

**JRF programme paper:**  
A Better Life

# A better life: Alternative approaches from the perspective of families and carers of older people with high support needs

*“looking inside and outside the box”*

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This paper:

- draws on case studies from Counsel and Care's advice service to highlight issues raised by carers of older people with high support needs;
- explores how 'traditional approaches' such as residential care and extra care housing could be improved and considers the importance of housing in alternative approaches;
- suggests key elements of a future agenda.

**The Joseph Rowntree Foundation (JRF) commissioned this paper as part of its 'A Better Life' programme, to stimulate and inform thinking on alternative approaches to a better life for older people with high support needs.**

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The Joseph Rowntree Foundation has supported this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy-makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the authors and not necessarily those of JRF or the Better Life programme.

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## Summary

There are many challenges in identifying alternative approaches to a better life for older people with high support needs. These include dealing with expectations which are often low, good practice which is not well disseminated and attitudes which do not value older people.

Our prevailing culture is more 'make do' than 'can do'. But our ageing population demands better. And when pressed, carers and families of older people want better. Carers want to be treated as 'partners' and want to be properly involved.

*We need to look inside as well as outside the box.*  
(Family carer)

'Better' – or alternative – approaches must start with making existing provision in residential or extra care work better for older people and their families. A lot could be done to improve the experiences of older people and their families and carers in residential and extra care.

Looking at alternatives, housing is key. Homes need to be adapted to lifetime living and families supported to make their homes more suitable. Home care and support needs to be good quality, affordable and consistent. Local neighbourhoods need to be 'age friendly' and enable families to live closer together with a mix of ages. There is also an opportunity to develop new models of co-housing – enabling older people to continue living in mixed communities while retaining control of their home and their life.

Carers and families must be involved throughout, and the differing make-up of families needs to be better recognised.

## Seeking alternative approaches

This essay is based on the following activity and research:

- a review of literature and web search;
- analysis of enquiries to Counsel and Care's advice service and case studies;
- interviews with individual carers and family members of older people;
- discussions with organisations and champions of carers;
- distilling lessons and practical ways forward from the above.

It does not attempt to provide a comprehensive approach to the subject, but rather give a flavour of what could be done better.

# 1. Issues raised with Counsel and Care

Counsel and Care is a national charity working with older people, their families and carers to get the best care and support. The charity provides in-depth, personalised advice and information, which informs its research and campaigning for better care. About 90 per cent of the people using Counsel and Care's advice service are carers and relatives of an older person, typically an older person facing a crisis. Many are in hospital, following a fall or stroke for example, and many are considering the option of moving into residential care, often under pressure.

Worries about older people who are losing or lacking the mental capacity to make decisions for themselves became the emerging issue for Counsel and Care's advice service in 2009. Ten per cent of all calls to Counsel and Care's advice service are from families and carers concerned about whether older relatives or friends starting to lose mental capacity are receiving the most appropriate and high quality care available in the setting of their choice.

Enquirers' other main concerns included:

- lack of available and meaningful information and advice for older people and their families and carers, particularly for those who pay all their care costs themselves;
- difficulty in accessing the care and support system;
- difficulty in navigating the complaints process if you experience poor quality care;
- the ever-increasing costs of care and support wherever the older person lives.

In 2008, paying for a care home was the biggest concern for older people contacting Counsel and Care's advice service on a daily basis, making up 30 per cent of all calls. While this remains a key issue – still making up over 25 per cent of all calls in 2009 – the emphasis has shifted.

Counsel and Care received a growing number of calls in 2009 from families and carers concerned about whether older relatives or friends starting to lose mental capacity are receiving the most appropriate and high quality care available in the setting of their choice. Enquirers are worried about situations where the wishes and wants of the older person seem to be disregarded in favour of the opinions of professionals (or sometimes other family members) once the older person has been assessed under the Mental Capacity Act Code of Practice as having lost mental capacity for all decision-making.

From April 2009, an older person who lacks capacity to consent to arrangements made for their care and/or treatment has, for the first time, legal protection under the Deprivation of Liberty Safeguards (DoLS), an amendment to the Mental Capacity Act 2005. If, to protect them from harm, an older person can only be cared for in a way that takes away their freedom to the extent that it deprives them of liberty and this decision raises concern or dissent, the care home or hospital must request authorisation from either the local council or the primary care trust to do this.

The aim is to make sure that older people who lack capacity are only deprived of their freedoms where there is no other way to care for them or provide treatment for them safely. All other potential options must be considered first and disregarded as unsuitable or unable to meet their needs before a DoLS is granted. Where concerns have been raised about a vulnerable person, the local council has a right to carry out a DoLS assessment in certain circumstances in line with the code of practice. However, Counsel and Care has received a growing number of calls about situations where the existence of DoLS has been used inappropriately.

**Case study: Mrs M**

*I am the main carer for my husband. I had to go into hospital for an emergency operation for a heart condition. My husband moved into a care home for a period of respite care. When I had returned home and recovered, I contacted my husband's social worker to let her know that he could now return home, which my husband was keen to do. However, I was informed that he could not come home as a Deprivation of Liberty Safeguards (DoLS) assessment was being carried out. My stepson had told social services that I was not able to cope and that my husband would be better supported in a care home. At this point, I contacted Counsel and Care for advice.*

*The Counsel and Care Advice Worker did say that where there is a breakdown in the caring role, the local council has a duty to step in and support the older person. However, at the point that I returned home, the local council adult social care team should have spoken to me about their concerns. Although they have a right to carry out a DoLS assessment if someone seems to lack capacity to make a decision, and is thought to be at harm, I should have been consulted as the main carer.*

*Ultimately, my husband's council delayed in carrying out the process, which I was told should not take more than 21 days. In the end, I was able to assist my husband to return home as he wished to do so. He is now supported at home successfully by me, with help from carers and Crossroads Care.*

Concerns remain that some older people lacking the mental capacity to make such a decision for themselves continue to be moved into a care home arbitrarily without first having a proper DoLS assessment carried out. Similarly, applications for such an assessment should only be made if circumstances warrant it. Concerns have arisen that DoLS has, in some situations, been used as a way of limiting a family's ability to support the older person, especially if there has been a conflict of interest between family members. It should not be used as a discriminate threat in order to control the family's access to the older person, but rather to identify or establish legitimate concerns about the older person by the relevant professionals and carers involved.

The family should be included in such assessments where appropriate, and the whole process should not take more than 21 days. If a better quality of care is provided that focuses on the older person's own individual needs, wants and wishes, with a greater awareness of the way the person likes to be supported and cared for, then in many cases there should be much less need for DoLS assessments to be carried out.

Evidence from Counsel and Care's Advice Service shows that more support is required for older people without mental capacity, their families and carers to raise concerns and make complaints about standards of care. The fear and confusion surrounding the idea of making a formal complaint must be removed, along with the amount of paperwork and effort involved, which can actively discourage individuals from raising their concerns.

Access to independent mental capacity advocacy must be promoted and facilitated whenever possible for older people, both for those who have support from family as well as those who do not, in order to help them make the best choices about their care and support, and raise any concerns they may have. Recognition must be made of the vulnerability of older people who are paying for their care in full, especially those with fluctuating mental capacity or dementia who have not been able to access council support or services.

Overall, the growing number of older people self-funding their care home place means that paying for care continues to be a major concern. Recent research has shown that since 2002 the percentage of older and disabled people paying for residential care without any financial support from their local authority has risen by a third. The number of people who are having to pay for all their care in a care home themselves increased to 41 per cent of all residents (155,000 in total) in 2009.<sup>1</sup>

These figures come as no surprise to Counsel and Care, as the increase is reflected in the number of calls to Counsel and Care's advice service in 2009 about older people who are paying for the full cost of their care themselves.

Appendix 1 provides a range of case studies from Counsel and Care's advice service, demonstrating the issues facing carers of older people with high support needs. Many highlight basic issues that need to be addressed to improve life for older people, their families and carers.

## 2. Carers' views

Starting points from family carers include:

*I am family and want to be treated as such.*

*Carers are expert partners and should be involved.*

*Don't separate us from our loved ones.*

*Respect our rights as a family member.*

Carers repeatedly talk about being kept at arm's length from the care of their loved ones, while being expected to continue providing high levels of care. Carers have much to offer the care system, not simply substitute care. They usually know more about the person needing care than anyone else. This knowledge should be better used by the care system and care staff at all key stages of the care process. Particular concern was expressed about contact at critical times such as discharge from hospital and admission to residential care, as demonstrated in Appendix 1.

This issue is reinforced by a recent report from the Association of Directors of Adult Social Services (ADASS, 2010) which argues that carers of people being discharged from hospital can often feel that they are unrecognised; that they are not treated as genuine partners by the agencies concerned; and that the procedures involved simply don't work as well as they ought to for them and the person they support. They say the discharge process should really begin at the point of admission to hospital, when 'all parts of the system – family, carers, hospitals, primary and community care services – should be working together to assure a quality experience for patients and carers'.

The report proposes that:

- All statutory services involved should have a lead professional devoted to carers.
- Specialist support should be available for people with dementia.
- Carers' issues should be embedded into training and organisational cultures.
- Information for carers should be accessible and available.
- Services should understand better the needs of black and minority ethnic carers.
- Everywhere should be as good as the best on hospital discharge.

The cases from Counsel and Care's advice service (as above and in Appendix 1) demonstrate how carers are not as fully involved as they could be. They also highlight the need for carers to have access to good advice and support at critical times. Making this advice easily available through one portal (web/telephone) is crucial. Services such as Carers Direct and FirstStop as well as Counsel and Care need to be better promoted.

Carers also talked about the care system needing to recognise that they have a life too, beyond 'care giving'. Carers have widely varying expectations of what they want to do and are able to do given their responsibilities – some are keen to study or work, others 'resigned' to limited options.

It was felt that available resources made a big difference. Whether a family could buy in support, respite breaks, 24 hour cover, from their own income or a personal budget/direct payment, made a big difference. For many, income and trying to maximise it are key drivers.

*Most carers don't have any entitlements or regular support.*  
(Family carer)

Throughout these cases and conversations, two powerful forces came through. Firstly, guilt about not being able to look after a loved one who is admitted to a care home – 'like sending a child to boarding school'. Second is the issue of potential conflicts of interest – who makes the decisions and in whose interests is the carer acting?

### 3. Alternative approaches to what?

The mere question suggests that ‘traditional approaches’ such as residential care and extra care housing for older people do not meet the needs and wishes of their residents. For many carers there doesn’t appear to be an obvious alternative. They can’t provide 24 hour care, can’t cope with dementia and can’t get the support they need in the community. At the same time expectations are low – used to surviving without much support and not wanting to say they can’t cope, carers are not full of ‘alternative approaches’. Indeed many of the comments go against the grain of current policy and practice.

Given the sheer numbers currently housed in residential and extra care (almost half a million older people) and the increasing numbers of older people living with dementia, a reality check is needed. There is a clear demand and need for these ‘traditional approaches’ but much more could be done to improve the experience of older people and their families and carers.

The cases from Counsel and Care’s advice service in Appendix 1 suggest some basic starting points. Improving the choice of home so that an older person can live near their family is key and ensuring that third party top-up payments are not demanded for this ‘privilege’. The pressure on local authority budgets may mean that this becomes an even bigger issue as councils restrict their standard fees paid to care homes.

*In an ideal world everyone would, of course, receive the degree of care they need (mental, emotional and physical) by staff with the right motivation, sensitivity and necessary qualifications.*  
(Family carer)

How a care home communicates with the older person *and* their family before and on admission to a home is seen as critical. Care staff have a vital role in communicating with carers and family members. Families and carers know the older person and should be closely involved in care planning, informing the home about the older person’s life, interests, wants and needs, as well as being helped to understand the issues facing the older person. A life story should be created reflecting these facets and their relationships. This must be where personalisation of care starts as well as ascertaining an older person’s wishes through advance care planning.

*Discovering the person’s background, hobbies, and passions can all be used to some extent. If someone loved poetry, was an actor, an artist, art lover, a gardener - use it. As demonstrated by Sir Gerry Robinson in his documentary when he gave a gentleman a paint brush.*  
(Family carer)

Good communications underpins these relationships. But it also requires staff and managers who are well trained and experienced. Quality of staff is a major concern for family carers, especially their ability to relate to families and to understand and respond to the needs of the older person. There are also concerns about the level of

staffing, particularly for caring for people with dementia. Comments from participants included:

*Stimulation is the aim, to engage with whatever memory the individual still has.*

*Improved understanding of the best and most sensitive way of caring for people with dementia which hopefully is now being better understood by some.*

*To energise the individual and create avenues for conversation with care staff, family and visitors who find it so hard to communicate.*

*Care staff should be looking all the time at the individual's capabilities and wishes and seeking ways to do whatever is possible. Use imagination or speak to those who have it.*

*I see it as listening to and learning from those who have already understood what the need is and crucially what is not the way.*

*Look at ways to stimulate that part of the brain/memory that remains undamaged, such as teaching people to sing.*

*Do you know of Dr. Norman Alm at Dundee University? Last year I invited him and others to give a demonstration of his touch screen project for people with dementia. We witnessed a lady who could only say Yes or No but became 'alive' and took control of the screen to go through songs she knew.*

Staff are central to facilitating visits to the care home by families as well as supporting older residents to spend time out of the home visiting relatives and friends. Having good transport is also important. Carers want more opportunities to host visits at their own home if possible. They also want better accommodation to be available on site in care homes to support family visits – including en suite rooms for couples and children – particularly where relatives have to travel considerable distances. Some care homes have facilities on site or nearby for children to play etc – Moreton Hill Care Centre, run by Barchester Healthcare, is one example.

*Arrange transport if there are family members who cannot get to visit. Perhaps they haven't seen them for a long time and will not unless something is arranged.*

(Family carer)

*Make sure the young ones are incorporated – especially new-born and very young who might not have been seen.*

(Family carer)

The final point in this section relates to the image of care homes. For many people residential care remains a positive choice, yet it is regularly portrayed in the media as being the worst choice. Counsel and Care is running media awards for the

positive portrayal of care but care home providers and others in the sector need to do more to market their services and promote positive images of personalised care.

*Music – to the individual's taste. Therapies under skilled hands. Reflexology. Head, hands and foot massage. Watch someone making something – creating something – where possible join in. Be read to – their choice – poetry, novels, biographies etc – choose films and programmes to watch. Make sure the room is attractive – gentle aromas.*  
(Family carer)

## 4. Staying at home

For carers, as for older people, the preference is for the older person to stay in their own home, provided that support is available. This support ranges from being able to access advice and information easily to getting practical support in and around the home. This features the perennial call for 'that bit of help' in the home – with gardening, cleaning, shopping and repairs – and getting out and about, with reliable local transport (JRF, 2005). Befriending can benefit the carer as well as the older person.

Getting a break is still a big issue for carers despite increased provision of respite care. But perhaps the biggest concern is about the availability of homecare that is good quality, affordable and reliable. Continuity of a carer is seen as being the most important factor.

*The most important factor is to have experienced and sensitive care staff with the appropriate specialist training across the spectrum of care. The ability to comfort and sympathise with each person's particular problems and with the time to do this. A thorough knowledge of the individual's medical, physical, mental, and emotional needs as appropriate.*

*24 hour care is what I need so that I can have a life.*

*I wish my partner could sleep outside of the home so that I could have a peaceful night's sleep.*

*Bring back old style values. Employ people who have life skills to offer.*

*Employ mature individuals with good communication skills with respect for the carer's knowledge, and their home.*

*We need more befrienders who could become a support to the whole family and bring other conversation into the house or care home.*

*Bring back day centres – they are a great source of relief for carers.*

*Just because they cannot move does not mean they have to remain immobile. Find ways of changing their environment – in good weather getting them outdoors – walks in the park, feeding the ducks. Coach trips to places they would be interested in visiting. Constant sensitivity to their needs, allowing them to use whatever movement they have no matter how painstakingly slow that might be.*

Recent Department of Health statistics<sup>2</sup> indicate that while an estimated 80,000 older people receive free personal care at home from their local council, 40,000 older people pay part of the costs and a further 50,000 older people currently pay all of the costs of their care at home.

However, these 90,000 older people with the highest needs who are paying for care will all have different experiences in relation to charging for the home care they receive. The amount an older person is charged for their home care is inconsistent and remains a postcode lottery, depending very much on where the person lives in the country as to whether it is a positive or a negative outcome. Over ten per cent of all calls to Counsel and Care's Advice Service in 2009 were about issues related to care charging and problems with getting care at home.

In the Isle of Wight, free home care for 2,000 people aged over 80 with critical and substantial needs was introduced in April 2007 by the council in partnership with the primary care trust. In addition, Derbyshire council does not charge for personal care services at home for older people with moderate needs and above. Two councils who responded to our queries on charging confirmed that they charge according to the cost of individual providers rather than by the hour as a result of the introduction of personal budgets. So far these innovative policies have been more the exception that proves the rule, rather than an indication of the direction of travel.

In its annual survey of councils,<sup>3</sup> Counsel and Care has seen a wide range in the level of charge that local councils are willing to set for essential home care services. Some councils charge £8 an hour to older people for their care, but other councils are now choosing to charge £17 or even over £18 an hour. This rate is simply unaffordable, especially for an older person who might need a high amount of care and support per day. An older person with critical needs may well require four visits a day from two care workers to support them out of bed in the morning and assist them to wash and dress, but if they also have over £23,000 in savings, they would be required to meet the full cost of the care themselves, less a small amount per week in Attendance Allowance.

**Case study: Mr M**

*I contacted Counsel and Care for advice after the amount my council decided to charge per hour for my care increased considerably. I had a great home care worker who I had developed a good relationship with, and I didn't want to lose the support. I contacted the home care agency directly and realised that they actually charged less per hour than my council was charging. It sounded like a good idea but I asked Counsel and Care for a second opinion as I was worried if I stopped getting care directly from my local council, I would be put at a disadvantage if I then needed more care. Counsel and Care acknowledged how expensive care had got in some areas, especially if you had savings of just over £23,000 which meant that you had to pay all the costs yourself. The Advice Worker reassured me that I would still be entitled to a re-assessment by my local council at any time if my needs increased.*

The Coalition on Charging (2008) has found that 80 per cent of people who stopped using council care services highlighted the high cost of charging was a key reason for taking such a step. Carers often then end up picking up the caring responsibilities, with a considerable impact on their own lives. The current system is clearly undermined by its propensity to hit the most vulnerable hardest, so they struggle with complex needs whilst also having to pay the most expensive care bills. One local authority highlights that 'a further review of the charging policy is imminent

to ensure that this complies with the principles of the personalisation agenda'. While this is a positive step, the same council also anticipates that 'income from charges will continue to be maximised where possible', surely a contradiction in terms.

The Welsh Assembly Government is taking steps to address the current variation in charging policies that currently also exists in Wales with a proposed unified charging policy and a universal maximum charge for care that councils will be able to charge less than what is considered reasonable, but not more.

The other key factor is the older person's home itself. As an older person's needs increase, many homes will need to be adapted to meet these needs. Availability of finance and suitable space can be two factors limiting adaptations. Some carers had suggestions to tackle this.

*For someone lying on their back: Use the ceiling - paint beautiful scenery – photos of their loved ones, if that will not upset them. Purchase a clock that shows the time on the ceiling so that they know what time it is, keep them in touch with the day.*

(Family carer)

Telecare and other technology can also provide greater support and reassurance for carers, provided back-up emergency response is reliable. While no substitute for home carers and family carers, telecare can provide round the clock reassurance. Increasingly family members will also be able to keep in touch with each other using their television and the internet for visual contact wherever they live. One such scheme is being promoted by Abilink Services for Independent Living. The withdrawal of wardens from many sheltered housing schemes has been opposed by many older people and their families.

## 5. Support for carers

Much of the focus of the debate around support for carers has been on working carers, as the economy requires many more to continue working, as will their personal and financial situation. For many of them, flexibility is the key issue so they can manage their time with understanding employers recognising the changing and sudden demands that their caring responsibilities involve. Maintaining and increasing income is key to tackling family poverty across generations but carers face greater risk of financial hardship. The complexities of the benefits system cause much despair.

Many carers of an older person with high support needs are also older people themselves, often with little financial compensation. They comment that they want acknowledgement and respect as well as support from care providers and other services. Emotional support for the carer and the older person could be much better developed – and not just at key times like bereavement.

*Laughter is a great healer and stress reliever for everyone.*  
(Family carer)

Supporting carers to lead a normal life while they support an older person with high needs shouldn't be a major ask. But it does require a sophisticated combination of formal care and support, voluntary agencies, public services, and family and friends. GPs are particularly important points of contact. Independent advocacy for both the older person and the carer needs to be much more easily accessible. And support services need to recognise that carers need breaks and help outside of normal day centre opening hours and at weekends etc.

## 6. Housing options

### New housing options

Many carers want to be able to live with or close to the older person they care for – and remain so. Housing and planning are therefore key to enabling families and carers to live closer together. New housing with care developments are often in peripheral locations and without general needs housing. Integrating older people into local communities (rather than building ghettos) has to be part of the solution.

*More purpose built centres with swimming facilities and other facilities that disabled people could use, I understand some councils have these amenities.*  
(Family carer)

*Young people need to see older people at the heart of the community.*  
(Family carer)

Carers are also keen to see more help available to adapt their own home to accommodate an older person. Relaxing planning regulations to build annexes, for example, would help families with the space and money to do so. Others would benefit from grants or loans to adapt homes or make gardens safe for people with dementia. Equity release schemes might help older people to stay in their own home. Local authorities should look at how foster carers have been supported to enhance their homes to care for children as a possible model to support carers of older people. Some councils provide grants to foster carers to extend and/or adapt their property. Learning from successful models of care for other user groups is important and local authorities could facilitate this across adults and children's services.

The recent HAPPI (Housing our Ageing Population: Panel for Innovation) report (Barac and Park, 2009) paints a vision of a range of attractive options, based on exciting European examples. They respond to a variety of care needs and different tenures. Space, light, accessibility and being part of a community are all common factors.

Other schemes worth exploring further are mutual self-help like homeshare and cohousing. Homeshare in the UK is relatively under-developed and low profile compared to the USA, Australia and elsewhere, but has great potential for enabling older people to stay in their own home.

### Mutual housing options: cohousing

Cohousing is a way of living which brings individuals and families together in groups to share common aims and activities while also enjoying their own self-contained accommodation and personal space. Cohousing communities are a means of compensating for the alienating effects of modern life where neighbours don't recognise each other and where day-to-day contact and collaboration are minimal. They offer particular benefits for children in terms of secure play-space and shared

activities with their peers. Older people can find companionship and mutual support in such communities.

There is a rapidly-growing interest in cohousing in this country. There are eight fully-established cohousing communities in the UK: Springhill in Stroud, the Community Project in Laughton, near Lewes, Thundercliffe Grange near Rotherham, Canon Frome in Wiltshire and the Threshold Centre in Dorset. Smaller cohousing schemes include Stroud Co-flats, Frankleigh co-flats and The Courtyards near Bradford upon Avon. All are based on owner-occupation, although the Stroud community has three shared ownership units.

There are two prevailing models of cohousing that offer older people a familiar, friendly, neighbourly environment in which to thrive in their later years. One is intergenerational, where families and singles share a cluster of buildings and the other is an age-peer group, where people of 50+ who prefer a child-free setting make their own mutually supportive community. Both models are widespread in countries like Denmark (where the concept started) and the Netherlands and older people therefore have a choice between them. In the UK, a handful of intergenerational communities exist ([www.cohousing.org.uk](http://www.cohousing.org.uk)) but, so far, no senior communities have got off the ground. The Older Women's Cohousing group in London ([www.owch.org.uk](http://www.owch.org.uk)), aims to be the first in the UK and is currently in discussion with an affordable housing developer.

Even in the US, where the cohousing movement has seen a healthy rate of development in the past two decades, there are only three cohousing communities dedicated to older people. There is, however, as recent US Cohousing Network conferences have shown, a strong interest in 'ageing in place' in America's family-based cohousing communities.<sup>4</sup>

Cohousing is about developing a 'mini-neighbourhood' managed co-operatively by its own members, where they share common space, meals and other activities but each household has its own self-contained accommodation. It offers an ideal blend of communality and privacy to older people. In the UK particularly, it presents an alternative to many who might otherwise be isolated (60% per cent of women over 75 live alone) or who are reluctant to join one of the more traditional options available to older people who don't relish living alone. In a cohousing community, older people retain their independence and autonomy, keep their own homes, find companionship and support on their doorsteps and generally stay active and healthy for as long as possible.

Both the Danish and Dutch governments have fostered the development of older people's cohousing communities for the last 30 years, with a view to reducing the volume of demand for health and social care services as their societies age. There are some hundreds of age-peer cohousing communities in each of these countries. Others, like Germany and Belgium, have similar communities but in smaller numbers. Making progress in the UK will require greater awareness of the concept and joined up working by planners, developers and housing providers together with appropriate funding models.

There are also lessons from other groups of people with high support needs, for example:

- The Judevine Centre for Autism (now Touchpoint Autism Services) provides 'cradle to grave' support, starting with intensive training for parents, from the time they get a diagnosis for their child, through to aged care of people in their own homes ([www.touchpointautism.org](http://www.touchpointautism.org)).
- Jay Nolan Community Services is renowned for its person-centred approach to teaching people to communicate and plan for a life that they want to live. They follow up with the provision of supports which enable people to live in their own homes close to family home ([www.jaynolan.org](http://www.jaynolan.org)).

## 7. Issues for further discussion

The Better Life programme provides an opportunity to develop an agenda for the future, building on best practice and sharing innovation. It is a real opportunity not just to support change, but to lead it. Raising expectations amongst older people and their families and carers that there are 'alternative approaches' to residential care is an important starting point.

Key elements moving forward include:

- Integration: particularly of housing and planning with care and health in local neighbourhoods and developing markets of support.
- Personalisation: putting older people first without putting carers second.
- Prevention: supporting older people and carers much earlier, at the right time and right place, rather than reacting to crisis.
- Technology: making sure access is expanded.
- Getting the best value from all resources: those of the older person and their family and those of the public purse.

### Joined up solutions now?

More resources are a key issue for carers, many of whom are struggling to keep their heads above water. But fundamentally action is needed across communities to 'join up' to better meet the needs of older people: setting local priorities, pooling budgets and integrating services around older people and their carers. The current pressures on public finances demand that we make the most of existing resources – from sharing sites across generations to helping older people and their families to help themselves. The economic imperative to better support carers will grow and grow; whether that leads to what carers want remains to be seen. There will also need to be matching cultural changes to promote reciprocity within families and communities.

## Notes

1. Statistics calculated by the House of Commons library on behalf of Norman Lamb MP. Calculated using Laing and Buisson's Care of Elderly People, UK Market Survey, 2009.
2. Statistics from Andy Burnham, Secretary of State for Health, provided to the House of Commons on 14 December 2009 during the second reading of the Personal Care at Home Bill.
3. Counsel and Care's Care Charging Survey 2009–2010, survey in progress.
4. Workshop held on 16.03.2010 in Chicago on Ageing in Place. 'Partners in Caring' is a uniquely organised collaboration of seven different agencies in the fields of aging and disabilities which provide services for seniors and people with disabilities.  
<http://www.aievolution.com/aga1001/index.cfm?do=ev.viewEv&ev=1354>

## References

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<http://www.homesandcommunities.co.uk/public/documents/Happi%20Final%20Report%20-%20031209.pdf>

Coalition on Charging (2008) *Charging into poverty? Charges for care services at home and the national debate on adult care reform in England*. London: National Centre for Independent Living

Joseph Rowntree Foundation Older People's Steering Group (2005) *The Older People's Inquiry: 'That little bit of help'*. York: JRF

# **Appendix 1: Case studies from Counsel and Care's advice service – enquiries from carers of older people with high support needs**

## **Case A**

Mrs J rang because her 94 year old father was being discharged from hospital and the homes offered were too far away. We were able to advise the caller of the hospital discharge/needs assessment and choice guidance to help her put a case forward for her father to be moved nearer to her.

## **Case B**

Mr T rang because his mother was becoming confused and was in hospital needing to be discharged into a care home. However he had had little information from the hospital. Points covered included enduring power of attorney (EPA) hospital discharge procedure, care home funding and spend down issues and contract details between home and her or him as EPA.

## **Case C**

Ms H called up as her mother had 'escaped' from her respite care and returned home to her frail and stressed father, who could no longer cope with her unpredictable and angry behaviour. However he was reluctant for her to go into a care home as he could not afford it. We reassured her that her father could remain at the family home and she would be entitled to local authority help from the information that she gave. However we also talked about the fact the mother could not be put into care home against her will without seeking a section order under mental health act. We also found agencies local to her father who may be able to support them through this difficult time.

## **Case D**

Mrs B called about the threat of eviction from a care home. The council were refusing to pay the full cost of fees and care home would not lower the fees requested. She was advised to look at the care plan – psychological and emotional needs, maintaining contact and caring relationships. We also advised her on the council's duty to fund full cost of the fees and to do a risk assessment and consider whether another care home would meet all her needs if she moved. As part of the feedback she stated that she was grateful for the information. The situation appeared to have been resolved and she was no longer paying a top up from her mother's income/savings.

## **Case E**

Mrs M called as her husband was in hospital and the indication was that the professionals were not going to recommend residential care although she could not care full time for him. She felt that he required this and his needs had not been assessed properly. However, the information we provided was comprehensive and her husband is now in a care home, although this may be temporary.

### **Case F**

Ms W called about her mother – her memory was not what it was and she felt her mother needed more appropriate accommodation as she was starting to struggle at home. She was finding it difficult to broach the capacity subject with her mother. She was advised about requesting a needs assessment from social services and a care plan would show where her care needs could be met. She was advised on paying for home care and sheltered housing. We stressed the importance of assessing capacity not assuming incapacity. She was directed to Alzheimer's Society for support and advice. Mrs W called to say that she had acted on the information and her mother has settled well into sheltered housing.

### **Case G**

Mrs B's mother in law has been living in an EMI care home for over two years, she has visual problems and high level mental health needs. Mrs B has enduring power of attorney and alerted the council of depleting capital. A social worker has completed a needs assessment which they have a copy of. The social worker has stated that it would be detrimental to move the mother in law, and that this would be the best home to support her needs. The council quoted a standard rate that is £100 less per week (£385) than the fees, and contacted the family to ask for a third party top up. None is available. We provided them with some legislation from LAC 2004(20), and they are willing to challenge. Eventually the council capitulated and agreed to fund the placement.

### **Case H**

Mrs G called as her husband was in a respite placement but was considering a permanent care home placement. She wondered what the financial implications would be as they had an interest mortgage of £618 per month and she asked about 'free' personal care. We advised on a needs re-assessment to ensure that the current care home was suitable. We advised on the 'free' personal care amounts but also advised that it is effectively only free if you are self-funded which her husband was not – he would still be paying from income as he already was. The council contribution would be reduced by the 'free' care element instead. We advised on the financial assessment and to check if it made financial sense to accept 50 per cent of her husband's occupational pension or to maximise other benefits. We also advised on disregard of property.

### **Case I**

Mr P called re Mrs M who was moved from hospital to a care home. Mrs M's need to move to a care home near her family was not recognised by the council as an assessed need, and subsequently a third party top-up was requested to meet the difference between the care home costs and the council's standard rate. The council did not consider raising their rate to a level where a care home could be found near the family. Mrs M's daughter and son-in-law Mr and Mrs P were told that they had to sign a third party top-up otherwise Mrs M would be bed blocking. They were not given any information about the future implications of entering into such an agreement, and were forced to sign out of concern for their elderly relative. After writing a complaint letter on their behalf, at some length Mrs M's social services addressed the issues that we raised, and finally came to the conclusion after a re-assessment of Mrs M's needs, that her care home was the only care home that

would meet her needs; that she had an assessed need to be in a care home near the family, and that consequently, the council would raise their rate to pay for the whole of the care home fees.

### **Case J**

Mrs A's mother was in hospital and had early onset dementia. She also had mobility problems. Mrs A thought her mother may have to go to a care home. We advised her regarding the delayed discharge process as well as needs assessment and care planning. We advised her on financial assessments for home care and care homes including the implications for benefits of each option. We advised her on the services/help available at home from social services and if her mother was self funded. We gave contact details and information about the Alzheimers Society and her local branch. We provided a contact for the Protection of Vulnerable Adults (POVA) team in the area in case her mother was discharged home and Mrs. A felt that she was at risk.