some salient differences existed in the perceptions of consistency of live-in care between the care home and live-in care groups.

Psychologically, sending the care recipient into a care home represented peace of mind for the family as care homes are perceived to be safe and secure places that aid interaction with others. Having medically trained staff available 24 hours a day was felt to be important for some respondents. This stood in contrast to live-in care, which was felt to represent a greater risk.

“What if something happens to Mum when the live-in carer is having a shower? What if she runs out of the house again?”

A perception of value is also apparent here, in terms of safety in numbers through knowing that there are always carers around, people on the door, cooks, beauticians, entertainers and so on – as opposed to having a single live-in carer, which represents a scarcer resource model.

These added bonuses also offset the guilt experienced by family members for sending their loved ones into homes. Some respondents from this group described experiences of live-in care that had been arranged via social services or local hospitals. All the stories were negative and shaped their impressions of live-in care early on. Having carers changing all the time (sometimes four different carers in one day) made the family feel less safe. Moreover, recipients very rarely saw the same carer twice, which meant that it was hard to create a relationship. The constant change in carer also reduced recipient’s sense of control as well as the sense of safety and security for the recipient’s family. Also, from a psychological standpoint, having a new person in the house all the time represented a new potential threat which elevated stress levels that were already quite high due to the loss and reduction of independence and control.

“A single carer is as good as having me do it really

For people who had put their loved ones in a care home who had not had this prior experience, perceived staff turnover in care homes seemed to be just as high in live-in care and therefore didn’t seem to represent a factor for choosing not to proceed with live-in care. In stark contrast, people who preferred live-in care perceived it as the most consistent option, as their loved ones could continue living in their home environment. They also believed that their loved one’s routine would stay the same – they would still get the tea the way they liked it, be visited by neighbours, and so on.

These groups put great emphasis on having the same carer for as long as possible and getting consistency from the carer perspective. There are two reasons for this (which endorse findings we have already described):

1) A constantly changing carer negatively affects decision-maker’s feelings about safety. Relatives constantly need to worry about if the next carer will be decent and a good fit. Over time this creates anxiety and frustration.

2) Older people are perceived to dislike change and have difficulties adapting to change.

4. Missing the family hub

“If Dad goes into residential care, we’ll lose a family home”

When family members depart for a care home, there is a loss of a family hub. Parental homes are associated with social events, gatherings, nostalgic moments and so have an immense emotional association. They were perceived as a place connecting various family units where everyone meets up and takes a break from their journeys, and where generations are brought back together. This perception was exacerbated for families with parents who need care.

Care home selectors and considerers felt that losing the recipient by sending them to a care home also meant losing their family hub. Family relationships became colder in almost all instances, and psychologically it increased anxiety as they realised that the family lost more than they had imagined in the first place. Grandchildren did not have the opportunity to spend that much time with their grandparents, which was perceived as a big loss. This realisation brought sadness and guilt to the families in question, which they attempted to off-set by finding the positives in care homes (e.g. activities, a sense of community, health care professionals) and also visiting as much as possible.

Live-in care selectors and considerers felt that there was a need to remain close with the ‘main’ home in the family, which is often the parental one, or wherever the parent may reside. Providing live-in care protects this need and also protects against feelings of guilt.

5. Personal independence

"I'll get my life back"

For the care-home group, independence seemed to be a term used to describe the advantages of care homes for their relatives (over carers at home). This was in direct contrast with their experiences when social services carers came in a few times per day to look after their relatives, which represented a loss of independence (for example having to pay attention, manage the visits, follow them up, and manage the stress of the relatives). "They have more activities there." Psychologically this creates a 'framing effect'. Respondents' first experience with care is usually social services care at home, which was perceived as being inconsistent, hotchpotch, unreliable and didn't really enable them to 'switch off' at all and gain any respite from caring from their loved ones. So in contrast they felt the 24-hour service that care homes could provide would be a step up and afford them time out from looking after their relatives. However, when challenged about this, the group admitted that independence was less present in care homes due to set times for meals and sleep, inability to watch what they wanted and when, or set aside time for reading. They quickly became unsure of how much actual independence people had. Once they became consciously aware of this participants started to show signs of anxiety.

The live-in care groups suggested a lack of independence in care homes. Instead they felt the loss of independence was prevalent in this context. They associated care homes with words such as 'institution', 'smelly', 'isolation' and 'inflexible'. "It's not really a home." "Next time take me to a prison, I will have a better time there." Despite there being other elderly people there, these respondents did not seem to feel like their loved one would have anyone to talk to or choose people they want to spend time with, which added to the sense of isolation. They also felt that being in such depressing surroundings would also have a direct impact on the mood and wellbeing of their loved one.

For some respondents whose relatives were in the later stages of dementia, independence was not seen as important any more and factors such as safety, security, medical care and attention became more a priority. In turn, this maintains the family members' peace of mind and disconnection from stress and guilt.

6. Socialising

“At least Dad will have people to interact with in a home”

While some respondents who had selected care homes over live-in care believed that putting family members in a care home seemed to have accelerated the recipient’s decline in health, they still thought the social advantages outweighed the physical or mental disadvantages.

“At least they’re all together doing stuff, being looked after in a home.”

“I am relieved that there is at least someone to talk to or look out for my mum.”

In essence, they perceived that they were buying a supportive social environment along with the medical and practical support a care home could provide.

In contrast, the group that selected live-in care gained a sense of safety from knowing their loved one was in their home, but also surrounded by neighbours they had known for many years. Their view on live-in care was highly positive; they equated it to a safety net as they still lived within their community.

Salient differences between the groups

Summarising the major challenges and opportunities identified above, it is worth noting that there are some salient differences between those who bought or were considering care home-based care and those who bought or were considering live-in care. In general, the perceptions of care homes amongst the critical care home buying audience are strongly positive – but post-purchase there is some potential ‘buyer’s remorse’. Perceptions of live-in care among this group were almost wholly negative.

“Let’s put aside our differences”

A cross-party call for a joint response

After reading our research findings, there was consensus across political divides of a real need for action. Here's how Members of Parliament responded:

Liz Kendall MP (Lab), former Shadow Minister for Care and Older People

"Too many families face a daily struggle to look after their loved ones. They feel stretched to breaking point because they can't get the help and support they need.

"One in three unpaid carers have to give up work or reduce their hours - so their incomes suffer, and the economy loses out on their skills and talents.

"The care crisis must be tackled as an absolute priority - we cannot leave it for yet another Parliament or yet another election. We need a cross party approach to deliver a sustainable, long lasting solution that puts the needs of older and disabled people and their families first."

Rt Hon. Norman Lamb MP (Lib Dem), former Minister of State for Care and Support

"Making decisions about the care of a loved one can be a confusing and distressing experience. Every year, thousands of families are confronted with the invidious task of finding the most suitable type of care and determining how this will be paid for, and this report shines a much-needed light on that difficult journey.

"We also know that finding suitable care provision is becoming increasingly difficult. The health and care system is facing unprecedented challenges, as funding fails to keep pace with demographic changes and growing demand for care in old age. More than a million vulnerable older people are left without the care they need, while patients suffer from longer waiting times in the NHS. This situation cannot continue.

"All political parties should put aside their differences and work together to guarantee the long-term future of these services. That is why I have been urging the Government to establish a cross-party NHS and Care Convention, which would engage with the public and the health and care workforce with the aim of coming up with a sustainable financial settlement."

Rt Hon. Andrew Mitchell MP (Con), former Secretary of State for International Development

“The Budget was an opportunity missed to search for a cross-party solution on care. We know the care system isn’t fit for purpose. We know the Health Service increasingly struggles to meet demand - that’s rising each year.

“All parties must come together to fundamentally re-think how we can guarantee the future of the NHS and social care services. That means real innovation, and real joined-up thinking. When addressing this existential crisis, all options must be on the table. We must not be constrained by the approaches of the past.

“The Government’s Green Paper next year is real opportunity. We need a long-term solution that provides great care for the elderly. Whether that’s a care home or live-in care.”

Expert view

by Dr. Simon Moore

Expert view: Dr. Simon Moore

Dr Simon Moore - the Chartered Psychologist who led on the fieldwork, summed up the findings:

Psychologically speaking, the care selection process is complex, characterised first by procrastination, then by a huge amount of guilt on behalf of the buyer. These powerful psychological forces can actually work against what's best for both care buyer and care recipient; for example, by leading to needless decisions to abandon the family home, which our research demonstrated is often the source of valuable memories and familial connections.

We were delighted to work with Elder to uncover the powerful, nonconscious drivers of consumer behaviour in the care category. Our unique psychological insight processes use specialist techniques that examine the non-conscious forces that influence around 85% of our decision-making - and which traditional research often struggles to uncover. With more of us than ever needing care, an in-depth understanding of the real forces shaping care choices is critical, and we are hopeful that our work will support the Elder team in continuing to develop its internal culture, and its already industry-leading approach.

Conclusion

How many people across Britain are today crushed under the emotional weight of the system? Our research has revealed that the decision-making process is a painful and complex one, and, if we are to ease the burden on families, we need to work collectively towards eradicating the Algorithm of Angst. Families should be well-informed about the various solutions and finance for long-term care, before a decision becomes critical. We think there are five considerations for care providers need to take into account when delivering care solutions.

5 steps to eradicate ANGST

A ***Ask*** about the needs of the buyer, as well as the person in care. In many cases the care solution needs to work first for the buyer of the service, typically a family member.

N ***Nurture*** the independence of those in care, as well as the decision-makers in acquiring care services. There is a balance that needs to be struck between both parties.

G ***Give*** decision-makers and people in care a connection to home. In both a care home and live-in solution, much angst is caused by change and, in some cases, a valuable connection to a family hub is broken. Greater personalisation in the service provided is crucial to gain back the sense of community that might otherwise be lost.

S ***Share*** information on every service of care available. There is no 'one size fits all' when it comes to care. decision-makers of care solutions should be made aware of the options, including funding, that might be available to them.

T ***Talk*** it through. Perceptions of care are low across the board, and, despite evidence[8] that many providers have improved care services, there is a lot of work to be done to ease these long-held concerns. Acknowledging the fears of buyers as well as people in care is a crucial step towards easing angst.

Pete Dowds

CEO

Elder is the first true alternative to a care home. Founded on the belief that no-one should have to move into a care home unless they want to, the organisation is now the UK's number one specialist provider of live-in carers. Elder is committed to helping reduce delayed transfers of care in the NHS by offering a faster, simpler and more cost-effective alternative to the care home.

Through using the latest technology, the company is also able to match one-to-one carers to recipients, based on personality, hobbies and interests. This means the standard of care is more personal and significantly less stressful. What's more, while Elder makes less than half the margin of traditional providers, carers working with the organisation can make significantly more. It's a fairer, better way to care for our elderly and fix the broken system.

[8] CQC State Of Care 2016/17 Report