

Right care Right deal

The right solution for social care

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It's Everybody's Business

Care and support for the 21st century



counsel + care 
for older people, their families and carers

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CARERS UK
the voice of carers

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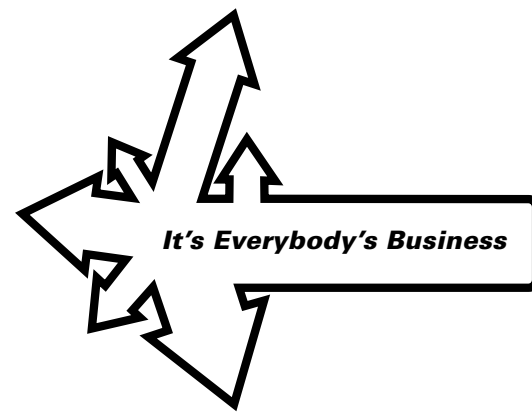
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The right solution for social care

In 2008, Help the Aged, Counsel and Care and Carers UK came together to form the Right Care Right Deal coalition and launched a high-profile campaign calling for a new settlement for social care in England.



WHO WILL NEED SOCIAL CARE?



The Right Care Right Deal campaign aims to raise awareness of society's reliance on the care system. In all its various guises, from meals on wheels to care homes, social care is an essential, yet often unseen, support system within our society. However, with reducing government expenditure on care and a minefield of red tape, social care is at crisis point.

At some stage in life, everybody will be involved with the business of care, perhaps because they are organising their own care or that of an elderly relative or friend. So while it may not be your business today, it could be soon. Like education and health, social care really is everybody's business.

Please show your support for a new, personalised and better funded deal for care, fit for the 21st century. Go to www.rightcare.org.uk to make a difference

Effective care and support services are essential to promote our health, well-being and independence. Yet our existing system is at crisis point. It is estimated that around 1.5 million older people need help but do not receive it from their local authority¹ and, with the number of older people set to double in the next 20 years, this crisis will only deepen. Many more people will also look to friends and family for financial and emotional support. Social care is an issue that could touch all of us.

Right Care Right Deal approached six people who receive care and support and asked them to describe their lives. Their stories form the basis of this report. From these accounts we can build up a picture of the struggle people face just to get on with daily living.

Their experiences serve to remind us that a system which, in principle, exists to help people get on with living full lives is in practice unfit for the future and incapable of delivering the quality of care people deserve.

As this report shows, some of those in greatest need of support are being let down – forced to fend for themselves and put up with a quality of life which no one would willingly accept. The Right Care Right Deal coalition wants a future where people can live their lives their way, supported by a care system funded through a clear, simple and sustainable deal, entered into by the state, community, family and individuals.

In short, we want:

- **a personalised system** which enables people to assess their own needs and to choose the right support
- **an affordable system** which is better funded, sustainable and more efficient
- **a supportive system** which supports families and unpaid carers as an integral part of the system

- **a preventative system** which reaches more people, at an earlier stage
- **a fair system** which offers individuals a fair, simple and consistent deal
- **an accessible system** which is easy to understand, access and use.

The next few years provide a unique opportunity to strike a new deal for social care in England, fit for the 21st century. The 1.2 million people who receive help from the current system know that the status quo cannot be an option.

The vision for change over the next few years must be ambitious. It must be broad enough to capture the things that make a real difference to older and disabled people and their carers and families – from better transport and housing to flexible employment, secure income and good information and advice.

We must be brave enough to put every aspect of our current system under the microscope. The national debate must include not only politicians and policy-makers, but also employers, care providers, users and future users of care. All of us must play our part in shaping the future.

As the stories in our report show, social care is **everybody's business**.

1. A PERSONALISED SYSTEM

‘We need a social care system that enables people to assess their own needs and to choose the right support’

Currently, local councils work out people’s support needs by arranging a Care Needs Assessment, which is carried out by a social worker. This assessment tends to put the main emphasis on people’s physical needs, above their social, emotional and mental health needs. And the assessment does not always give people the opportunity to say that their needs might change frequently or be unpredictable.

As a result, the care and support put in place are often either too intensive or too limited, and lack flexibility. They also take up a lot of professional time, which could be better spent working with people to help them meet their needs.

Many individuals are not only willing and capable, but are also the best person to assess their own care needs and decide how they should be met. Their choices may not be the same as a professional’s, but that is the whole point. Their carers will also have valuable expert knowledge and should be seen as partners in care.

Older and disabled people should be able to access support to complete their own assessment of their needs, with professionals providing guidance and expertise where needed.

Self-assessment tools should be available to people at all levels of need, with support for those whose needs are still relatively low to bring in the services which will help them stay independent. Such support should also be flexible, so that people who have changing needs can be supported in a way that suits them.

²Community Care Statistics 2006–7: referrals, assessments and packages of care for adults, England, NHS, 2008

³Based on 11 self-assessment pilots projects being conducted out of a total of 150 councils with social services responsibility. *Self-assessment Project Update*, Fagg, M. CSIP website 2007

About 17,000 over-65s in England were using direct payments in 2006–7²

‘Being able to assess my own needs and support is so important’

PAMELA'S STORY

Currently, only 7 per cent of local authorities offer people the opportunity to assess their own care needs³

PAMELA'S STORY



My name is Pamela. I have an inherited disabling condition which started quite slowly when I was about 18 and gradually deteriorated over the years. I was 65 when I had to give up walking altogether.

As my condition got worse, I eventually needed 24-hour care to stay in my own home. I have been using Direct Payments for about five years now. My borough gives me a set budget which I use to pay for live-in care workers. I have an arrangement with an agency which manages this for me.

However, I still need to 'top up' my care and I am only able to do this because I have an occupational pension. I pay for an additional member of staff to visit in the morning and evening to help the live-in care workers lift me. This isn't funded by the care package as I already use up the budget that I have been given, yet it is required due to the regulations on handling people.

Direct Payments are pretty good. I started using them after a mini-crisis in my condition which meant that my needs increased and a decision was made that I couldn't live at home without this package. I would never have got the same amount of care using traditional services.

Despite the flexibility of my care package, there are still restrictions on my ability to make snap decisions. I can't suddenly decide to eat at a different time, stay out late, or have a lie-in in the morning because of the extra staff coming in. Everything must be planned in advance.

When this package was put in place, I had a particularly good key worker who fought for me. But it was put in place when I was under 65 and I was still under the physical disabilities team, rather than the older people's team. I fear that I wouldn't get the same kind of package if it was decided under the older people's team.

For people to be given the help they need, the system needs a lot more money. It needs to be directed to the right places, care workers need to be better trained, and there needs to be an increase in the professional status and profile of care workers.

Being able to assess my own needs and support is so important. It means that I can live in my own home, I can employ the people and the agency that I choose. It also means that my package is quite flexible and allows me to do what I want – for example, have a part-time job and do voluntary and committee work.

WE SAY

Pamela's experience of care is better than most people's. She has a great deal of influence over her care package and can decide for herself what kind of support she wants.

However, this is achieved only because she puts in her own money and is able to express what she wants. Even then, her care package is not perfect.

One of the problems Pamela faces is that there is too little room in the assessment process for taking account of her needs as a whole person. There is too much focus on her physical needs and not enough on her well-being. She is denied the ability to make basic decisions about how she lives her life, such as when to get out of bed, simply because she has a disability.

Too few people in our current care and support system get the chance to fully express their needs and choose services to meet them effectively. People like Pamela are pioneers, but others feel the barriers to taking on Direct Payments – such as lack of information, advice, and advocacy support – are too great. We need to make sure that choice and control are a reality for all care users, no matter how much support they need to get there.

2. AN AFFORDABLE SYSTEM

‘We need a social care system which is better funded, sustainable and more efficient’

Tight budgets mean that over recent years councils have cut back on the services they provide to older and disabled people. Two-thirds now provide care only to people whose needs are high – either ‘critical’ or ‘substantial’. They are struggling to provide for the increased numbers of people needing services because there is not enough money in the pot.

Councils face a difficult choice – spend money on people with urgent needs, or invest in low-level services which could prevent more expensive needs occurring. They cannot afford to do both.

There is no doubt that there needs to be more money in care and support, along with better and more efficient use of existing funds. Through self-assessment and better choice of services, less money will be spent on services that many people neither want nor need – and more money on services which people are calling for.

The cost of care *will* increase, and it is likely that individuals themselves will continue to be asked to contribute to their care. If this is going to work, there needs to be a method of payment and saving that people can trust, and more information earlier in life about what the costs could be. The system needs to be suitable not just for the forthcoming generation of baby boomers, who are, on average, relatively wealthy (particularly if they are home-owners), but also for future generations who may not be so lucky. There should be a long-term solution.

6,000 older people with high support needs receive no care at all⁴

‘We have had to take out a loan to cover the gaps in care and living costs’

EMILY’S DAUGHTER’S STORY →

The cost of community-based social care in England is estimated to increase by 130–150 per cent between 2002 and 2026⁵

⁴The State of Social Care in England 2006–7, CSCI, 2008

⁵Expenditure on Social Care for Older People to 2026: projected financial implications of the Wanless Report, PSSRU 2006

EMILY'S DAUGHTER'S STORY

My mother, Emily, was diagnosed with Alzheimer's in 2004. I live just up the road and was on hand whenever she needed me. At first, I was keeping her company two or three times a day, getting meals ready and running errands. But as the dementia took hold, Mum needed more support and eventually she couldn't be left alone. She was confused, had hallucinations and was always anxious. It also made her aggressive and agitated, and this was always directed at me. But I also missed Mum – I felt that I had lost my relationship with her.

After Dad died, I had to battle for 18 months to get a 24-hour care package for Mum. She now needed constant care during the day, and when she woke in the night she would call me. It was exhausting. When the care package was put back in place, it meant that I could care for her because I wanted to – not because I had to. This greatly eased the burden on me and Mum became more settled in her routine. She became a little calmer and less anxious.

Then the local authority reviewed the care package in 2006, advising that they would withdraw it. They told us it had only ever been temporary and instead wanted to offer significantly less (five care worker visits of half an hour per day and one or two days' care). I battled for six months until it was finally agreed that the 24-hour care package would stay in place, but with only about half of the financial contribution from social services. So we had to find more money ourselves. They suggested that I ask my brothers and sisters to fund more and do more of the caring,

despite us already paying Mum's bills and helping with shopping.

We ended up with a £200 per week shortfall because the local authority's contribution decreased so much and we have had to take out a loan to cover the gaps in care and living costs. We were advised that our only other option was for residential care – but, if this was to be accessible for the family and a nice environment for Mum, we would still have to contribute money.

By January 2008 Mum's financial contribution had gone up again but there had been no reassessment of her. In March, all we had was two 15-minute chats and that was the annual review. Throughout this time I couldn't get through to anyone who would tell me what was supposed to happen. You don't have the time or energy to find the information and, when you have it, it's too difficult to understand. It's a constant battle to get and keep what is needed.

In all this time I was never asked if I needed any help or how I was coping with Mum, my family and work commitments. It was just assumed that I would, and could, do it all. The burden of coping has had such a huge impact on my own health and state of mind.

It seems like the local authority's main priority is to spend the lowest amount of money they can. Mum deserves more, as do all elderly people who (through no fault of their own) are not enjoying the remainder of their lives as they should, due to finances.

This individual has asked to remain anonymous

WE SAY

The stress of caring for someone who is very dependent can be overwhelming, as this story shows. All too often financial constraints mean that families have to battle to get the care they need and live in fear that it will be taken away from them.

The inadequacy of the current system means that many families are left picking up the pieces between themselves – to the detriment of their health and wealth. Too often, social services leave families to bear the responsibility of arranging and providing care. Families like this one should not be left to shoulder the burden in this way.

We want our care system to be clear and consistent, adequately funded to meet everyone's needs. People should not have to fight for what they are entitled to and financial constraints should not lead to vital help being taken away at a moment's notice.

A clear and consistent deal for paying for care would mean everyone would know where they stand – what they can expect and what is expected of them.

3. A SUPPORTIVE SYSTEM

‘We need a social care system which supports families and unpaid carers as an integral part of the system’

The current care system considers each person as a wholly separate individual, ignoring the vital networks of links with family and friends who depend on them and on whom they may depend, and who ultimately make us all who we are.

As a result, when care needs are identified, and the individual is considered for support, the existence of a family carer is taken into account only when their presence might reduce the individual's need for formal support. The carer's own needs are left to a separate assessment, which they may or may not be lucky enough to get.

Very few unpaid carers are judged eligible for services or support and too many are left fending for themselves, or find that they rely on piecemeal solutions to paper over the cracks, without thought for the long-term impact on the carers' own health, or other commitments.

The reality is that the formal care system would collapse without the care that is provided by families and friends. So our new care and support system should acknowledge that supporting these existing unpaid care networks is crucial.

Many carers are happy to care for their loved ones. But as a result of taking on these responsibilities they need help with other domestic or everyday tasks. Providing a small amount of domestic support to carers is cheaper for the local authority, but the outcome for everyone is better.

Focusing on the needs of the family unit as a whole makes it possible to consider the people with care needs *and* their carers – giving everyone an equal right to support to get on with their lives. Support could be provided to oil the existing machinery, as it were. Everyone in the family could continue caring for one another, without pressure to accept services, give up work, or go without support when it is needed.

⁶Valuing Carers: calculating the value of unpaid care, September 2007, Carers UK, ACE National and University of Leeds

⁷Census, 2001, Office for National Statistics

‘We haven’t got any support that I haven’t fought for, and I’m still fighting for more’

HELEN'S STORY



The economic value of the contribution made by family carers in the UK is a phenomenal £87 billion per year⁶

In the UK, 12 per cent of the adult population – almost 6 million people – provide unpaid care⁷

WE SAY

Helen's story is not an unusual one for family carers, whose dedication and care are taken for granted by social services departments. Her support for Matthew is accepted as a given, but it is not reinforced or stabilised by any intervention from social services. Not only that, but Helen has to fight for everything that Matthew is entitled to.

Helen's story also shows what effect reducing or changing services for the older or disabled person has on a family left to pick up the pieces. It makes it impossible to plan ahead or make arrangements. Carers are left with a crisis on their hands.

Helen has also had to put aside her own interests and priorities, and those of her family, in order to look after Matthew. Her needs and life chances are made second-rate by the existence of a system which carelessly piles more responsibility and stress on to family carers without consideration of *their* needs.

HELEN'S STORY



I have looked after my younger brother for the past 43 years. Matthew has Kid Syndrome, which means he is deaf, is becoming blind, and is unable to walk because his spine is crumbling. He needs help with all aspects of his life – everything has to be done for him.

Matthew can't cook or make a cup of tea, because if he burns himself he cannot stop bleeding. He has to bathe in water with oils and needs assisting in and out of the bath. His knees have splints on them because they act as his feet. He has recently been diagnosed with autism. I have cared for him my whole life. I've always lived with him, or close by after I got married. He lives down my street with Mum, who is now in her 70s and really frail herself. I have two sons of my own, who are 15 and 17.

It's been difficult caring for Matthew, but I wouldn't have it any other way. I do feel I've had to battle through everything for him, though. We haven't got any support that I haven't fought for, and I'm still fighting for more. We have such problems with social services accepting all of his needs, and they are very reluctant to put in place proper services for him. When he was younger, he went to special clubs after school, but as soon as he got older he wasn't

able to go any more. It seems like social workers are only concerned about the money it will cost to look after him properly, so their assessments only take into account his physical needs. This is really unfair because they're choosing not to take into account his total situation. It puts the strain on us.

After the social workers do their assessments, they've always said that it's up to the family to look after each other. It's assumed that we can drop everything to look after him. It feels like we're treated almost like slaves without any of our own rights. I go in at night to look after him sometimes, so I'm on call the whole time. Both me and Mum have had a Carer's Assessment, but we don't qualify for support. And Mum can't get Carer's Allowance because she's over 60.

Matthew's and Mum's lives revolve around what I can do for them. It's such a responsibility. I'm over there all the time, which means I can't have a full-time job. I used to be a hairdresser and work for Transport for London but, because I'm needed so often with Matthew, it became impossible for me to keep everything in the air all at once. We're totally broke now. I have hardly any money of my own.



4. A PREVENTATIVE SYSTEM

‘We need a social care system which reaches more people, at an earlier stage’

It is not known exactly how many people are struggling behind closed doors to manage everyday tasks. This could be because their needs are not high-level enough to qualify for care, or because they do not know what support is available.

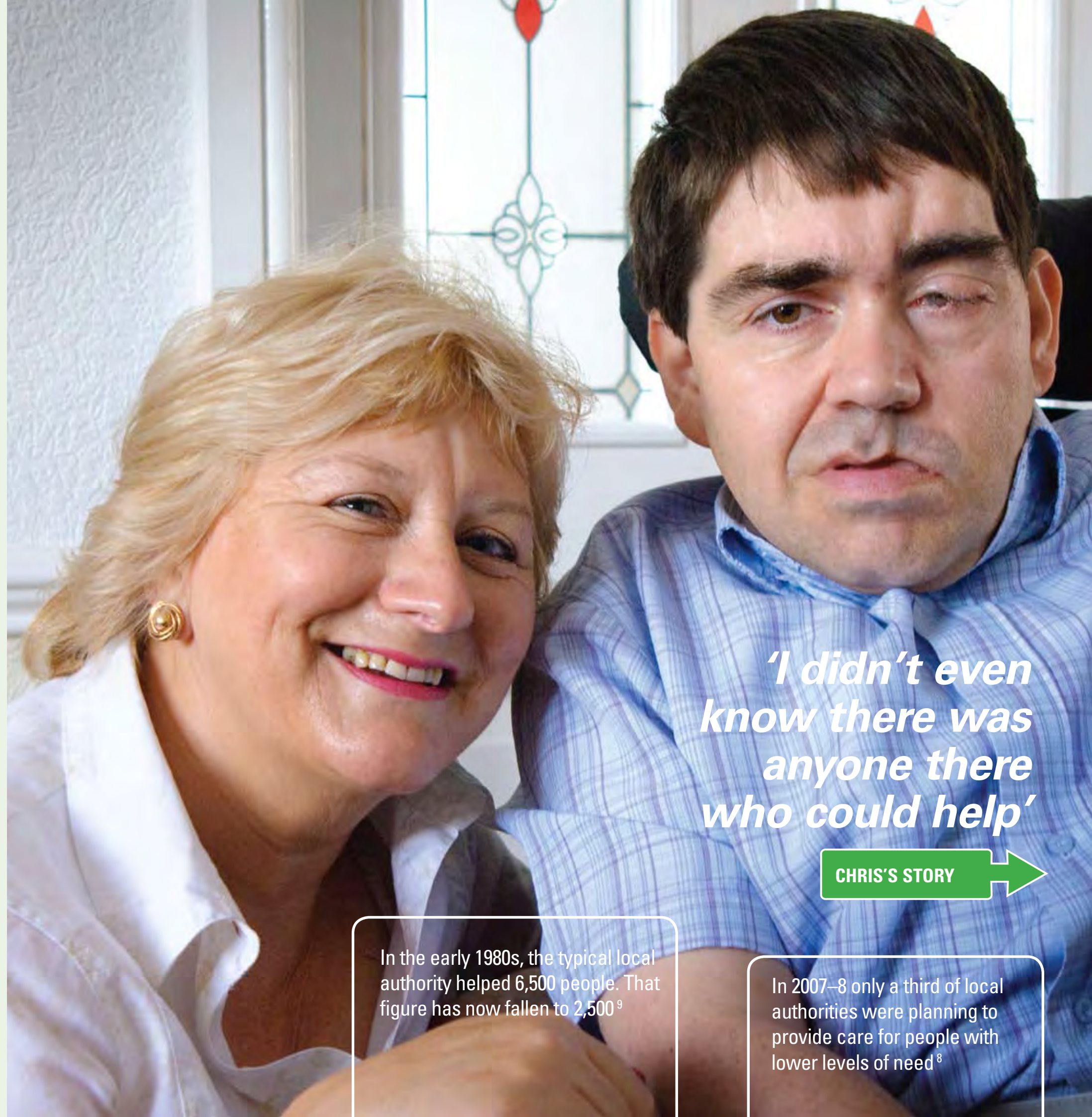
A care and support system that works well will be one which anticipates someone’s need before it gets severe. This does not have to be guesswork, but it means reading the signs that things are getting difficult for an individual and being flexible enough to respond to them. This is not just the responsibility of social care professionals, but everyone who has contact with older or disabled people in public, welfare or voluntary services.

In recent years there has been much talk of preventative and low-level support – for good reason. Many people do not qualify for social care currently because their needs are too low. Social care should not exclude. It should support when it is needed, but too often the care professionals have become gatekeepers, not enablers. The state may not always be able to provide services without charge, but it should always support and enable people to identify and meet their needs when the aim is maintaining independence.

At the very minimum, an entitlement to good local information and advice should be a right for everyone. Well informed, positive care decisions can then be made. This will benefit both the individual and the statutory services, which would otherwise have to pick up the pieces further down the line.

⁸*The State of Social Care in England 2006–7*, CSCI, 2008

⁹Evidence submitted to the Older People’s Inquiry into ‘That Bit of Help’, Joseph Rowntree Foundation 2006



‘I didn’t even know there was anyone there who could help’

CHRIS’S STORY

In the early 1980s, the typical local authority helped 6,500 people. That figure has now fallen to 2,500⁹

In 2007–8 only a third of local authorities were planning to provide care for people with lower levels of need⁸

CHRIS'S STORY



I am 60 years old. I have cared for my son Simon for 34 years. Simon was injured in a road accident at the age of seven – he's now 42. He has brain damage, epilepsy, is blind in one eye, and suffers from short-term memory loss.

I wash, dress, cook for and feed Simon, who spends most of his life in a wheelchair. These years have been really hard. They put a lot of pressure on the family. I have put so much energy into looking after Simon because he has needed so much, but of course my other son has needed attention as well.

When Simon had his accident, I was working as a sales assistant in Debenhams. I had to give that up because there was no option of flexible working at that time. As a result, I have missed out on years of employment and pension contributions. I'm sure that I have also missed out on benefits through not getting the right information and advice.

I feel completely let down by the powers that be. I have never had any support from social services. I would have liked advice on alleviating the strain in practical ways, like with managing Simon's incontinence. Pads are so expensive and I was constantly doing the laundry and changing sheets. A charity once gave me a grant for a washing machine and that was a great help.

Until very recently I didn't get any break from caring. I didn't even

know there was anyone there who could help. I just got used to managing day to day. I thought it was our problem and I worried about people intruding. But I do worry that Simon has missed out on things – things that he could have done without us. Then, in March 2008, this all changed.

Simon became extremely sick and was admitted into hospital. Since then, Carers UK have worked closely with me to make sure that I get full support from my local authority. I now receive two hours' help per day for personal care for Simon (morning and evening), as well as an additional ten hours per week for respite care. I will receive this via Direct Payments so that I can keep my independence.

This has made a great difference to our lives. It's brilliant to go from having nothing to having this help. I even have a laundry service to help with cleaning. They come and collect all our washing and I can get incontinence pads delivered. We might also be eligible for a grant to make adaptations to our house. If we get that, it means Simon will be able to have his own bedroom downstairs.

When I think of all the years we managed without help, I wouldn't say that I'm bitter. However, it's disappointing to think about what we missed out on and what Simon missed out on. I don't even know if the help would have been there if I'd needed it – how would I know?



WE SAY

It is not always possible to prevent disability or to delay the onset of old age and associated frailty, but it is possible to anticipate that difficulties may arise and to put in place care and support to help people before things get too bad.

Chris had to wait until her son Simon needed hospital care before she was able to access any help. No one should have to wait for a crisis before they get support. Chris lost out on many years of work and her future financial situation may well also be difficult because she did not make pension contributions. Her story shows that caring can have a lasting effect, and is not just about short-term sacrifices.

Many of Chris's problems could easily have been avoided with better support from social services. What she needed was some good-quality advice about what she was entitled to and where she could access support. The system is flawed because it expects people to approach for support, rather than be made aware that it exists.

However, Chris's story also shows us that giving people control over their situations can change the outlook.

With a more proactive approach to support provision, we could prevent so many more people reaching crisis point.

5. A FAIR SYSTEM

‘We need a social care system which offers individuals a fair, simple and consistent deal’

Social care is there to help people live a better life. It should expand their opportunities, not just manage their needs. This means that it should do more than simply provide the bare human essentials of food, warmth and cleanliness.

Those people who have complex care needs often have complex packages of support. They are designed to be comprehensive, but in practice are often erratic, confusing and chaotic. Reliable and trustworthy services are difficult to find, and when things go wrong individuals and their families are left high and dry.

Social care needs to be presented to people differently, in a simple, straightforward fashion. That way, people will know what care and support is, who can get it, how much it costs, and how to pay for it. Care and support should also be of high quality. Paid care workers should visit when they are asked to, and people should know that they can expect the same person to arrive every day. Social care should not be a mystery.

¹⁰GfK/NOP care survey for Help the Aged, January 2008

¹¹Securing Good Care for Older People: taking a long-term view, Wanless D., King's Fund 2006

In the UK in 2008, 45 per cent of people aged 65+ who were surveyed found the subject of social care for the elderly ‘confusing’¹⁰

80 per cent of people in need of home care do not get it from the state¹¹

‘Today was just the same as yesterday’

JENNIE'S STORY



JENNIE'S STORY



I am 66 years old and I live in my own home. After a long career as a nurse in Kent and London, I was medically retired in 1996 following a stroke. In 2004 I fell over and fractured my leg and then contracted MRSA whilst I was recovering. I do not think I received the care I should have done in hospital, and I actually fractured my leg again after another fall. All my current problems stem from mobility.

The care which I receive is the bare minimum. It meets my physical needs,

but nothing more. I am visited by care workers four times per day. It would be nice to have the same people so I can get to know them and so I know who's coming. With the good care workers, the care is good. But the others leave a lot to be desired.

It would be nice not to have to worry about using so much cash on indifferent care. People like me should have more say about the care they receive. That would be fairer.

MY DIARY

Monday A typical Monday. 9am, up and dressed by care workers as usual. Sat in my chair. After breakfast, watched some TV and read my book. Thinking about my holiday at the end of the month. 12pm, Sarah came to heat my ready-meal in the microwave and give me lunch. 5pm, Lorna made me a cup of coffee and emptied catheter bag. 7.45pm, put to bed. Each day I feel so isolated. One day, I might go out. It is so difficult to access a day centre – to pay for it and arrange transport to take me in my wheelchair.

Tuesday Today was just the same as yesterday. I tried to locate my dial-a-ride application form, but I need more help to do this and Rosie (who sometimes comes on a Tuesday afternoon) did not come. It was a really lonely day. TV is the only company. I tried to read but got so fed up when I could not concentrate properly.

Wednesday Same routine as usual. This afternoon, the lay reader from the church came and gave me Holy Communion. I was able to talk to him after the service. He has just been on a short holiday to North Wales. I do not feel physically ill, just very bored and fed up. I

am finding it hard to stay positive.

Thursday Tried to pass the time by reading, doing crossword puzzles, watching some TV and listening to the radio. Before I went to bed, I prayed – trying to get rid of my negativity. I feel very negative today.

Friday Just routine until 2pm when Rosie came. It was nice to see her. She washed my hair and then checked some of my equipment for going away.

Saturday Washed and dressed as usual and sat in my chair. Phoned a friend. Contacted care agency to find out who will be coming on Sunday, when Iwona is off for the day. As so often happens, the person in the office didn't know who was coming. They eventually rang me back, late afternoon. This extra hassle makes life tedious and does nothing to raise my spirits.

Sunday Washed and dressed, sat in chair. Watched some good TV and listened to my tape of local news and events. Tried to sort out in my mind what extra things I need to go away next week. Felt a little better today. But oh, how I would like to go out.

WE SAY

Jennie's heartbreaking story shows how far we have to go in creating a system which is fair, simple and consistent. The care she receives is low-quality and barely meets her physical needs, never mind her other needs,

Her difficulty in finding out who will visit her is a common problem experienced by many people. Care services often find it difficult to make sure that the same care workers visit every day, because their own staffing levels are unpredictable. Care workers carry out very intimate tasks, and it is undignified and unacceptable for care users not to know whom they can expect to carry out these tasks day to day.

Providing a care system that is fair, simple and consistent will mean more than just establishing a secure funding regime. It will mean ensuring that we can provide fairly for people's needs, offering services of a consistently high quality.

We cannot expect individuals to engage with the debate about the future of care when what they are being asked to buy into is of such low quality, so inconsistent and so hard to understand. We want a system that states clearly the minimum standards of care – with which everyone can expect to be provided – and makes clear our rights and responsibilities to each other.

6. AN ACCESSIBLE SYSTEM

‘We want a social care system which is easy to understand, access and use’

Our social care system was never meant to be confusing, but it is. It is far-reaching, in high demand, and expensive. Its interaction with healthcare is a legal and organisational minefield. As a result, it is perhaps not surprising that people fall down the gaps between services, and find it impossible to gain the support they need.

If we are to meet the increasing demand for care, we are going to have to get better at supporting people to find their way around the system. At the moment, many people never gain access to it because they do not know where to go for help. When they do access services, they are confused about what they should expect.

The new system must have a new, clear rulebook. People should be able to access care easily, understand what is available and know what their financial contribution will be. There must be freely available information, advice and advocacy to support those who need guidance to plan for the future – and to seek help when they begin to need practical support.

A recent poll, 81 per cent of respondents agreed that politicians must do more to inform people about social care for older people ¹²

1.5 million people in England have care and support needs that the state does not meet ¹³

‘We both wonder if life is worth the effort’

ALAN'S STORY

¹²Voting for Social Care survey, ICM for Help the Aged (unpublished) 2008

¹³The State of Social Care in England 2006–7, CSCI, 2008

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I am 63 and I have been caring for my wife Linda for the past 20 years. She is quadriplegic and has no movement in any part of her body except her head. She can speak but is totally deaf. She suffers heart disease, is diabetic, has severe epileptic seizures every three weeks and has had several strokes.

Twenty years ago, I gave up my career as an insurance agent to care for my wife and two small children. I was earning four times the amount which I now live off in benefits. I provide 24/7 care. At first, social services provided respite care, two days a week day care, and some help from a care nurse.

Then, in 2004, we came home from holiday to find a phone message from social services saying

that all the services had been cut off. Shortly afterwards, Linda had 17 weeks of hospital treatment because of her severe epileptic seizures. Because the nurses had trouble coping with her complex needs, they strongly recommended she should only be discharged with a full care package in place. She was discharged without the care package and she remains under my full-time care.

After a long battle to get more support, Linda now receives full NHS Continuing Care. She is entitled to respite care in a BUPA home four times per year, but this is not yet available. She also gets 1½ hours' care assistance night and morning, plus two nurses to bathe her once a week.



MY DIARY

Tuesday Took Lin to nursing home for four hours' care. I have to pay for this, even though it should be covered by the NHS. It's hard work loading the hoist into the vehicle, plus manoeuvring the wheelchair. All for a few hours' break, at what cost? We both wonder if life is worth the effort.

Wednesday Two district nurses bathed Lin at 11.30am. (I wish they would stick to a better time, but they say she is not a priority.) Went to town for three hours while our daughter looked after Lin and cooked us a meal. Feel tired.

Thursday Quite uneventful as usual. Lin in bed for half the day, then in recliner chair. Doctor visits and gives more antibiotics for chest infection.

Friday I want to go to my aunt's funeral, but there are no vacant beds at the BUPA home, the PCT couldn't help and I can't afford to employ someone. I do usual chores and tidy up.

Watched village carnival procession to brighten the day. Feel depressed and Lin feels a burden. This should not be.

Saturday After care worker had been, Lin did some reading in bed. Then she was changed, hoisted to wheelchair and taken to daughter's house. Care worker put Lin to bed, 9pm. Her chest infection is improving at last – it's seven weeks now. A lot of pain in my joints today.

Sunday Watched Wimbledon final with Lin. Cooked meals, fed and changed Lin, hoisted her to chair. I feel OK, but tired.

Monday Still no emergency respite care available from the PCT. Depressed and annoyed. The usual care worker failed to turn up at 9am. Rang office and another person was sent at 9.40am. Lin is in bed waiting for the doctor, reading with a cooking spatula in her mouth. Paid a lot of expensive bills.

WE SAY

Alan is typical of many unpaid carers who give up work, their social life and hobbies to care for someone they love, often at great personal cost. Many choose to do this, but others feel forced to undertake this work because they do not feel they have any other option.

Alan has found that the current system can be unreliable and hard to navigate. He describes the battle he has had to get support. He, like many others, has found himself caught between local authority provision and the NHS. He has never been kept informed of his family's options, where responsibilities lie or how to find support for Linda.

It is simply unacceptable that so many older and disabled people and their carers are left to seek out the information for themselves, without any help or support.

We need a system that reaches out to people, providing personalised help to find the way round it – with more support for those who would otherwise struggle. Making care more accessible to individuals means that they will have a better chance of knowing what they are entitled to. This knowledge gives individuals and carers power.



CONCLUSION

These challenging stories show the reality of our broken care system, where the issues of quality, choice and control are a million miles away.

Our challenge is to respond.

The Government has called for a wide-ranging debate on the future of care. This is not just a debate for care users, older people or practitioners. It is a debate for all of us as human beings – a debate about everyone’s future.

Each one of us has experiences, desires, hopes and dreams. But, as our report shows, there is little room for aspiration in our current system. We challenge anyone to read the six stories captured in this report and not be moved by the frustration, disappointment and loneliness that they describe. We challenge everyone to respond.

We in the Right Care Right Deal coalition believe that building a new care and support system is the biggest political challenge facing government in the 21st century.

But care is not just the business of government. It is everybody’s business.

Just as no person is an island and people operate in a complex network of support, the Government cannot change social care for the better without a network of support across authorities, communities, families and individuals.

Only radical action will help people like Alan, the sole carer for his quadriplegic wife for the past 20

years. Only real ambition to achieve improvement can help the isolated carer who feels she must take on the responsibility for looking after her mother who has Alzheimer’s, but also misses the love and support she once had from her. And only radical change can help Jennie, who faces boredom, isolation and loneliness every day with little chance of being able even to visit friends for a cup of tea.

None of us can shy away from the fact that delivering this change will cost money and that the existing funding mechanisms are not adequate for the job.

Any government fit for the 21st century must be prepared to make care funding a key priority, alongside schools and hospitals. Our political leaders must make clear their commitment to this vital agenda.

But we must also acknowledge our own part in the future of care and support. The system is part of all our futures – as taxpayers, as communities, as families and individuals. It is everybody’s business.

Play your part in shaping the future – go to www.rightcare.org.uk to make social care your business.

