



End the care crisis:
stories from people
affected by MS
in England



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Foreword

We know the social care system in England is in crisis. 1 in 3 people living with MS aren't getting the support they need with essential everyday activities like washing, dressing and eating. In this report, we move beyond the statistics. People affected by MS share what social care really means to them and their families.

Their diverse experiences demonstrate the transformative impact social care can have when delivered well - enabling people with MS to live full independent lives, to work, stay healthy and take pressure off the NHS. From Edith, whose support enables her to get to work each morning, to Martyn, who with the support of a carer, is able to do things others might take for granted, like go to the cinema.

The stories in this report also highlight the problems with a chronically underfunded social care system in crisis that is denying people the care they need, with devastating consequences. Take David, who survives on ready meals after his support was cut, or Angela, whose husband, her carer, is at breaking point. The system continues to fail them and it is totally unacceptable.

These stories are becoming all too familiar and commonplace. The experiences of people affected by MS shared here provide an undeniable imperative for action. The question of how we fund and deliver quality social care has been the subject of debate in this country for at least 20 years. We've seen more than 10 government consultations and reviews of social care in that time, yet political parties of all stripes have failed to make the difficult decisions on the back of these.

Now, the Government has promised to find a long-term sustainable solution and improve social care in England. None of us can afford



for this to be another missed opportunity. Too often, social care is thought of as something only older people need - you could be forgiven for assuming the Government thinks so too. But the reality is that people of all ages can need care and support. In fact, more than 280,000 working age disabled adults rely on social care, accounting for almost half of the social care budget.¹

The Government must tackle the difficult questions and make a commitment to fix social care in this parliament. There a clear moral imperative to act, as stories like David's and Angela's show all too clearly - but actually this is a win-win. We have growing evidence that fixing social care makes sense for other reasons as well. Reform would benefit our NHS in terms of reduced hospital stays and more efficient services. Our economy and society would gain from more disabled people and carers supported to stay in work and take part in their communities, as well as improved employment opportunities for the professionals who provide care.

Ultimately as one man who has MS, David, told us, "the conversation needs to be about people's quality of life." We must see a system fit for the future that enables all disabled people to lead independent, dignified and productive lives. The time to act is now.

Michelle Mitchell
Chief Executive, MS Society

About MS

Multiple sclerosis (MS) is a chronic, neurodegenerative condition for which there is currently no cure. In MS, the body's immune system attacks myelin, the protective cover around nerve fibres. Damage, which can occur anywhere in the central nervous system, interferes with messages travelling from the brain and spinal cord to other parts of the body. Symptoms are many and varied, but unique to each person. They can include problems with balance, vision, the bladder, bowel, speech, memory, fatigue and painful muscle spasms, among many other things. MS affects 89,000 people in England, many of whom experience their first symptoms during the peak of their working lives, in their 20s and 30s.

MS is both a fluctuating and progressive condition. While the progression and symptoms of MS vary from individual to individual, primary

progressive MS affects around 10 to 15% of people with MS. This is progressive from the very first symptoms. 85% of people with MS are initially diagnosed with relapsing forms of MS, where people have distinct attacks of symptoms with the underlying damage building up over time. Secondary progressive MS is a stage of MS which comes after relapsing remitting MS for many people. With this type of MS disability gets steadily worse, and relapses, when symptoms get worse but then get better, are no longer likely. The progressive and fluctuating nature of MS means person-centred, flexible care and support is particularly important.

About social care

Social care helps people who are in need of practical support due to illness, disability, or old age. Common forms of social care involve supporting people to carry out essential everyday tasks like getting out of bed, washing, dressing, and eating, in order to help them live an independent life. Social care support can also help people get out and about, to move into or stay in work and take part in their local communities.

Because social care is separate to medical care, it is not provided for free on the NHS. Local councils have responsibilities to provide certain social care services, however people



are expected to pay for care and support. Local councils will provide financial help and arrange services for those less able to pay.

Affected by MS and need support?

- › If you have MS and require care and support to complete activities in your daily life, you have a right to a social care needs assessment from your local council. This is where a social care professional talks to you about your needs and considers what kinds of support might help.
- › Having a needs assessment is your right regardless of your financial situation or the amount of support you may already receive from family or friends.
- › Similarly, if you care for someone with MS, you should be entitled to a carers' needs assessment.
- › You can find the contact details for the social services team in your local area by typing in your postcode here: <https://>

www.gov.uk/apply-needs-assessment-social-services

- › Find out more about your rights to support and how to access it in our booklet, **Social care: getting support from your council (England)**. Information resources for the other nations in the UK are also available on the MS Society website.

MS Helpline

Our MS Helpline provides emotional support and information to anyone living with MS. Please call 0808 800 8000 or email helpline@mssociety.org.uk to speak to our helpline team.



About this report

This report is based on eight interviews, capturing the experiences of people with MS and their carers aged 30-72 in England. Participants were identified and recruited by the MS Society, and interviews were conducted by The Focus Group. The interviews covered individuals' and carers' care and support needs, experience of services over time and the impact of receiving or not receiving social care on their lives. Individuals' stories are presented in this report in their own words.

This report builds on the findings of the MS Society survey, My MS My Needs 2, in 2016 - the largest survey of people with MS to date.

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Photography: Simon Hadley
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Introduction

In March 2017, we published *Social care and the MS Community in England*, the results of a 2016 survey which included more than 9,000 people with MS in England's experiences of care and support.ⁱⁱ We were able to compare these results with those of a similar survey we ran in 2013. Among the key findings were:

- A larger proportion of people reported needing care and support, but a smaller proportion reported getting the care they need.
- 1 in 3 people with MS reported they were not getting the support they needed.
- A higher proportion of people fully fund their own support while a smaller proportion receives local-authority funded support.

- Younger people with MS are less likely to be getting the support they need than older people with the condition.

These are very worrying trends and so we wanted to find out more about why people were not getting the right support, the impact that has on their lives, and what good care looks like and the difference it makes. We particularly wanted to highlight the experiences of people with MS under the age of 65. In this report, we explore the crisis in care through eight stories and three themes; being shut out of the system, the variable quality of care, and availability and choice of care.

The crisis in care: time for action

We welcome the Government's commitment in the Queen's Speech 2017 to 'work to improve social care and bring forward proposals for consultation to put the system on a more secure financial footing'.ⁱⁱⁱ

Change is urgently needed to create a sustainable system that can deal with increasing demand and complexity of need. The number of adults receiving social care support decreased by at least a quarter between 2009/10 and 2013/14, and it is likely that the trend has continued.^{iv} Currently at least 1.2 million older people and disabled people do not receive the care they need, a 48% increase since 2010.^v Meanwhile, 67% of councils reported provider closures in the first five months of this financial year and 48% reported homecare providers handing back contracts.^{vi} This situation has had an unacceptable impact

on the quality and availability of support for people with MS, as demonstrated through a number of the stories in this report.

Improving social care is about more than money, but simply won't be possible without it. Social care is chronically underfunded. By the end of this financial year, over £6 billion will have been taken out of the system in real terms since 2010.^{vii} Welcome investment of £2 billion over three years was made in the Budget in March 2017 but it doesn't fix the problem. There will be an estimated £2.5 billion funding gap in social care by 2019/20.^{viii}

While estimates of the funding gap do vary, there is consensus that social care funding remains inadequate. Any sustainable solution must increase the overall funding.

Solving the crisis: what we stand to gain

Investment in social care will bring economic and social returns. As at 2016/17 the adult social care sector was estimated to contribute £41.8 billion per annum to the English economy. That is almost three times the amount local authorities spent on social care in 2016/17.^x

There is an opportunity to create thousands more jobs in the care sector, if social care is put on a sustainable financial footing and a workforce strategy is implemented to address the ever-growing recruitment and retention challenge. In 2016, the number of people working in adult social care was estimated at 1.45 million, an increase of 19% since 2009, but vacancy rates are still too high.^{xi}

Such employment would also of course provide support to enable more people to maximise the quality of their lives and contribution to their communities. For instance, for some of the estimated 3.4 million disabled adults of working age that are in work in the UK, including Pam and Edith who feature in this report, social care support is a vital component in making work possible.^{xii} It only works when that care is both reliable and flexible, which requires decisions to be truly person-centred and local authorities being able to take a long-term view rather than being motivated by reducing spending as an imperative.

Providing relatively low-level, inexpensive support can prevent more costly care needs developing further down the line. For example, research demonstrates that people suffering from loneliness are more likely to have a higher incidence of falls, early entry into residential or nursing care and use of accident and emergency services independent of chronic illness.^{xiii} Too

often these opportunities for preventative care are missed.

Social care also plays a well-recognised role in keeping people out of hospital and enabling them to be safely discharged, reducing costs for the NHS. There were 26,679 emergency hospital admissions for people with MS in England in 2015/16, a 13% increase since 2013/14, costing the NHS £46m.^{xiv} More importantly, being admitted in an emergency or being delayed getting home from hospital is often a terrible, frustrating experience for people with MS. Yet, a large proportion of these admissions were for problems which could have been avoided with proactive, preventative care and earlier diagnosis and intervention in the community. The Government is rightly tackling delayed transfers of care at the discharge-end through the Better Care Fund (BCF). However, a sustainable system that prevents people from being unnecessarily admitted to hospital would be of much greater benefit to older and disabled people. It would certainly be more sustainable for the NHS than moving from one winter crisis to the next.

For example, a home adaptation significantly reduced Doug's - whose story is in this report - risk of falling in the shower and ending up in A&E. Not receiving the care you need or receiving poor quality care has clear health implications. For example, when Pam came home from hospital not all of her carers had been trained how to change her stoma bag, which could potentially have led to infection and a re-admission.

If social care is put on a sustainable financial footing and its potential economic and societal benefits realised, it would become a sector to be proud of rather than bemoan.

A system that works for everyone

Any proposed long-term solution to the social care crisis must take a whole system view. For more than 280,000 working age disabled adults, social care is the support they rely on for decades of their lives to lead independent, healthy lives. Yet, working age disabled adults are too often overlooked in the social care debate.

This does not make sense given 48% of spending on short and long term social care support is spent on supporting this group, totalling £6.83 billion in 2016/17.^{xv} This figure is expected to grow. It is forecast that by 2035 the number of adults aged under 65 years with an eligible care and support need will have increased by 35%.^{xvi} Already, the Association

of Directors of Adult Services (ADASS) 2017 survey found that meeting the needs of people with learning disabilities, physical disabilities or mental health needs combined accounted for a higher proportion of expected pressures on adult social care budgets in 2017 than those for older people.^{xvii}

Developing a long-term condition early in life, or being born with a disability, can make paying for care and support potentially expensive, difficult to manage, and hard to plan for. Any long-term sustainable funding solution for social care must take into account the particular circumstances of prospective social care users of all ages and how they are expected to change in the future.



Recommendations for the Government

- Government must commit to a long-term funding settlement for social care before the end of this Parliament, based on regular, independent forecasts of need.
- The £2 billion invested in social care in the Spring Budget 2017 must be made available to all local authorities in full for the stated purposes of supporting social care providers and funding care packages for more people, not only reducing delayed transfers of care from hospitals.
- Government must deliver further short-term investment in local authority adult social care to prevent services for disabled adults worsening or disappearing. An estimated additional £2.5 billion will be needed by 2019/20.
- Government must publish the national carers' strategy in 2017 to ensure improving support for carers is a priority across government departments.
- Address unmet need. More than 1.2 million adults do not currently receive the support they need with essential daily activities and this number is set to grow each year we continue with our current broken system.
- Improve support for the 6.5 million unpaid carers in the UK. This must include reducing waiting times for carers' assessments and making sure assessments lead to carers receiving the support they need to provide care, rather than just acknowledging it.

Provide local authorities the necessary resources to implement the full ambition of the Care Act's prevention duties in a meaningful way, so that people receive preventative support before reaching a point of more costly crisis.

- Review the Care Act eligibility criteria. These are currently too restrictive and exclude people with genuine needs for support, and could be rectified via secondary legislation to include people with lower level needs.
- Make the costs of care manageable for those that may have to pay. The Government should reform the charging system as follows:
 - Increase the means test threshold.
 - Equalise the minimum income guarantee for working age adults receiving home care with that of older adults, to ensure that working age adults have a sufficient amount of money to live off per week.
 - If the Government is considering implementing the cap on care costs, it should be a tapered cap (meaning a lower cap for younger adults who have had less opportunity to save) and not set so high that only a handful of individuals benefit from protection against catastrophic costs.

The Government must publish a full consultation on proposals for a sustainable care system by summer 2018. Additional funding and the forthcoming consultation should:

- Build a sustainable system for adults of all ages. The consultation must include within its scope working age disabled adults and carers, addressing their particular care and support needs and financial means, as well as those of older people.
- Put the social care provider market and care workforce on a sustainable footing. This is fundamental to ensure the availability and choice of quality provision appropriate for people with conditions like MS in local areas. It should also better enable local authorities and people with MS to procure flexible and reliable care that works around the needs of the person.

Recommendations for local authorities and health care professionals

- Improve information and advice services. As per the Care Act 2014, every local authority should maintain an accessible information and advice service. This should include support to manage a direct payment and advice and signposting to alternative sources of support for those who aren't eligible for social care.
- Improve the flexibility of support on offer. This should include offering people with MS the option of a direct payment and support to manage the responsibilities that entails. Social care recipients with fluctuating, progressive conditions like MS should have contingency funds within their personal budget so that they can access extra support if and when their needs suddenly increase for a period of time. This can help reduce unnecessary admissions to hospital.
- Ensure personalised care planning. As per the Care Act 2014, people with MS should have a written, co-produced care plan that captures their needs for care and support, the effect on their lives and the care & support that will be provided to meet their eligible needs. This must appropriately capture the fluctuating nature of MS and ensure that any family carers are properly supported.
- Ensure, in line with NICE Quality Standards for MS (2016), that people with MS have a single point of contact for their care, who coordinates care across a wider multidisciplinary team.

Recommendations for people affected by MS

- Know your rights. As the stories that follow demonstrate, understanding the support you are entitled to and fighting for it is unfortunately seen as essential by many people affected by MS.
- At the MS Society we will continue to fight together to ensure our recommendations are implemented. These would make it easier for people with MS to get the support they need in future. In the meantime, further information about your rights to support and how to access it can be found on page 7.



Angela, 35



Theme 1: Shut out of the system

“ Day to day the biggest challenge is my low energy levels. I’m mobile but fall from time to time. My speech is affected, I get brain fog, so I can’t think of words quickly. It is very frustrating and upsetting, because things you could have done before without a second thought, you no longer can.

I have two small children, 9 and 6. By the time I’ve gone to collect them from school, my energy is completely sapped. I really need support with the domestic tasks, like laundry and cleaning. Making the bed used to be easy, but now it tires me completely.

The first time I contacted the council, they told me they only help people who are in wheelchairs

We can’t afford to pay for support privately and have asked our local authority for help. The first time I contacted the council they told me ‘we don’t do that’. They asked ‘what is wrong with you? What is your condition? Are you mobile?’ They told me they only help people who are in wheelchairs, that if I needed support getting up the stairs then they could help me. When I said we wanted a carers’ assessment they said, ‘no, you don’t need to worry about that.’

It was very off-putting. Then I read on the MS Society website that carers are entitled by law to have a carers’ assessment, so I thought we

should try again. Sometimes I find it hard to find the right words or thoughts in my head and I find I get unsympathetic people on phone. Filling out any forms for the council is really stressful and I cry every time I have to do it, because I am forced to think about how MS affects me and how I have changed.

Eventually I got through to the council again and was told my husband could have a carers’ assessment. We have been waiting for about three months now and haven’t heard back.

My husband is at breaking point. I wonder, does he need to have a breakdown before we get support?

He works full time and there is more and more stuff that he has to do, looking after me, the kids and the house. He tends to not take as good care of himself, because he is taking care of everybody else.

With his new job, my husband will have to travel occasionally. I asked the council whether a carer could come in for a couple of nights occasionally and they said no, I would have to have one permanently. But I don’t need one permanently. It feels like you have to fight for every bit of everything that you get. You have to muddle your way through, do your best and find someone high up who is helpful

Angela’s experience demonstrates the missed opportunities for prevention within the social care system. A bit of practical support around the house would relieve Angela’s symptoms of fatigue and make caring more sustainable for her husband alongside his job.

There are an estimated 6.5 million unpaid carers in the UK providing care worth £132bn,

almost equivalent to the UK’s total health care annual spend.^{xviii} Without unpaid carers, the social care system would already have collapsed. In 2016, 85% of people with MS who needed care and support received unpaid care and support from a friend or family member, while 36% of people with MS who needed support told us they relied solely on unpaid care.^{xix}

”

David, 58



“ I was diagnosed with primary progressive MS in 1996. I remember being discharged from hospital and a social worker visiting me the same day to talk about the support I needed. He spent the time to understand what was important to me. It was quickly agreed that I would get six hours a week help at home with the domestic tasks I struggled with, cleaning and making meals.

I was assessed as having to pay a small amount towards my support and I actually felt quite good contributing something. For many years everything worked seamlessly.

Things changed in 2010. I was financially reassessed again and told me to contribute £48 a week – a massive jump from what I was paying before, which was just under £3 a week! I challenged the local authority, but I was getting so worried thinking about what I was going to do. They started billing me the higher amount and the debt was building up.

It got so bad that I would wake in the night with panic attacks. It got to the stage where I put a stop to my own care to make the stress go away.

From that point on, I just struggled alone. Fatigue is my biggest demon to cope with. It can quickly bring me to a grinding halt simply doing the housework. I get a lot of neuropathic pain in my arms. My fine mental dexterity is poor and I have a tremor. I struggle to prepare meals.

David's experience demonstrates how the current charging system can prevent or deter people from getting the support they need. David's was happy contributing towards the costs of his care, but his health and wellbeing have clearly suffered since those costs became unmanageable and he had to put a stop to his care. Our research shows that people who feel they are living really comfortably on their current income are more than twice as likely

It's risky for me to cut up food, pour hot water or use a hot stove. I rely on shop bought ready meals. I know I should be eating healthy, fresh food. I trained as a chef, I'm qualified to do it – but physically, I can't prepare it.

One of my friends kindly comes round once a week to do some hoovering and ironing.

My worry is there will come a point where my friend will no longer be able to help.

My only option then would be to pay someone, but financially that's probably unachievable.

I'm increasingly finding that my legs are starting to go on me after shorter distances. It's having an effect on my ability to have a social life. I'm not going out so much, I've started to become isolated. Fortunately for me I enjoy my own company, I have my own garden, but even that is getting more tiring. It's the simplest things that people take for granted.

I gave up work in 1996 and qualify for a full state pension. I know there is a crisis in social care and the Government have to look at a new system to make sure it's paid for. But for those of us who are part way through our working lives and have paid in, there needs to be some kind of transition.

The conversation needs to be about people's quality of life. ”

to have their care and support needs met that those who feel they are really struggling on their current income.^{xx}

It is also the case that since David first received social care, the eligibility criteria has become more restrictive, so that it would be more difficult today to qualify for the kind of support he once did.



Doug, 50

“

I came out of hospital last February with a 6-week re-ablement package of support. After 6 weeks I was told I was going to have to start paying for that support, so I said no, I can do it all myself. Within a few months though, I couldn't cope and had to get carers again.

I am only entitled to one half an hour care visit each day, but it actually takes over an hour for the carer to do everything they have to do it.

My regular carer goes above and beyond, she's spectacular. Apart from my sons, it's the only contact I have during the day, so it's nice that we do get along so well.

She stays for an hour, helps me dress every morning, empties all the catheter bottles, makes the bed and makes me a cup of tea before she goes. We spend the whole time talking and laughing.

When I think she is only being paid for half an hour with me it makes me cringe. If she does the same for other people it's probably a few hours a week that she's not getting paid for. She should get better paid for what she does. I tell her, don't make me a priority, get all the others done first. If she visits me last then she can stay longer.

When she isn't around and I have different carers and they are often too busy to spend the time with me. But overall, the carers really amaze me, they are actually caring people, they don't just do it for a pay check.

Sometimes I can do things for myself and other times I can't. One day it took me 10 minutes to get me from my chair to the wheelchair and so if you consider leaves 10 minutes to get washed, empty my catheter and make a cup of tea, a half hour call is just not realistic.

Theme 2: Variable quality of care

I'm still fighting for an hour visit in my care plan, but I'm very close to needing more help than that.

I can't reach my feet at all – if I stand up to use one of my catheter bottles and my shorts go too far down and get under my feet, I can take them off but I can't put them back on. I've had to spend the rest of the day in my underpants before.

I pay towards the cost of my care, it's as much as I can manage. The council have told me I won't have to pay any more than I do already, but the care company says that if I wanted any more I would have to pay for it. It makes me anxious not knowing.

My two boys are a major part of my support system.

They help around the house, help me get into the car and so on. I do bits myself, but when they come home they realise how difficult I'm finding it and they do things for me. The 18 year old does too much for me, but he is off to University in September. It will be very difficult

when he goes. My youngest son one will have to take on certain things.

I don't get any other support from social care. They have mentioned things like day centres, but it doesn't appeal to me. When I was in hospital I was taken to an activities room and I felt completely out of place, the youngest was the age of my father!

I had a wet room installed last December, which has made a huge difference. Previously there were times I fell in the shower and had to wait for my son to come home to help.

I got a disabled facilities grant to help pay for it.

There is a number I can call if I suddenly need extra help– if I have an accident. But it's not something I feel I can do. I don't like to ask for the help. It would be good if there was someone who would check in on me on the phone every now and then.

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Doug's experience shows the difference good care can make. Doug has a regular carer that he has a good relationship with. He also benefited from an adaptation to his home, making his bathroom safer and reducing the risk of his being admitted to hospital. These are examples of good practice where social care – and housing – promote a person's health and wellbeing.

But Doug's support system is precarious. It is only with the support of his young sons and regular carer going 'above and beyond' his care package that he is able to meet his basic

needs. He clearly requires more support, but instead he is having to fight to keep the care he already has which is wrong. Unfortunately, we know that some local authorities are restricting the amount of care they provide in response to national budget cuts. If the social care system was adequately funded, Doug would get the level of care he needs.

Fairer pay for professional carers like Doug's, with clearer plans for rewarding quality care and career progression, would mean more good people coming into, and staying in, the profession.



Paul, 72

“ My wife Lesley is quadriplegic and I am her full time carer. She can't use her hands so everything has to be done for her, she also has pressure sores and incontinence problems. The blessing is that she has all of her mental faculties. That is very important to me as her carer, because we can still chat and laugh.

We had paid carers about three years ago, but it was such a horrible experience that in the end we decided to cope on our own.

In the morning we didn't know when they were coming, it was unpredictable. District nurses visit daily to change the dressings on Lesley's pressure sores, which meant the carers couldn't do much in the way of washing her. It was poorly timed, so she wasn't getting washed properly.

They would come at 7pm in the evening to put her to bed. We would be sitting down watching television together then they'd turn up. Our quality of life went out the window.

The carers weren't what I would call professional. Lesley's first pressure sore was caused by a sling being positioned incorrectly, so it slipped and rubbed on the skin causing a sore. It's still there and that was three years ago.

They were there to do a job and they got on and did it, but the empathy wasn't there.

Lesley is extremely vulnerable and they treated it like 'we have to do this and do that and get on to the next one'. No real personal contact at all. I did feel sorry for the carers. They weren't

paid travelling time or expenses, yet they were hounded from pillar to post. They would keep getting phone calls telling them to move onto the next person. But ultimately, I felt sorry for Lesley, because the quality of care was not good.

I had a carers' assessment 4 or 5 years ago. They basically said you're doing fine, carry on. I spent an hour and a half going through an assessment and it was a waste of time.

It is a very isolating disease for many reasons. We don't go out socially and if I have to go out on my own to do some shopping, Lesley is incredibly vulnerable. If anyone got in, or there was a fire, she is extremely vulnerable.

There are so many problems that arise as a carer and how do you know who to talk to? There is a baffling array of people and when you get through you find they've gone on holiday! Having contact with a care coordinator could really help us.

MS being a progressive disease, what we need today is not what we'll need tomorrow or a few days ago. It's changing all the time. It sounds weird, but we are happy at the moment.

The big problem will be if something happens to me. Without me, she couldn't cope at home.

When I am ill Lesley just has to stay in bed until I am able. It would be lovely to have carers for those times. I've seen some of the care homes and I hope she never ends up there, but what can you do, she has to have that 24/7 care. ”

Paul and Lesley's experience demonstrates that unless care works around the person and is high quality, it doesn't fulfil its purpose. Social care is meant to enable people to live independent, meaningful lives, not restrict their ability to do so. People with MS and their families need care they can trust and rely on, which requires care

providers and local authorities to take a person-centred approach and a caring, well trained workforce.

Carers' assessments must lead to support. It is not right that Paul has to struggle to look after his wife's basic needs alone.

Martyn, 58

“ In 2008, overnight my MS just came on. The doctors thought I had done a muscle in my leg, but I found I actually had MS. I was a chauffeur for the BBC and taught disabled people how to use computers.

I didn't want to retire at 49, far from it, I loved working.

It's been challenging for me and for the family. It took me three years to accept the condition and three more to accept having a wheelchair. There are daily challenges, from going to the toilet to transferring from my wheelchair to a chair and the really bad spasms in my legs.

I receive direct payment from my local authority for care. A carer comes for an hour in the morning, gets me up, showered and makes me breakfast. He comes back for half an hour in the evening to get me ready for bed.

When the carers aren't here, Mandy my wife is my carer. But because she earns over £100 a week she doesn't get carers' allowance. I think that is wrong.

Before our home extension was built, I was sleeping on a hospital bed and didn't go upstairs for three years.

Mandy used to have to take me to a special facility to have a shower, which was hard work

Martyn's care enables him to live a meaningful life - to get out and about, spend time with his family and enjoy new experiences. He has an invaluable relationship with a regular carer that he trusts. The adaptation to his home meant he was able to sleep upstairs for the first time in three years, making a big difference to his quality of life.

But Martyn has had to battle to get to this point and is worried that his support might reduce in

for her. The extension created a downstairs bedroom and accessible bathroom which made a huge difference.

Nowadays, I enjoy going out with my carer, to the cinema and to restaurants, and with my family to visit our daughter at university. I also go to the local MS group every week. I have to have the carer with me everywhere I go in case I need the loo or anything. I've even done disabled sailing. They hoist me out the wheelchair and put me in the sailing boat!

I've got tremendous support, I feel like I've got a life. I have managed to battle to get that little bit extra support for going out, but it's hard, it feels like you are always battling.

My council is trying to reduce direct payments at the moment. They are umming and aahing with me about whether I need all the care I receive.

I am also in the process of changing care agency. I love my carer to pieces, he goes above and beyond, but I don't like the agency. When my regular carer has been ill, I have been left waiting until 12 in the afternoon and the agency never phoned to say that no one was coming. My regular carer and I have built a really good relationship, I will miss him. I've found another agency run by someone who has MS himself, so it's a case of third time lucky I hope.

The advice I would give is if you want to do something and you want a life you have just got to try and build it. ”

the future. Budget pressures have led some local authorities to look to reduce personal budgets as a means of making savings. 20% of local authorities in England plan to make savings in 2017/18 from reducing services or personal budgets. 46% of Directors of Adult Social Services said that the identified reductions to services will directly affect services for working age adults.^{xxi} Too often people with MS are unable to get the support they need to live a meaningful life.



Pam, 51

“ Five years ago I had an operation and was sent home with a care package.

I was delayed getting out of hospital, because I had to have a care package in place before they would let me out.

I have had carers ever since, two each morning and evening.

My son who lives with me has always been my carer and proud to be. When I first told him at the hospital that I was getting paid carers, he was 15. He said ‘does that mean I’m not your carer anymore?’ Neither of us wanted them – I wanted to stay independent –, but after a couple of weeks my son said, ‘they aren’t so bad, are they?’, because they did make an effort to talk to him and include him.

I work four days a week in an accounts department for a hotel.

The carers used to be very good about coming on time in the mornings, but now they are coming later and later, when they know I need to go be up for work.

If the carers are not here on time, then my son has to do everything, which is wrong. He’s 21 and he doesn’t want to have to provide personal care for me. Meanwhile my evening calls are getting earlier and earlier, which is not ideal either. I think I am younger than a lot of people the carers see, a lot are bed bound.

But at the end of the day I still have a life as well. I don’t want to put my nighty on at 7.30pm at night, especially in the summer.

They used to be more reliable. I used to be able to say on Monday it would be this person and Tuesday this person, but not anymore. I find that frustrating, because you used to get to know the carers.

Some of them are really nice, I can have a laugh and a joke with them. Others are so rigid they won't move an inch. One of them, I feel I can't say anything to her. It's bad enough that you have to have someone helping you -it's humiliation enough-, but it's very hard when you feel you're not allowed to say what you want and need.

With some of the carers I used to have, I was included in the conversations – they both had kids the same age as my son and we had a lot in common.

Now most of the time my two carers chat across me to one another. I feel like I'm taken out of the equation.

I know it's hard the job they do, I appreciate that, but I think that's very rude. It's just frustrating when you have two people in your own house just yapping away to each other and you're being ignored. I've gone out and burst into tears on occasion.

Training is another issue. I recently had another operation and have a stoma bag now.

When I came home from hospital, my carers didn't have the training to change the stoma bag and I can't change it myself.

The agency has now trained two of my regular carers, but I am still waiting for the others to be trained.

I am entitled to a call on a Sunday, but the problem is trying to fit it in with what the care agency can do. I wanted a slightly later call so I could have a lie in and still be up and ready for church late morning. The agency complained that it wasn't worth their while carers coming out to me, because they only had three calls in that area. So, my son has to help me get ready on a Sunday. I know I am not going to be able to have my calls at exactly when I want them, but more flexibility would be nice.

My situation would change drastically if, say, my son were to get a part time job. He cooks all the meals, I can't even butter a piece of bread or make a cup of tea. I don't know what would happen then. ”

Social care enables Pam to continue working. Without it, she wouldn't be able to get up, washed and ready each morning. But the increasing unreliability of her care is undermining her ability to do this.

Pam's experience demonstrates the importance of social care being person-centred and age-

appropriate. Younger adults should not be expected to go to bed early to fit into the system. Social care can be a very intimate experience, and accepting strangers into your home and putting trust in them is not always easy. The attitude and skills of the people providing care makes all the difference.



Janet, 55

“ Mike, my husband, was diagnosed with primary progressive MS in 2001. We managed without any social care to start with and then as Mike deteriorated we tried respite care, so I could take a break.

The nightmare is actually finding the right care. There is not even one bed suitable with people with a physical disability in our area.

The lack of appropriate respite places is appalling. Last time I went away, I didn't find out until the day before that Mike had actually got a place in the care home. The stress was just horrendous.

In the care home, Mike couldn't eat in the dining room because his wheelchair wouldn't fit under the tables. The staff had no experience of the catheter system he was using, so I still had to go in every day to change the catheter. The beds weren't adjustable, which was no good because Mike can't sit himself upright. There were no recliner chairs either, so he either sat in a wheelchair or in bed all day. They even forgot to feed him. Someone came to pick up the tray and just remarked 'oh, you haven't got one – you've not had any dinner.' They were always short staffed and as nice as the staff can be, it was just a totally inappropriate place for him. Two years ago, to try and get around the problem, we started having regular carers through social services. It's much easier to increase the amount of care Mike gets at home when I need to go away if you are 'on their books' than it is to try and arrange temporary support from scratch.

Mike now has a carer each morning and evening. Before we had the help I was really struggling. My father has recently had a brain haemorrhage so at the moment I am quite often rushing between them.

We did have to wait 8-9 months to get a suitable evening slot, as the only time they could offer us at first was 7pm. He doesn't want to go to bed at 7pm at night, to spend 12 hours

Theme 3: Availability and choice of care

in bed and not to spend any of the evening with me if I've been out all day.

We are lucky that most of the time there is one particular person who comes in the morning and they get on with Mike really well. It means I get a little lie in, because if it's somebody who doesn't know what they are doing, I will be called down. I've been told I've had a carers assessment about two years ago, but I didn't even know one was done, I've never had a copy! It was only when someone mentioned 'my carers assessment' that I asked 'what carers assessment?'

I'd like more flexibility in the system. If over a month we had even four extra hours of support we could draw on if and when we needed, it would mean I could go out during the day. I would like to go and spend the day at the seaside or have a night away with family every now and then.

But there isn't that flexibility. If Mike or I are ill, and we need extra support for a period, there is nobody.

No emergency system in place to cope with that scenario. For example, I had an operation on my foot just before Christmas and my leg was in plaster. Unfortunately, Mike got vomiting and diarrhoea. I had to change the bed three times

and in the end I had to leave him on the mattress with incontinence sheets. There wasn't anybody to call on. The regular carer came in the morning, didn't even take his coat off and didn't offer to help.

Having being a nurse, I am more clued up as to who does what and where.

But it is a constant fight to get the level of care and support that you want, which is tiring. If I wasn't here what would happen to Mike?

There should be somebody who is overseeing what is going on. You know, are the carers coming on time, are they doing what they are supposed to be doing, does he need to see a GP, does he need a referral back to the consultant and so on.

It is challenging knowing what support is out there. Most of what I've found out has been through other people affected by MS at the local MS Society branch. We both went on a holiday with our local group. It's good to talk to other people who are in similar situations and putting the world to rights over a coffee or gin and tonic! We both get a lot out of it.

”

Janet and Mike should not have to struggle to secure suitable respite care. It is vitally important that carers can take regular breaks to avoid carer breakdown. According to a survey by Carers UK, a quarter of carers (25%) said they hadn't had a day off from caring for more than five years. Common reasons carers say they struggling to take a break include replacement care for the person they support not being on offer (27%) or not being confident in the quality of care available (19%).^{xxii}

Social care should be responsive to changing needs and emergency situations, not leave unpaid carers like Janet to struggle alone. A good care plan should take account of the fluctuating nature of MS, including contingency plans for emergencies. If Janet and Mike had a dedicated care coordinator, the increased support they needed could have been arranged quickly during those periods of crisis and they would have felt less alone.

Edith, 30



“ My MS started worsening about five years ago. I moved back in with my parents and they became my full time carers, helping me every day to get dressed, get out of bed and ready for work. I can't get out of bed myself, overnight my legs really stiffen up and I can't move them at all in the morning.

I didn't want to be living with my parents forever, so I looked into moving into an accessible flat and getting carers. It was a very long, convoluted process.

It took nearly a year from the point of approaching social services to my care being in place.

I contacted social services. The financial assessment was really stressful. I didn't know if I would have to pay or not, because I work.

I couldn't find any information online about whether and how much of my employment income would count.

I was granted direct payments and then it felt like I was on my own – I had to find my own carers. I phoned the care agencies in my area and they were all full. It was suggested that I put adverts for carers up in local shops. I just couldn't believe that was the official process, that there was such a lack of structure and process to it. I'd bought a flat of my own and made the adaptations, but wasn't able to move in until I had carers which was so frustrating.

I didn't get a positive response from advertising.

I work four days a week as an accountant, so I need a carer at 7am every morning...

...to help me shower and that's not what people are looking for, they say 'oh I can help you on a Thursday afternoon' and that's not what I need. At one point it was suggested that I use my direct payments to pay my parents to care for me. Why would I move out and then pay my parents to come to look after me every day? It didn't make sense. The whole point was that I wanted to live independently.

I had similar trouble finding out if I could get an adjustable bed. I was eventually told social services could only provide a hospital bed. I was only 28, moving into my first flat - I didn't want a single bed, a hospital bed!

I was told no care agencies had availability, I felt completely lost.

worker asking 'what am I meant to do?' They said they'd tried everything and couldn't do anything more. If I didn't have my parents to support me what would they have done, keep me in hospital? There is no one person who oversees your care - you don't have one social worker who is helping you.

I got really frustrated and wrote to my MP. A few weeks later, I got a letter from social services telling me that a care agency with capacity had been found. Then things started happening quite quickly.

The care agency came round and met me, and started planning my care plan. I have been with them ever since. I have an hour long care visit every morning. My carers help me get up, get dressed, have breakfast, take my meds and

make me breakfast. In the evening the carers help me shower and put me to bed at about my normal bedtime.

The carers are all lovely people, I have a group of familiar faces that I recognise.

But there are limits to this flexibility. They often seem to be struggling for enough staff. I would like more flexibility so if I unexpectedly need extra care, I would be able to pay for it.

I would also like extra support with help around the house, changing the sheets, doing the laundry. My mum still does all my laundry. That's fine at the moment, but it's not really a long term plan. The carers can sometimes do those things, but only when they have the time. Even things like cutting my nails, I can't do that, so my mum does it. My carers aren't allowed to do it for me because of health and safety.

”



Without social care, Edith would not be able to live independently or continue to work. It should not have taken so long for Edith to get the right care. Local care markets should offer a variety of provision to meet the different needs of their populations. However, the ability of local authorities to meet their market shaping duties is being undermined by increasing numbers of

providers leaving the market and their limited ability to pay the true costs of providing care.

Personalisation of care must be meaningful; people who opt for a direct payment should be supported to find the right care for them if genuine choice and control is to be enabled.

Conclusion

These experiences of people with MS and their carers capture the diversity within the social care system in England. From the incredible difference social care makes to peoples' lives when delivered well, to the damage that is done when delivered badly or not at all.

Some people with MS, like David and Angela, are simply being shut out of the local authority social care system **(theme 1)** with no viable alternative. Our research shows that the proportion of people with MS receiving fully funded local authority care more than halved between 2013 and 2016.^{xxiii} High eligibility criteria and high costs of care prevent people accessing the support they need. This presents a missed opportunity to prevent, reduce and delay needs developing that are more costly to individuals and the state. Spend on prevention itself forms 6.3% of budgets this year, both a decrease as a proportion of budgets and a decrease in cash terms from the previous year.^{xxiv}

For those that do get into the system, they experience variable quality of care **(theme 2)**. Many like Martyn and Doug benefit from care that is truly caring, thanks to the hard-work and attitudes of their paid carers, though Doug worries that his carer is not paid fairly for what she does. They have both benefited from home adaptations grants, which have given them independence and security within their own homes. However, both feel that the care they currently receive is at threat of being reduced or limited in future. Indeed, many people in this report described trying to get the care they need as a 'battle', something one has to 'fight for'. Another common theme is social care failing to work around the person and their individual needs. This is prominent in Pam and Paul's stories, in which the inflexibility and unreliability of care prevents them getting the support they need.

A lack of available and appropriate care is a key challenge for others, like Edith and Janet **(theme 3)**. The fragile care market is failing to provide the care people need, due to the limited amount local authorities are able to pay care providers, increasing numbers of providers leaving the market and the recruitment and retention challenge in the care workforce.

The difference our recommendations would make

What is clear throughout these stories is the vital role family and unpaid carers play in supporting people with MS. Our 2016 research shows that 85% of people with MS report receiving unpaid care or support from a friend or family member, whereas in 2013 71% told us they received this type of support.^{xxv} If support for carers was improved, Angela's husband would have had a timely assessment that led to practical support or respite, enabling him to sustain his caring role.

Another common theme is people feeling lost in the system and not knowing who to turn to for reliable information and advice. Paul talks about the baffling array of people involved in his wife's care. Their experiences in the social care system would be improved if everyone with MS had a single point of contact for their care, who coordinates care across a wider multidisciplinary team. Janet refers to the challenge of knowing what kind of support is out there, while Angela was turned away on first inquiring about support. Their experiences would be improved if local authorities maintained a comprehensive, accessible information and advice service, and did not deter people from seeking support.

A sustainable funding solution for social care would make it more likely that Doug's local authority could offer him the increased care package he needs to meet his basic needs. He would not be left alone at home in vulnerable situations and would be offered support to combat social isolation, improving his health and wellbeing.

A reformed charging system that makes the cost of care more manageable and lower eligibility criteria would have enabled David to continue to receive the care he needs to eat healthily and maintain a clean, safe home.

Greater flexibility and choice around when and how care is delivered would enable Paul to take a break from caring for his wife, Lesley. Not being able to rely on or trust the quality of the support on offer meant they decided to struggle alone without support. Local authorities must offer that flexibility and commission support that enables it.

Edith would have been able to find paid carers to meet her needs more quickly and not have waited a year to live independently, if the care market were on a sustainable footing and the workforce recruitment and retention challenge addressed.

Time for action

The stories of Angela, David, Doug, Martyn, Pam, Paul, Janet and Edith show that social care can be a vital to removing the barriers to an independent life that disabled people and their carers so often face.

However, their experiences also demonstrate how often the system fails people with MS. It is simply unacceptable that in modern Britain people are forced to go without basic care because they can't find support that fits the life they want to live, they get exhausted fighting through an unresponsive system – or because they simply cannot afford it.

The difference quality care can make is clear. The benefits to an adequately funded, sustainable and quality care system are numerous. There is unanimous consensus across political parties, academic experts, Local Government, and third sector organisations that without urgent and sweeping action, the care system will continue to fail more and more people in the same ways. Not only are these stories heart-breaking in themselves, but to carry on like this just doesn't make sense. The longer we go on like this, the more we will store up problems for the healthcare system and for the economy.

This Government must urgently consider our recommendations and set out proposals to address the needs of all adults that need care and support. Government statements on the issue often give the impression that social care is exclusively for older people – yet half of social care spending is on those under 65 and the stories in this report demonstrate how crucial this support is to people of all ages.

We must see a full consultation published by the summer of 2018, setting out a sustainable path for younger and older people to get the care they need, when they need it.

▶ **The time to end the care crisis is now.**

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We're the MS Society. Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

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