The Care Choice Gap

Overcoming the challenges in elderly care provision

A report commissioned by Consultus Care & Nursing

Foreword by Esther Rantzen CBE,

Founder and President of The Silver Line

I never planned my life. I used to pride myself on going with the flow, grabbing whatever lucky chance came my way. I always used to advise young people against rigidly planning their lives, because, I said, that tends to limit your options, and the crucial thing is to stay flexible enough to take full advantage of every opportunity. That was before I reached what Lord Best has described as an "extended middle age", the time in life when we have far too many candles to fit on any birthday cake, but we still don't feel "old". Which is where I am now, aged 74, and suddenly I have become aware that I really must plan for the changes that must happen over the next 20 or 30 years. The fact is that changes will come, however reluctant I am to admit it.

Esther Rantzen

This report outlines the various choices that face us as we grow older, and suggests that we need to plan for them far earlier. We may already know about sheltered housing, and assisted living, and residential care. But one choice that is seldom discussed or offered, but is described in this report, is the contribution of a live-in carer, who can keep us independent, and ward off loneliness. So many people surveyed say that they really do not want to have to move out of their own homes, even if they become too frail to be able to care for themselves. We know that many older people themselves fulfil the role of carer, looking after a partner who may be ill or disabled. But that is a demanding responsibility, and some of us may not have a partner who can take it on. In those circumstances, if one is fortunate enough to have sufficient funds, and enough room in one's home, employing a professional carer with the practical skills and the kindness and humour to provide not just practical support, but also companionship, may enable us to stay happily at home until the end of our lives, the way my own mother and my grandmother did.

So now, at my advanced age, I do think that planning is a great idea. At least, we need to consider the options. Alas, doctors cannot tell us the one thing that would make planning my life and yours a great deal easier. I really need to know how long I'm going to live. But even without that vital piece of information, I do think that this report is extremely helpful, making it far easier to consider whatever option may work best for us. And above all, it makes the overwhelming case which planners and politicians all too often ignore when they are making pronouncements about us, the older population, the case for choice.

Preface by Peter Seldon

CEO of Consultus Care & Nursing

As a provider of full time live-in carers and nurses for over 50 years we understand all too well how important it is to be able stay in your own home with familiar things around you. It's also vital for both the person needing care and their friends and family to have the peace of mind that comes from carers who are well-trained professionals, and not just capable, competent, and trustworthy but genuinely caring and warm people.

We feel our experience of providing carers and nurses to thousands of elderly people across the UK allows us to have a clear insight into the care needed and wanted by many elderly people today. This report, informed by independent research from One Poll , surveyed over 2,000 people (with over 50 per cent of respondents being over 50 and 7 per cent over 75), reinforces our belief that there is currently a significant gap in the awareness of care options available, and that care choices are also being limited by a lack of forward planning.

According to the research 97 per cent of people feel most comfortable in their own home and 71 per cent would ideally still want to be living in their own home when they are 75+. However, a lack of planning often means care choices can be limited by circumstance or finances. A key concern for people when faced with elderly care options is the potential cost implications. As public resources are increasingly stretched, funding our own old age care will become an increasing reality. Greater awareness of ways to fund elderly care is urgently needed, whether this is through specialist mortgages, tax incentives or saving initiatives. We do feel the government needs to help people to help themselves and their recent liberalisation of pensions legislation allowing access to pension 'pots' is a good start. Tax breaks for the costs of care would further help in line with the existing incentives to save via ISAs. The country's changing demographics demand that we all need to take positive action to plan financially for our future care.

Whether the care need is respite, palliative or long term, we want people to be able to choose the right care for them and to feel that staying in their own home should be a real and achievable choice – and where the associated costs of care are transparent and easily understood. This report outlines the challenges faced in the UK by our growing ageing population, highlights the gap in care choices and asks for greater consideration of the role live-in care can provide to those individuals who would prefer to remain in their own homes.

Introduction

The UK is facing a 'choice gap' in the way we care for our older generation. All those involved in care – family, state, community and the private sector – are facing the challenge of an ageing population in the context of limited resources.[1]

This report makes the case for more choice in elderly care provision to reflect people's real wishes. It calls for a rethink on how we make decisions and discusses options that meet the needs of the individual and their wishes, not on what provision is available by default. It highlights the need for re-evaluating what choices there are before a person needs care so that decisions are not made in a crisis situation, and questions whether new financial approaches need to be adopted to support the growing funding challenge.

"Older people want personalised care from people they know and trust"

Key findings of the report:

- **Older people want to remain in their own homes for as long as possible**
- **They want personalised care from people they know and trust**
- **There are many misconceptions and lack of clarity over the choices of care available**
- **There is great anxiety about what elderly care means and low expectations on what the average person will receive**
- **Despite all of the above there is an unwillingness to discuss wishes and failure to plan to make those wishes a reality**

Reality of care today

The number of older people is rising sharply as the baby boom generation passes retirement age. According to the latest Office of National Statistics figures, quoted by Age UK, there are already 10.8 million people aged over 65 in the UK, and the number is expected to rise by nearly 50 per cent over the next 20 years.[4] The number of adults aged 85 or over, the age group most likely to need care, is rising faster than the population as a whole.[5]

Combined improvements in healthcare, nutrition and medicine have all had a positive impact on life expectancy; however, this conversely means that the number of people suffering comorbidity and the care needs of this older population will also grow exponentially. Around 40 per cent of the over 65s already have a longstanding illness that limits the activities they are able to carry out.[4] The number of people with late onset dementia is expected to hit one million within the next ten years.[4] Dementia costs the UK approximately £23 billion per year, about twice as much as cancer.[4] It is, therefore, inevitable that most of this group of people will need some form of care.

Increased longevity leading to growing numbers of older people in our society should be unequivocally good news, but the current care system is plainly showing signs of struggling to cope with meeting the needs of this population increase. The independent development and social research charity, The Joseph Rowntree Foundation, has described a situation in which older people are "perceived as commodities", their voices unheard and little recognition given to their "rights, entitlements or purchasing power".[3] Traditional packages of care, combining provision from family, state, community and private providers, are under increasing strain and appear unable to offer the 'own home', person-centred support that older people say they want.

Most people spend their final years receiving care from a mixture of providers, the NHS, local authority, support from family, friends and neighbours, charity and voluntary groups and services bought in from private providers. However, collectively and individually, every member of this care network is facing a growing challenge.

A typical care package involves a person having their needs assessed, and then (if assessed as having assets below the funding threshold) being offered home care visits, commonly described as domiciliary care, and/or district nurse support. Alternatively a person relies on care from a mixture of family and community support. Once their care needs progress and 24/7 support is required, residential home care is usually the default plan of action. The number of older people using residential care homes rose by 21 per cent from 135,000 to 164,000 between 2005/6 and 2012/13.[11]

The reputation of the care industry generally has been damaged by media reports rightly highlighting poor care standards and a lack of professionalism where it exists. This coincides at a time when there is a real need to attract more of the right people, with the right training into the industry to fill the care gap. The value and importance of 'caring' as a career needs to be rebuilt if we are going to have the right carers available to look after our growing elderly population.

"Most people spend their final years receiving care from a mixture of providers"

The cost threshold for care across the UK [13]

Type of care	England	Wales	Scotland
Care	• Personal budgets, no minimum or maximum, based on needs assessment and Local authority • The 2014 Local Authority funding limits state that; - if savings and assets are above £14,250, a person must pay a contribution - if over £23,250, the person must pay for the whole of their care *NB Limits are under discussion currently, the upper limit is likely to be raised to £123,000, the lower limit is expected to be raised to £17,500. A cap of £75,000 spent on care costs is expected to be introduced*	• Direct payments, similar to Personal budgets in England. No minimum or maximum, depends on Local authority assessment of need and reasonable cost of providing care • Top ups up to a maximum of £55 per week allowed • Capital Limit for funding - £24,000	• Personal Care up to £169 per week (2014/15) • Capital Limit for Local authority funding - £16,000 lower, £26,000 upper limit
Nursing	• NHS Continuing Care will fund nursing only • NHS-funded nursing care is paid at £110.89 a week (standard rate 2014/15) dependent on assessment	• NHS Nursing Care fund, £138.65pw +/- (2014/15) • Focus around nursing homes (home care not usually considered) • NHS Continuing Care – fully funded by the NHS	• £77 per week • NHS Continuing Care – fully funded by the NHS

Note: The value of a resident's home as an asset, is ignored now and will be in future if their partner or a relative aged 60 or more lives there.

State-funded care

Recent austerity measures have impacted on State-funded care, with the Local Government Association assessing that £20bn will be removed from local authority budgets within this parliament alone.[6] Care homes, which rely on local authority funding, are finding it equally difficult to cope with the combination of funding cuts and a growing demand to demonstrate higher standards, with an increasing number being forced into insolvency.[7]

Councils have responded by steadily raising the eligibility criteria for social care. According to the National Audit Office in 2005, 59 per cent of councils offered care only to those with 'substantial or critical needs'. Today that figure stands at 87 per cent.[8] Standard national eligibility criteria due to come into effect in The Care Act 2015 will end the postcode lottery, but only by setting every threshold at the 'substantial needs' level.[10]

Despite the growing need for care, the numbers of people actually receiving care from their council is falling. The Personal Social Services Research Unit estimates that 453,000 fewer people received care in 2012/13 than would have done in 2005/6 given a consistent level of eligibility.[9] Local authorities' total spending on adult social care fell 8 per cent in real terms between 2010-11 and 2012-13 and it is projected to continue falling.[8]

State-funded respite care/post-operative or reablement care accounts for around three per cent of Social or NHS funded care. This is only temporary care (with a six week limit) until a more permanent solution is found or the individual is able to return home.[12]

Family support

The State, however, is not the biggest provider of care for older people in the UK. That distinction lies with the 6.4 million unpaid carers, whose care for older or disabled relatives has been valued at £55 billion per year.[1,3]

With increasing numbers of family members now required to work, the signs are that the limit is about to be reached.

Rising life expectancy combined with falling birth rates mean that by 2017 there will be more older people in need of care than there are family members able to provide it.[1] By 2032 the number of older people in England who need care will have risen by 60 per cent.[1] However, the numbers of family members able to care for them will have risen by only 20 per cent, creating a huge care gap.[1]

The social consequences of this gap could be enormous. The Institute for Public Policy Research (IPPR), one of the UK's leading think tanks, estimates that by 2030, 230,000 older people in need of intense care could be left to cope alone.[1] Unmet social needs can very quickly turn into medical needs and it is inevitable that A&E departments and hospitals will also be affected.

"I knew Mum wouldn't survive in residential care, because she loves her own home so much," says Anne. "Being at home for Mum means she can make some decisions about her day, get her breakfast when she wants etc. Live-in nursing care was essential when she first left hospital, in fact it was assumed by her specialists and doctor that they were providing end of life care, but because the nurse cared for her so well she survived. We continued with that because it seemed the safest option for her."

Anne Whitby, whose mother receives live-in nursing

Community spirit

Traditionally, local communities have been the bedrock of support for older people – friends and neighbours watching out for each other; church, charity and voluntary groups all offering care and companionship. However, in recent years the presence of traditional community hubs, such as pubs, post offices and libraries, has declined.

Many older people are becoming isolated from their communities and, current projections from the IPPR suggest, nearly 2 million older people will be experiencing chronic loneliness by 2033.[1]

Loneliness is a serious health issue. Its effect on health has been compared with smoking 15 cigarettes a day and there is a direct link between high levels of loneliness and the onset of Alzheimer's disease.[3] In the UK, nearly half of all people aged 75 and over live alone.[1] On Christmas Day 2010, five per cent of people aged 65 spent the whole day alone.[3]

> ***"Loneliness is a serious health issue. Its effect on health has been compared with smoking 15 cigarettes a day"***

> **"I don't like to think about my own old age, who does? But in my heart I know that I am not going to get any stronger than I am now.**
>
> **Physically I may well become more frail, mentally I may lose some of the faculties I rely upon. When I found myself putting the kettle into the fridge a few months ago, I wasn't too thrilled.**
>
> **And for the last two years I have been listening to older people as I helped to create our new helpline, The Silver Line, offering information, friendship and advice."**
>
> ***Esther Rantzen, CBE, Founder and President of The Silver Line***

> **"We decided as a family that my father's needs would be best served at home with a nurse who could cope with the demands of the disease and maintain my father's dignity."**
>
> ***Dr Sampson, whose father received palliative care from a private live-in nurse***

Private provision

Private provision of care services has grown significantly over the past decade due to a combination of outsourcing by local authorities and a growing number of 'self-funders'; those who pay for part or all of their own care.

In 2010/11 the National Audit Office reported that self-funders spent £10 billion on care and support.[8] This figure is increasing and expected to continue to do so. Indeed, there is a growing market of financial services designed to improve the affordability of self-funded care.

There is also evidence that many older people prefer to pay for care than to call on family members for help.[1]

However, for the private sector to rise to the challenge of providing continuing care, it needs to ensure that the care it offers is sustainable and the kind of care people actually want and can afford. Private providers currently offer a range of different care services (see Appendix for full explanation of care descriptions).

These include:

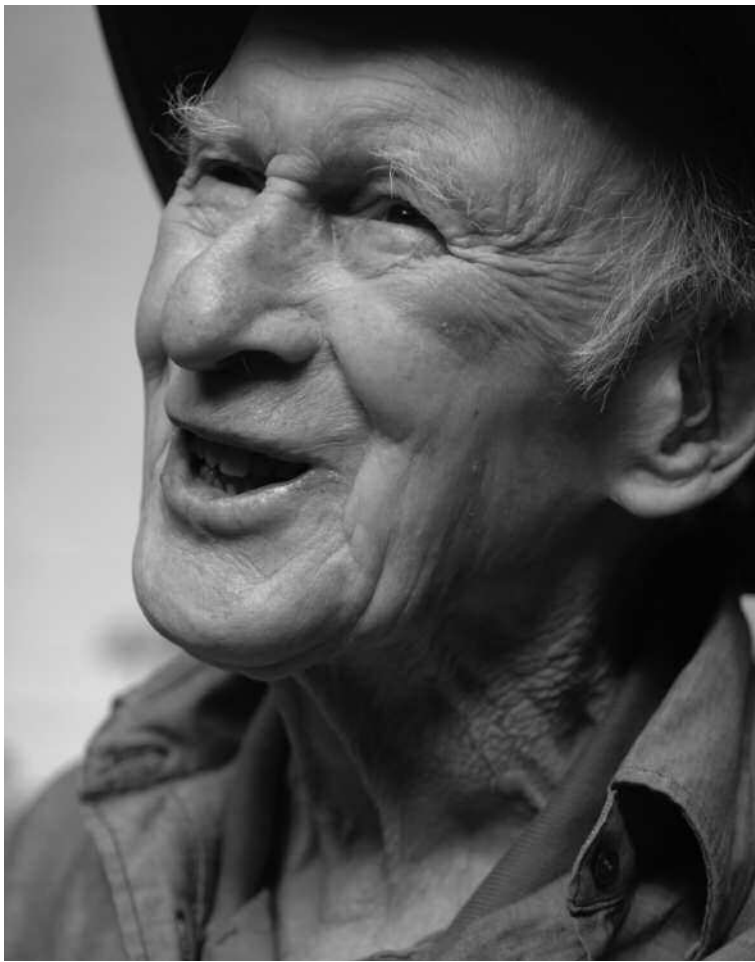
- **Domiciliary care (care visits in your home)**
- **Live-in care (24/7 care and companionship)**
- **Live-in nursing (24/7 nursing care and companionship)**
- **Sheltered or specialist housing**
- **Residential care**
- **Residential care, e.g. Elderly Mentally Infirm (EMI) homes**

Funding for these services may be through self-funding, the NHS, direct payments from the local authority or a combination of the three.

There are many choices but it is often difficult to find out how to access each type of care or where to go to find out which providers suit a person's needs best. All forms of care are often deemed expensive and, combined with the lack of information in the 'mainstream', means that many people end up making the choice that seems easiest and most attainable rather than the care they would ideally choose.

> **"At The Patients Association our motto is 'Listening to patients, Speaking up for change' and the challenges facing elderly care today are many. We feel action and change needs to happen if we are to avert a social care crisis. Provision of timely and compassionate care for the elderly and the options available to them needs to be addressed further by government through an expansion of funding for care in the home, rather than leaving elderly people in hospital - who either don't want, or don't need to be there on medical grounds. This could actually save public money by avoiding patients staying needlessly in hospital. In addition, we must empower individuals to have greater control over their choice of care. We can do this by providing practical measures such as financial incentives to support the growing number of people that will need to fund their own care in their old age.**
>
> **This useful report identifies the existing gap in the choices of elderly care available, and how that gap can be bridged."**
>
> ***Katherine Murphy, Chief Executive, The Patients Association***

"In 2010/11 the National Audit Office reported that self-funders spent £10 billion on care and support. This figure is increasing and expected to continue to do so"



What people want . . . for the rest of their lives

The survey of 2000 adults aged 18-75 conducted on behalf of Consultus, offers a revealing insight into the kind of care people want and expect during their later years.[2] Adults say they would choose to live in their own home as they grow older, with 71 per cent identifying this as their ideal option.[2] However, over a third do not envisage they will end up with their ideal choice of care. Worryingly, it also revealed how poorly prepared people are when it comes to plans for elderly care. 85 per cent of adults between 51 and 75 have not made any plans for care in their old age.[2]

The survey showed that people consider staying in their own home and sleeping in their own bed as among the most important factors when choosing their favoured type of care. Over 70 per cent of all adults surveyed said they would like to be living in their own home after the age of 75, although only 54 per cent said they thought this would be possible. Only three per cent said they would actually choose to go into residential care.[2] The IPPR clearly highlight that older people want to have a positive and fulfilling relationship with the person who cares for them.[1] They want to know they can call on their carer when they are in need and be confident that the carer knows their circumstances and can give tailored advice. In an ideal world they do not want the inconsistency of potentially unfamiliar carers undertaking regular home visits.[1]

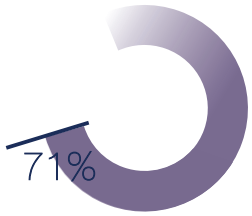
When asked about their plans to receive such personalised care, most people said they had made few, if any, arrangements. They were more likely to have discussed their preferred funeral arrangements (58 per cent) than how they wish to be cared for in older age (48 per cent).[2] Uncertainties associated with growing old and the unwillingness to contemplate our own frailty, probably goes someway to explain peoples' reluctance to plan for their future care.

However, in an ideal world planning for old age needs to be considered when a person is in their 40s or 50s. Thinking about the future earlier and being realistic about the type of care a person thinks they will need, provides people with greater choice. It is the accepted normality to save for a pension, so could there be potential for other mechanics to be introduced to incentivise people to save for elderly care in a similar way?

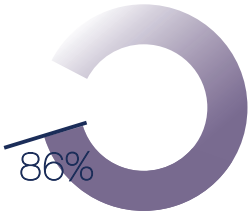
It is arguable that there needs to be a fundamental rethink of government policy to meet this challenge, with new products, approaches and tax incentives designed to support elderly care funding in the future.

> **"Providing one-to-one nursing care, you build up a rapport with your clients, you get to know them as a whole person, and can really see the benefit that your care is bringing to them. This brings great job satisfaction; getting involved with the family, social situations and working across different specialties."**
>
> ***Sally, a live-in nurse based in Sevenoaks***

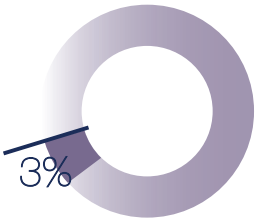
71% of people say they would still want to be in their homes aged 75+



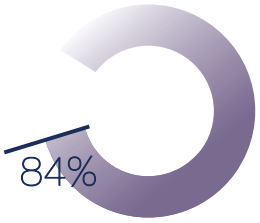
86% of adults have not discussed their care wishes with loved ones



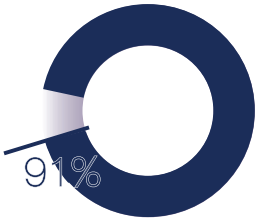
Only 3 per cent said they would choose to go into residential care



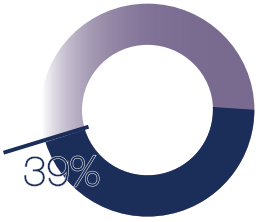
84% of adults have made no plans for their old age



97% of elderly people feel most comfortable in their own home



39% of adults' greatest concern about growing old was not being able to look after themselves



Data from the Consultus Choice in Care survey carried out by One Poll (4th-17th July 2014) with a sample of 2000 adults.

Addressing the choice gap

The question seems to be, how do we make living at home a reality in our older age? It seems clear that there is a significant gap between what older people want from their long-term care and what is actually being delivered.

Older people want to stay in their own homes. Yet approximately half a million currently live in care homes that only around three per cent would choose.[2,3] There is a range of care options that could provide an 'at home' solution.

Sheltered accommodation may be the solution for some but most people over 65 own their own homes and do not want to move into rented accommodation. Only around one quarter of the specialist housing for older people is available for purchase.[4] Often sheltered housing offers limited space for overnight stays for family and friends.[4]

Domiciliary care or home care visits can help older people retain their independence, but interviews with older people have highlighted the importance of building trust with carers who enter their homes and how disruptive it can be when there is inconsistency in carers.[1] Live-in care is where a person is cared for on a one-to-one basis in their own home. Carers live in the home of the person needing the support and care. A carer provides 24/7 care and companionship on a long or short-term basis, even after recovering from an operation. Live-in nursing offers 24/7 professional nursing and companionship and is appropriate when the condition of the person being cared for needs medical supervision. Live-in care obviously requires the individual to have a spare room for the live-in carer or nurse to stay in whilst receiving care.

And when the time comes, most people would prefer to die at home. However, of those who die over the age of 65, only 18 per cent currently do so in their own homes.[4]

> **"The reality is that the public sector is not going to be able to fund care for everyone when they reach old age. Now is the time to encourage people who could help themselves by saving for old age care to start doing so. The state can help with this by offering incentives which allow people to enjoy tax free savings that will fund the type of care they want in their older years. As parents we are encouraged to save for our children's future, so it seems right that we continue saving for our own futures."**
>
> ***Ros Altmann, Government adviser on older people in employment***

"Older people want to stay in their own homes. Yet approximately half a million currently live in care homes that only around three per cent would choose"

Widening the choice and access

If the long-term care of older people is to become truly person-centred, then older people need to have more choice and a greater say in the kind of care they receive.

There are three obvious stakeholders integral to making this care choice a reality.

Commissioners - NHS Clinical Commissioning Groups (CCGs)

Too often the choice of care on offer is too narrow. There needs to be a greater awareness of the different options available, not just the options that meet a set of problems but options that offer the care people really want. Sheltered housing, domiciliary care and residential care all have their place in older people's continuing care. However, an expanding role for live-in care is likely to offer more people the kind of service they say they want: personalised, professional one-to-one care, available around the clock from someone they know and trust. Person-centred care need not be an expensive option. Indeed, offering more care within older people's own homes has been shown to prevent crises and expensive admissions to emergency care.

Families

Talking with your family about preparation and planning for old age should not be a taboo subject. If we are to ensure that older people's views are taken into account then we must ensure they are involved in the 'care conversation'. Both the individual and their family need to address the realities of old age and discuss their future care needs, their preferences and whether they will need to self-fund.

> **"My father had the best death he could have had, surrounded by his family and supported to the end. I think everyone should have that opportunity, to die in the way they choose to die, with dignity and respect."**
>
> ***Dr Sampson, whose father received palliative care from Consultus in his own home***

Individuals

The inevitable planning that starts in your late 40s and 50s should ideally include consideration of your own long-term care. Make your views known and start to plan to future-proof your continuing care. With multiple ways to pay and a variety of care options available, there are many affordable ways to ensure that your final years are spent in comfort and with dignity. Consider how you would like to live the rest of your life and where. Discuss your wishes with your family and understand the options that are available, so you can plan early for the care that you want.

Whether planning for our own retirement or for the long-term care of an elderly relative, cost is always a significant concern. There are a range of options available to finance care including equity release, specialist mortgages, downsizing, investments etc. and recent pension reforms offer further financial scope.

Conclusion

The survey suggests that there are misconceptions from individuals and their families. We know from what is offered to people that even NHS Commissioners are not clear on all the choices available. Often the choices offered are too narrow and they do not always match what people want and need.

From our research it seems clear there is some anxiety about what elderly care means in the UK today, and also low expectations about what care the average person will receive for the rest of their lives. There is obviously an unwillingness to talk about our care wishes with our family, friends and to commissioners; and a lack of knowledge and failure to plan for making those wishes a reality.

> **"Older people, varied and individual as they all are, have taught me how crucial it is to have the right support, the right place to live, the right company and companionship; these are the basics that will enable us to enjoy a happy old age. And most important of all, we all need to have the choice to find the solution that suits us as individuals, because we all have differing tastes and widely different needs."**
>
> ***Esther Rantzen, CBE, Founder and President of The Silver Line***

Appendix

Elderly care and nursing options

- Domiciliary care - also known as homecare or homecare visits. Over 650,000 adults receive homecare each year, either paid for by the local authority (around 500,000) or through self-funding (around 150,000). Domiciliary carers visit the older person within their own home and offer a range of services including housework, personal care, shopping and managing bill payments. Nearly 90 per cent of domiciliary care is provided by the independent sector although 80 per cent of this is commissioned by local authorities

- Live-in care - one to one 24/7 care and companionship. A small rota of live-in carers stay in the person's home and provide continuity of care. The care may be long or short term and can cover both care and social needs. Services include personal care, general housework, companionship and help with family pets. Approximately 27 per cent of private home care is currently purchased on a live-in basis[9]

- Live-in nursing care – one to one 24/7 professional nursing care and companionship. Nurses live in the home of the person and provide 24/7 nursing maintaining the individual's dignity and promoting their independence. Nurses are regulated by the Nursing and Midwifery Council. The Consultus Nursing at Home Department is also regulated by the Care Quality Commission (The adult social care regulator)

- Sheltered or specialist housing - a range of different housing options that offer varying degrees of supervision, support and independence. There are currently 550,000 units of housing with support for older people in the UK

- Residential care - designed for elderly people who do not need 24-hour nursing care but are unable to live independently. They typically provide a furnished or unfurnished room, together with all meals and housekeeping and laundry services. Depending on the needs of the individual they will provide assistance with daily activities such as personal hygiene, dressing, eating, and walking. As of April 2012 there were 414,500 people over 65 in residential care in England. Around 95 per cent of care home residents are aged 65 or over

- Residential nursing care – there are around 3,800 nursing homes in the UK. Most look after older people who require 24/7 nursing care, although some also care for younger physically disabled people. There are also residential nursing homes for people with mental health problems and for those with learning disabilities. There are also residential nursing homes for people with mental health problems e.g. Elderly Mentally Infirm (EMI) homes

About Consultus Care and Nursing

Consultus, founded in 1962, is the UK's leading independent provider of live-in carers and nurses offering 24/7 care and nursing for the elderly in their own homes.

The Company provides affordable private carers and professional qualified nurses for people with a range of conditions, including all types of dementia and long-term chronic ailments. It also provides support for clients requiring respite or short-term care, recovering from an operation or illness, and for individuals who might have become frail or disabled, and for those who require palliative care.

The carers and nurses provide encouragement, companionship and support, giving family members peace of mind knowing that a much loved parent or relative is being cared for by a trustworthy, reliable and compassionate individual.

Consultus is also a training provider and The Consultus Care Training Centre is accredited and approved by Edexcel/Pearson to offer Level 2 & 3 Diplomas in Health & Social Care.

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Consultus Care & Nursing Limited
www.consultuscare.com

For further information please contact Say Communications
email jpetherick@saycomms.co.uk
email lbanks@saycomms.co.uk