CARE & SUPPORT ALLIANCE

# Portraits of care and support

**Stories of adult social care provided by members of the Care and Support Alliance**

The Care and Support Alliance (CSA) is a coalition of over 60 of England's leading charities, campaigning alongside the millions of older people, disabled people and their unpaid carers who deserve decent care.

For more information about any of these portraits, or if you wish to invite them to any engagement opportunities, please contact csa@nas.org.uk

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# Foreword

The Care and Support Alliance (CSA) Pen Portraits project was created to assist the Independent Commission on Adult Social Care, chaired by Baroness Louise Casey, to understand the real-life experiences of people who need, use, or provide care and support. Through these personal stories, we wanted to ensure that the breadth of lived experience within social care was seen and understood - not as abstract policy, but as daily reality.

These portraits reflect the diversity of individuals across England – including older people, disabled people, and unpaid carers – whose lives are directly shaped by the social care system. They are personal and reflective, offering insight into the individual beyond their diagnosis or care plan. Each story shines a light on what it truly means to live with, and to rely on, care and support.

The portraits reveal not only the challenges and barriers people face – such as gaps in provision, difficulties accessing services, or the emotional and financial pressures that too often accompany care – but also the positive difference that good care can make when it is available, personalised, appropriate, and consistent. They show what is possible when care works as it should, and what is lost when it does not.

By sharing these stories, we aim to highlight common themes across the system and demonstrate what needs to change. We believe that everyone deserves good care and support, and that reform must be shaped by the voices of those with lived and frontline experience. These Pen Portraits are an opportunity to make those voices seen, heard, and central to the case for change.

Championing the real-life, lived experiences of carers and care users is what we do at the Care and Support Alliance. We hope these portraits will inspire parliamentarians and policymakers to look beyond the statistics and see the people at the heart of social care, and to work with us to build a system that is fair, sustainable, and truly focused on people's lives.

Caroline Abrahams CBE, Charity Director at Age UK
Emily Holzhausen CBE, Director of Policy and Public Affairs at Carers UK
Jackie O'Sullivan, Executive Director of Strategy and Influence at Mencap
**Co-Chairs of the Care and Support Alliance**

# Andrew

## Andrew had a life-threatening aneurysm at the age of 41. Good social care helped him recover, re-learn to walk and regain his independence.

In 2017, Andrew's life was turned upside down when, at the age of 41 and just three years into marriage, he suffered a life-threatening aneurysm that led to a severe brain haemorrhage. The emergency surgery that followed required part of his skull to be removed, and for months he wore a protective helmet before a bespoke cranial plate could be fitted. The injury left him bedbound, barely able to speak, and fully dependent on others for his care.


When Andrew arrived at Leonard Cheshire's Agnes Court service in Banbury in May 2018, he was facing a long and uncertain road ahead. Social care was his lifeline, providing not just somewhere safe to live, but the skilled staff, structured rehabilitation, and emotional support that made recovery possible. He could not have managed alone, and his family could not have met his needs without specialist help.

Andrew's goal was clear from the start: to return home and live independently. With expert support from his physiotherapist Ewa and the wider care team, he began a carefully planned programme of therapy. Staff encouraged him to set realistic goals, celebrated his progress, and adapted their approach when he faced setbacks. The benefits of social care extended beyond physical rehabilitation — it provided emotional reassurance, daily structure, and a community that understood the challenges of brain injury.

His journey was not without personal loss. The breakdown of his marriage during recovery was a heavy blow, but social care staff provided continuity, stability, and encouragement at a time when his life outside the centre felt uncertain. They worked alongside his close-knit family, ensuring they were part of decision-making and could see the progress he was making.

Andrew's determination and the consistent support from Agnes Court produced extraordinary results. He progressed from standing with help, to walking with a frame, to completing a six-mile charity walk using a walker. He later learned to walk unaided and achieved a major personal milestone — walking independently into his former workplace. These moments were not just physical achievements; they were milestones in reclaiming his independence and identity.

By January 2023, Andrew had reached his ultimate goal, moving into his own home in his former hometown, close to family. Social care services supported his transition, ensuring he had the right adaptations, ongoing therapy, and community links to live safely and well. Today, Andrew lives independently, regularly attends the gym, volunteers weekly at the local food bank, and takes part in 5K, 7K, and 10K walking challenges.

Andrew continues to stay connected with Agnes Court, recently returning to make a generous donation to the physiotherapy team as a thank-you for their role in his recovery. He says the combination of expert care, encouragement, and a structured environment gave him the foundation to rebuild his life:

**"Without the care I received, I wouldn't be where I am today. They gave me the skills, the confidence, and the belief that I could live on my own again."**

**Looking ahead, Andrew is determined to maintain his health, continue challenging himself, and use his story to inspire others. His experience highlights the life-changing benefits of good social care: it can restore independence, rebuild confidence, and give people back control over their lives after catastrophic illness or injury.**

Andrew's real story was provided by Leonard Cheshire.

# Angela

## Angela cared for her husband, who has dementia, until he moved into a care home. As self-funders, they have had a lot of difficulty getting the right support.

Angela lives in north Nottinghamshire with her hearing dog Maggie, and previously, her husband, who has dementia and now lives in full-time residential care.

**"I love my husband dearly. He was generally easy-going, funny, and co-operative; he didn't deny his diagnosis, he understood the importance of maintaining his physical health, and enjoyed going out and about. From working full-time to becoming a carer in retirement was not what I expected, but I had no choice."**

Angela was a tax specialist in the steel industry for the last twenty years of her working life. Angela and Maggie's typical day always includes a walk or two, they visit Angela's husband several times a week, and go to the gym on Fridays. Angela also volunteers with the Nottinghamshire Wildlife Trust and Hearing Dogs for Deaf People.

When Angela's husband was first diagnosed with dementia, caring was not too difficult, but there was no ongoing NHS support for either of them. During the last twelve months Angela's husband was living at home, they employed someone to provide respite day-care, and then care workers to get him washed and dressed each morning. Angela found the care workers herself and the couple self-funded. They received no help with this and were not entitled to any financial support.

Prior to this they tried residential respite care but it was a disaster. They got incorrect, misleading information from both social services and the nursing home about managing his insulin injections and, as a result, they paid far too much. When Angela collected him, he cried all the way home.

**Angela swore not to take him there again, thinking that help at home would be the solution, but she found that "having care workers come into your home is exhausting, even though it generally worked well for us. I found that I still needed a break, so we tried residential respite care again."**

**This time, Angela's husband stayed in residential care. "I was so tired, distressed and alone; I was just not able to function any longer."**

Before her husband moved to residential care, Angela sometimes found herself having to call 999 for ambulance or police assistance as they did not have the support they needed at home and she was unaware of alternative support available. She said: "When you really need it, the help is just not there." Angela feels her husband could have stayed at home longer if they'd had the right support.

Angela says their biggest problem was the lack of any ongoing 'official' support. Her husband was discharged following his dementia diagnosis, which she describes as 'unbelievable'.

**"It felt like being 'dropped off a cliff', and it still angers and upsets me. We didn't need much support initially, but when more support was needed it was more difficult to find because there had been no ongoing 'official' contact of any kind, and I didn't understand or know my way around 'the system'."**

Now, Angela's husband has basic Funded Nursing Care (related only to his diabetes), nearly all of his pensions contribute to his nursing home fees, and the balance is paid by the County Council now that his savings have been depleted.

Angela says "it's probably too late now for us" but she would like to see:

- A dementia diagnosis getting the same level of NHS care and support as other life limiting and terminal illnesses
- All carers treated equally regardless of their education, social and financial status.
- Social services staff properly trained so they all provide the same accurate information.

**"Dementia has left us with a broken family. It has left me with anger and resentment that I didn't previously have. It has left me with sadness and guilt that I will have to live with always."**

Angela's real story was provided by Dementia Carers Count and edited by the CSA for clarity and conciseness.

# Brian and Marianne

## Brian has complex health needs including Alzheimer's, and requires care at home. His daughter and carer, Marianne, has had trouble getting Brian the right care.

Mortimer (better known by his second name, Brian) is 92 years old and lives in Ascot, in the same house he has lived in for over 40 years. He now shares this home with his daughter, Marianne, who has been his constant advocate and source of strength throughout his recent and complex health challenges.

Brian has late-onset Alzheimer's disease, aortic stenosis, coronary heart disease, and suspected Long Covid. His health declined dramatically after contracting Covid-19 in hospital in December 2022, leaving him with severe fatigue, limited mobility, and cognitive decline. Before this, Brian was frail but relatively stable; the infection marked a turning point.

Despite these challenges, Brian remains a gentle, cheerful man who enjoys simple pleasures including watching birds in the garden, spotting squirrels, and listening to nature. With support from a carer and a wheelchair, he occasionally ventures outside for brief interactions with neighbours and old friends.

Brian requires round-the-clock care. He currently has a live-in carer, supported by additional visits for personal care. Routine and familiarity are essential for his well-being; even minor changes in environment or care arrangements cause confusion and distress.

Residential care is unsuitable due to the increased risk of Covid reinfection. A noisy, unfamiliar environment would be overwhelming, and his extreme fatigue means even short conversations are exhausting. Brian is happiest and safest in his own home, where he feels secure and settled.

Brian's application for NHS Continuing Healthcare (CHC) funding was refused, with assessors ruling that his needs did not meet the threshold. Marianne found the process extremely challenging, requiring families to gather vast amounts of evidence, while the views of long-standing medical professionals were often disregarded.

The local authority initially proposed a minimal care package of four short daily visits, despite warnings from Marianne and care workers that Brian was unsafe to be left alone overnight, as he could no longer use a phone or alert pendant.

**Through persistent advocacy, Marianne secured a three-week trial of a live-in care package which worked well. However, the council later revealed they never intended to continue it long-term. When the trial ended, they offered to fund only up to the cost of the cheapest care home that could meet Brian's needs – an amount far below the actual cost of home care. That care home was later rated "not always safe" by the CQC and placed on special measures.**

Errors in funding calculations also led to an unlawful attempt to reclaim an overpayment in one lump sum, causing significant distress before being reversed.

Marianne has escalated the case to the Head of Adult Social Services, but the council maintains that avoiding Covid reinfection is a medical need beyond its remit, while still refusing to support a CHC appeal. At the time of writing, Marianne is pursuing joint funding to meet Brian's care needs.

**Brian can remain at home only because he tops up the council's contribution via direct payments. "It cannot be right to leave my father with an unmet need," Marianne says. "The process is bureaucratic and inhumane  decisions are made by panels who never meet the person and rely on assessors with no specialist knowledge of their conditions. The gap between local authority care packages and the high threshold for CHC funding leaves people like my father and families like ours fighting a broken system."**

Brian and Marianne's real story was provided by Dementia UK and edited by the CSA for clarity and conciseness.

# Bryony

## Bryony is a young adult with a learning disability and additional health needs. With the support of her parents and a Personal Assistant, Bryony lives with a degree of independence, which she values deeply.

Bryony is a young adult with a learning disability and additional health needs that affect her daily life. She receives Personal Independence Payment (PIP), Universal Credit, and relies on these benefits to cover the extra costs associated with her disability. With the support of her parents and a personal assistant, Bryony lives with a degree of independence - something she values deeply.

Bryony's social care package is central to her ability to manage her life safely and independently. It helps cover the cost of a support worker who accompanies her when she travels, as she cannot go out alone, and other additional expenses.

**Without social care provision, Bryony would have to rely entirely on her parents for financial and practical support. She describes her social care package as the difference between dependence and autonomy. "What matters most to me is being able to live my life without relying on my parents for everything."**

**"PIP gives me independence while keeping me safe in whatever I'm doing", she says. When her benefits are stable and her support worker is funded, Bryony can participate in daily life with confidence. She feels safer, more in control, and less reliant on her family. Talking with friends who also receive PIP has helped her feel less alone and more supported.**

However, Bryony found the PIP application process confusing and inaccessible. Her parents had to help her complete it, and she often didn't understand what was happening. The threat of losing PIP or having it restricted has made Bryony feel anxious and unsettled, and she worries about how proposed changes to how PIP is paid, (such as replacing cash payments with vouchers) will affect her social care support. She doesn't know whether her support worker will still be able to stay with her if things were to change with her package, and whether she'll be forced to give up the independence she's worked hard to build. She says: "I want to keep my independence and stay safe."

Bryony wants the government to talk about disabled people more positively and include them in decisions.

Bryony's real story was provided by Mencap and edited by the CSA for clarity and conciseness.

# Dennis

## Dennis is a wheelchair user with high support needs. He lives in local authority sheltered housing, but staff and services have been drastically reduced.

Dennis is a 91-year-old resident of a local authority run sheltered housing scheme in Luton. Dennis enjoys reading, occasionally watching television to keep up with current affairs, and attending church events twice a month. He also tries to visit the local community centre on Wednesdays. He is an activist too, advocating for older and disabled people's rights and dignity and campaigning against digital exclusion.

A former British Rail employee, Dennis first suffered a stroke around 15 years ago, uses a wheelchair and requires substantial daily care and support. He receives four double-handed care visits daily—at 6:30am, lunchtime between 12.30 and 1.45pm, between 4:30 and 5:00pm, and at 8:00pm. His care workers operate his hoist to help him in and out of bed, deliver personal care, carry out household tasks and prepare his meals. These visits are rigidly timed and often not long enough. Despite his request for a later bedtime he has been told that flexibility is not possible and 8pm is the latest visit that his care workers can do. This means that Dennis has to go to bed much earlier than he would like.

Dennis would love to be able to go out more but this freedom is limited by his care package, and if he is able to secure support to go out, he may miss his care visit and therefore not get the personal care that he depends on. He says "I would love to go to a Day Centre if they would accept me, but it's not being made possible for me at the moment".

The sheltered housing scheme where Dennis lives has one member of staff overlooking 40 flats over three blocks, whereas previously there was a dedicated member of staff just for his block of flats. He isn't getting the same support he did when he first moved there just after his stroke. Dennis says "unfortunately there are not the facilities here now that there were when I came. When the last warden retired, her post was downgraded to a sheltered housing assistant. We don't have any entertainment during the day at all now, because there is nobody to organise it". This has left a noticeable gap in social stimulation and community engagement for all residents.

Dennis is fortunate to have a devoted family who call and visit as frequently as they can, though they live some distance away so cannot provide day-to-day care and support. He values the continuity of care from familiar care workers though. Dennis says "one of my care workers has been with me for over 4 years, I have never had any problems with her – care workers should be valued more". He acknowledges that others are not as lucky and don't have that continuity. Still, he faces significant barriers: inflexible care schedules, care workers being unable to perform some vital healthcare tasks and a lack of overnight support to help when he feels uncomfortable in bed. Above all, Dennis is determined to maintain his independence. He is clear that he does not want to move into a care home, preferring to remain in his own flat where he can eat the food he enjoys and retain as much choice and control as possible over his daily life.

Dennis' real story was provided by Age UK and edited by the CSA for clarity and conciseness. Dennis' name has been changed for privacy.

# Donna and Simon

## Donna cares for her husband, Simon, who has Motor Neurone Disease. Donna describes the physical and emotional toll of caring for a loved one without formal support.

Donna lives in Manchester with her husband, Simon who has Motor Neurone Disease (MND) and was diagnosed in 2021. They had two children, Eliza who is 23 and Samuel, who sadly passed away in 2020 from Sudden Arrhythmic Death Syndrome at the age of 23.

Donna and Simon have shared a love of outdoor activities, including mountain walking, swimming, and Simon's passion for sports such as cycling, rugby, marathons, triathlons, and Ironman challenges. Since Simon's diagnosis, their lives have changed significantly, and Donna is now his main carer. She has stepped away from her career in modelling and television to focus on caring for Simon.

Donna provides full-time care for Simon, supporting him with daily activities, mobility, and managing his NIV (non-invasive ventilation) at night. She assists him with dressing, bathing, and moving safely around the home, as Simon's muscle weakness is progressing. They haven't got a stairlift yet, delaying the decision as Simon didn't want one. Now they really do need it as Simon is unable to come up or down the stairs on his own and needs Donna's help.

Donna rarely leaves Simon alone due to his risk of falls and increasing care needs. This limits her independence and contributes to exhaustion. She previously suffered a slipped disc and now experiences worsening back pain due to the physical demands of caring. She describes feeling physically and mentally drained, coping with both the ongoing grief of losing Samuel and the anticipatory grief of Simon's illness. Donna says "It's an honour to be there for him because we get on so well and we love each other so much, but it's also so very sad".

Donna acknowledges the emotional weight of her situation, describing it as "a pressure cooker." She has not yet had a carer's assessment, which could help identify practical and emotional support.

Donna and Simon have an excellent relationship with the Manchester MND Care Centre and other health professionals who have provided invaluable advice and interventions since his diagnosis. Simon has also volunteered to participate in MND research studies, which gives has given them both a sense of purpose and hope.

Donna is aware of St Ann's Hospice and its "Being You" service, which offers support for both patients and carers. She recognises the potential benefits but finds it emotionally difficult to make the first step.

Social isolation is a concern, and finding accessible activities and venues is becoming increasingly important as Simon transitions to wheelchair use. Donna wants to keep Simon comfortable, safe, and engaged in meaningful activities. She hopes for practical solutions like the stairlift and wheelchair-accessible venues to maintain quality of life.

**Donna's story highlights the emotional difficulty of asking for and accepting help, even when support services are available, as well as the challenge of balancing love, caring responsibility, and personal wellbeing.**

Donna and Simon's real story was provided by the MND Association and edited by the CSA for clarity and conciseness.

# Dorothy

## Dorothy cared for her husband, Melvin, who had a degenerative neurological condition, until he died in 2025. They had consistent trouble getting and maintaining appropriate care.

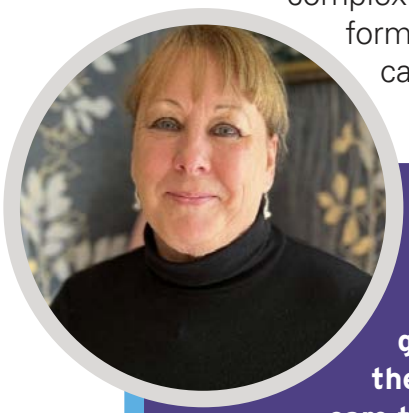
Dorothy cared for her husband, Melvin, for 17 years until he died in June 2025. Melvin had ataxia, a degenerative neurological condition which affected his movement, communication and ability to do daily tasks; Melvin's cognition was not affected. Dorothy says that, in spite of Melvin's condition, they had a great relationship, laughed together, and were always a strong team.

About seven years ago, Dorothy gave up her career as an occupational therapist, running her own business, to care for Melvin full-time. He could no longer be left alone safely, was experiencing frequent falls, and increasingly relied on Dorothy's help to move around.

**"He needed my care," she says, "that was it. I just couldn't leave him alone and I thought, I have to do this."**

As Melvin's needs increased in the last few years, Dorothy struggled with the care responsibilities. She said, "you don't realise how caring creeps up on you." As an example, Melvin used to be able to drink from a cup, then half a cup, then a special cup, then a straw, and then somebody needed to hold the cup to his lips to drink.

Melvin was referred to St Peter's Hospice, despite not being a terminal patient at the time. The hospice could not provide any support but did help Dorothy with an NHS Continuing Healthcare (CHC) funding application, which was incredibly complex and took a long time. They were eventually granted funding, in the form of 3x weekly visits to Melvin which provided Dorothy with respite care, allowing her to do household and admin tasks.



**Dorothy and Melvin continued to receive this support until the COVID-19 pandemic. Due to Melvin's condition, they had to shield and care support was paused as care workers could not guarantee they had been vaccinated or were infection free. Once they had both been vaccinated, Dorothy wanted to reinstate the care they have previously received. Dorothy was told that Melvin's needs had increased beyond the point that care workers could offer support. Because of this, Dorothy received no respite or care support for 5 years.**

Throughout this period, Melvin was frequently hospitalised. On one occasion the multi-disciplinary team (MDT) decided that it was safer for Melvin to return home, but this decision only came following up to three weeks of disagreement among professionals. Dorothy said it felt as if "they were fighting over him." During this time, Melvin contracted infections in hospital and Dorothy asked for him to be sent home. Melvin was discharged with a five-week package of care, but after that, Dorothy was left with full responsibility for his 24/7 care. She said following this hospitalisation "he'd already lost a lot of conditioning." Dorothy said that on multiple occasions decisions were made around discharge that were not appropriate for Melvin; on one occasion, Melvin had an unfit discharge and was re-admitted to hospital within 24 hours.

Even when Dorothy did have financial support, she found accessing appropriate care difficult. "When I had CHC funding, I still couldn't find a care agency to meet his needs. About 15 months ago, when he was in hospital, he had CHC funding – but they removed it and told me to go through social services. I said that he would get worse, he had a degenerative condition, and it would only get worse".

When Melvin was readmitted to hospital earlier this year, Dorothy faced a panel of five professional teams: Occupational Therapy, physio, CHC, social services and medical consultants. Dorothy says, "they said now that he's on End-of-Life care, you can have your NHS funded care back again. I asked what End of Life care was, what does that mean? Do we get the care that we haven't had in years?"

At this point, Dorothy and Melvin were granted 12 weeks of NHS-funded care. However, once again, no care agency had the capacity to meet Melvin's needs. A care agency conducted a three-hour assessment with Melvin, but following this Dorothy was informed that due to a shortage of care workers, the agency would not be able to provide any support.

When the 12-week funding period ended, Dorothy was told that they had reached the limit of the care provision. Dorothy said, "but I didn't actually get any care", but was told that her 12 weeks had nonetheless come to an end.

Shortly after this, Melvin was readmitted to hospital as an emergency. Dorothy was able to ensure that he came home, and Melvin died at home in June this year.

Dorothy was part of the campaign Carers UK ran to protect carers' rights during the passage of the Health and Care Act 2022. Dorothy campaigned with us by sharing her experience of her engagement with the NHS with MPs, Peers and Minister. As a result of this campaign, and carers like Dorothy sharing their experiences, the Government brought forward an amendment which placed statutory duties on the NHS to consult with carers when commissioning services, promote the involvement of carers where appropriate in relation to decisions about prevention, diagnosis, treatment and care, and in planning for hospital discharge.

Dorothy's real story was provided by Carers UK.

# Emma

**Emma, 38, uses a wheelchair. Social care has supported her to move out, live with her partner and lead an independent life.**

Emma is a 38-year-old wheelchair user who lives in Hucknall, Nottingham with her partner, Wes, and their foster dog. The couple have been together for 12 years and moved in together 3 years ago. Before moving in with Wes, Emma lived with her mum, who was her main carer.

Emma is passionate about music and enjoys going to gigs. She also loves socialising, playing bingo, and has a large collection of handbags. She used to DJ at the local pub and still enjoys being part of her local community. Emma is also an active campaigner, with a goal to get a zebra crossing installed in her area.

Social care plays a vital role in Emma's independence and quality of life. It enables her to live with Wes, pursue her interests, and avoid isolation. Without it, Emma says she would likely have to move back in with her mum and lose the independence she has fought for.

Emma has a Personal Assistant (PA) but has found finding the 'right' PA particularly difficult – it has caused a lot of stress and upset. Emma feels that her support package is not enough. She says that ideally, she would have 24-hour care. Gaps in care mean Emma relies on Wes to fill the gaps instead of having full independence. Emma feels this is unfair, as people who live with a partner are often penalised by the system.

Emma wants to work from home and be an active, valuable part of society. However, lack of adequate support makes this difficult. She believes that with the right care in place, she could achieve her employment goals and contribute more to her community.

Emma believes social care should be properly funded, and that everyone should have access to the care they need to live an independent life. She wants politicians to fight for people who rely on social care, because "we are on the backburner, and we are still members of society."

Emma's real story was provided by Leonard Cheshire and edited by the CSA for clarity and conciseness.

# Faiza

## Faiza is in her 70s and lives in East London. She is a lifelong carer, looking after family members with complex needs. Faiza also has her own health conditions and is disabled. Faiza has had to fight constantly for support to keep her family together and against discrimination.

"I am a disabled Muslim woman and a lifelong carer. I am what's known as a sandwich carer, currently supporting both my husband and my son. My caring role began in childhood. As a young girl with a talent for languages, I accompanied my mother to GP appointments from the age of five. I later cared for my sibling's emotional wellbeing when both our parents were hospitalised.

Today, I care for my son, who has autism, learning disabilities, sensory processing difficulties, and a life-threatening condition. I also care for my husband, who has multiple long-term conditions including autism, cognitive impairment, diabetes, stroke after-effects, and depression."

**"I have fought tirelessly not only to keep my family together, especially when the system questioned the value of my children due to their disabilities, but also to ensure they receive the care they need. I now live with multiple acute health conditions myself, including angina, and it's urgent that I put care arrangements in place for my loved ones for when I am no longer here.**

**My whole life has been caring. I've supported my family through a range of emotional, medical, and behavioural challenges. Now, as both my husband and son have complex needs, I continue to be their primary advocate and carer."**

"However, I am extremely concerned that neither has received the appropriate NHS Continuing Healthcare packages, largely because their sensory needs and autism are not fully understood or acknowledged by services. The situation is further complicated by behavioural needs that are often misinterpreted and labelled as violent, rather than being recognised as related to their conditions.

My own care package is working well at present. I have good care workers who help me manage my personal care. I am fortunate to have reliable care workers who support me with my needs. This consistency has made a significant difference to my ability to manage day to day."

"Despite the system, I continue to do everything I can to protect and support my family. I am always hopeful that things will get better and their quality of life could improve.

The biggest challenge I face is persistent state failures in safeguarding. My family and I have experienced disability discrimination, institutional neglect, and a lack of understanding from healthcare professionals. My own GP labelled me a fraud, removed vital medical conditions from my record, and cut off my access to work support, effectively ending the business I had started.

Mental health has also been used against me. I have been wrongly labelled as having Munchausen by proxy, despite caring for children who were under hospice care and managing adolescent mental health crises. This discrimination has damaged my self-esteem and left me financially vulnerable.

My son and husband remain without adequate care because professionals do not grasp the nature of their needs. Their behavioural expressions are criminalised rather than properly assessed, and the lack of proper support has left us in constant crisis.

**The toll on my health has been severe. I now have angina, and I believe I face early mortality due to the relentless battle with a system that fails disabled mothers. I've lost my business, my confidence has been shaken, and my mental health has suffered."**

**"My life revolves around advocating for others while getting little understanding or support from others in return. But I carry on because the stakes for my family are too high. I want the discrimination we face from state services to stop.**

My husband and son need support from the autism and learning disability social work team. I need a community care needs assessment for both of them and urgent recognition of their hidden needs, such as masking behaviours.

**More broadly, disabled carers like me must be valued and respected as part of the hidden workforce, saving the government billions of pounds. We should be treated with dignity and respect, not suspicion. I want to see my family supported properly and living with dignity and a good quality of life."**

Faiza's real story was provided by Age UK and edited by the CSA for clarity and conciseness. Faiza's name has been changed for privacy.

# Gareth

## Gareth is autistic and has a learning disability. He has a support worker at work but has struggled to navigate the care system and wishes communication and processes could be better and clearer.

Gareth is a thoughtful and creative young man who lives in London with his parents and brother. Diagnosed autistic at the age of five, Gareth also has a learning disability. Despite these challenges, he leads a largely independent life and takes pride in managing most aspects of his day-to-day routine without external support. Though he feels that he doesn't need a lot of support at home, he needs it when stressful situations arise, like when there are deadlines, computer issues and appointments or with managing emotions.

Gareth works with Mencap, where he is supported by a workplace support worker funded through Access to Work and Action on Disability. This support is crucial in helping him navigate meetings, understand complex information, and stay on top of tasks. Outside of work, Gareth enjoys reading, drawing, writing in his diary, listening to music, and going to the theatre when he can.

Gareth doesn't require extensive care, but the support he does receive is vital. His workplace support helps him feel confident and capable in a professional setting. However, he has faced challenges with the administrative side of care—particularly around communication and clarity. Confusing paperwork, unclear guidance, and inconsistent information have caused frustration for both Gareth and his family.

**"I want to live a life I can really feel proud of."**

Having a support worker at work has made a meaningful difference to Gareth's life. It allows him to engage more fully with his role, understand what's expected of him, and feel part of the team. This tailored support helps him manage information overload and stay organised.

Gareth has found the care system difficult to navigate. He describes the process of managing his support as overly complicated, with unclear communication and a lack of transparency. He feels that the people responsible for his care often fail to understand his needs or communicate in a way that works for him. This has led to feelings of frustration and being let down.

**"I don't need lots of support, but I do need the right kind of support."**

While Gareth's independence remains strong, the stress caused by poor communication and lack of clarity has affected his emotional wellbeing. He's particularly concerned about how to build emotional resilience—especially when navigating the world outside of work. He finds it difficult to cope with negative interactions and would welcome support in developing confidence and self-belief.

Gareth wants care providers to communicate more clearly and honestly, and to be patient and understanding. He believes that good support means recognising when someone isn't ready to take on new information or tasks, and adapting accordingly.

**He also dreams of living independently one day, but worries about the practical and emotional challenges this would bring such as managing bills, staying safe, and dealing with strangers. He'd like support to help him prepare for this step.**

Gareth's real story has been provided by Mencap. Gareth's name has been changed for privacy.

# Gillian and Anita

## Gillian cares for her adult daughter who is autistic and has a learning disability and needs round-the-clock care. Anita's care has been reduced to just one day each week and the family are experiencing serious financial pressure.

Gillian is 75 years old and lives with her husband and their daughter, Anita, who is 47 years old. Anita has a learning disability and is autistic, and has always required round-the-clock care. Gillian has been the main carer for Anita's entire adult life, because Anita needs a reliable routine in order to feel safe and secure each day. Since retirement, Gillian and her husband have found that their income has drastically reduced, and they rely on a modest pension to supplement the income of the whole household.

Anita only gets a small amount of support through her social care package. She used to get local authority funding to get help from support workers to get out into her local area for a few hours a week, as well as three days a week at a local day centre. These opportunities are the only chance that Anita has to get out and socialise with people outside of her home.

Since a recent reassessment of her care package in 2023, she has been told that she is now only entitled to financial support to attend the day centre once a week, even though her support needs have not changed. Anita previously had to contribute a small amount towards the cost of her social care package, which came from her Personal Independence Payments (PIP) and Universal Credit (UC), but because of the increasing cost of care, she is paying almost the same amount as she used to, but for less support.

Her benefit payments, alongside her parents' retirement income, are essential for the family to cover the essentials in the house, so the charges that they have to pay towards Anita's social care package make a huge impact on their ability to cover bills, food, and housing costs.

Anita gets a great sense of joy and stability from attending her local day centre, and although she is now only able to attend once a week, this still provides her parents with one day each week of respite from their caring duties. Normally outside her home, Anita finds it difficult to feel safe and make friends, but the local day centre makes her feel calm, is a part of her normal routine, and offers her an opportunity to get involved in stimulating activities.

Due to the family's cost of social care remaining roughly the same, but Anita having a reduction in her social care support, the family have found the financial burden of care increasingly difficult to manage. Anita is in the house more, and therefore costs for the household have gone up.

Gillian and her husband often have to make difficult decisions about whether they are able to heat the household or eat three meals a day. Gillian and her husband make sure that this impact is never felt by Anita, so they make sure that if they turn the central heating off, they keep one electric heater close to Anita and will all spend time together in one room. Similarly, if they are not able to afford enough food for all of the family to eat three meals each day, Gillian and her husband will skip meals to make sure that Anita can still eat three meals a day.

Other family members are worried about how much they have to go without essentials, like heating, particularly over the colder months, because keeping the house cold could lead to negative health impacts for everyone in the household.

Because Anita is in the house more often as a result of her reduced caring hours, Gillian and her husband have asked their local authority for help to fund exercise equipment so that Anita can do some exercise. The local authority refused this request, so the family instead had to purchase an exercise bike on finance and repay the costs (with interest) in instalments.

One of Gillian's main concerns is that as her and her husband get older, it is becoming harder to support Anita. The reduction of social care support and increased costs of care and living have led them to feel abandoned by the support system that should be there to help them during these difficult times. Gillian is concerned about what happens when they reach a time where she and her husband are no longer able to look after Anita, because support has already been reduced.

**Gillian feels that her family, and particularly Anita, have been let down by every system that is in place to support them. The care that Anita has accessed has been brilliant and she loves going to her day centre, but she is now getting less support than she used to. Because of the rising cost of food and energy, Gillian and her husband are unable to afford to pay more for Anita's social care. At the moment, the family are often not able to afford essential items for the household, so they are also unable to pay more for essential care for Anita.**

Gillian wants to see a social care system that is truly caring and affordable for everyone, regardless of their background. She also wants to see a system that will provide consistency and security for Anita so that Gillian and her husband can be sure that Anita can lead a fulfilling and safe life after they can no longer look after her. Gillian also believes that unpaid, family carers should be properly recognised and supported, because they provide a lifelong commitment to their loved ones and understand their specific, personal needs.

Gillian and Anita's real story was provided by Mencap. Gillian and Anita's names and some details have been changed for privacy.

# Holly

## Holly is a mother of four and full-time carer to three of her children who have complex needs. Their lives are shaped entirely around their children's needs, which are intensive, varied, and emotionally and physically demanding.

Holly, 39, is a mother of four and a full-time carer to three of her children - Kye (18), Freya (14), and Tommy (11) - who have complex disabilities and require round-the-clock support. She and her husband provide all care themselves. Their lives are shaped entirely around their children's needs, which are intensive, varied, and emotionally and physically demanding.

Kye has a learning disability, autism, and global developmental delay. He is unable to work, requires full personal care, and cannot go out alone. He receives Personal Independence Payment (PIP). The family also relies on Universal Credit, Child Benefit (for two children), and Carer's Allowance - though this is deducted from other benefits. This financial support is vital for therapies and activities unavailable through the NHS or social care but essential for the children's wellbeing. For example, one-to-one horse riding and swimming sessions help build strength, coordination, and confidence. Group activities are unsuitable due to sensory and behavioural challenges. With the right support, Holly's children thrive.

The family faces significant additional costs, including paying privately for respite care when needed - even for essential tasks like attending reviews or medical appointments - as they have no external support network. Despite legal assessments confirming her children's needs, Holly has struggled to secure local authority funding for therapies. "You can't get them to fund anything without hammering them in a tribunal," she told the Mirror newspaper as part of media work with Mencap, where she regularly shares her story to raise awareness.

Holly has growing anxiety about the future. Under proposed welfare reforms, her family could lose up to £400 a month, alongside her Carer's Allowance top-up of £83.30 per week. "They'd expect me to go back to work," she said, "but my children can't be left at home on their own." The emotional and financial strain is immense. Holly and her husband are stretched thin, both physically and mentally, trying to meet their children's needs while navigating a system that feels adversarial and inconsistent. The threat of losing vital benefits compounds the stress, while the lack of accessible NHS therapies forces the family to fund alternatives themselves.

Holly believes care assessments must reflect the full reality of families like hers – not just physical ability, but also the need for constant supervision, stability, and emotional support. She wants a system that recognises the complexity of caring for multiple disabled children and provides reliable, long-term help. Access to therapies through the NHS, fair benefit assessments, and respite options would make a transformative difference.

When asked what message she would send to the Prime Minister, Holly said: "Come and spend a day in our life, so you can see how broken everything is."

Holly's real story was provided by Mencap and edited by the CSA for clarity and conciseness.

# Ian

## For 25+ years, Ian lived in secure mental health hospitals. Ian now lives in a supported living home with FitzRoy which helps him be safe and independent.

For over 25 years, Ian lived in secure mental health hospitals. His life was shaped by constant supervision, institutional routines and high levels of risk management. But in February 2024, after an 18-month carefully planned transition, Ian moved into his own supported living home with FitzRoy.

**When Ian first joined FitzRoy, he needed 2:1 support 24/7. He never went out independently and relied heavily on staff for everyday tasks. But through patience, consistent support and building trust, Ian has started to take control of his life.**

After years in institutions, we are working with Ian to build his independence without triggering his anxiety or having a negative effect on his mental health.

Ian, who is now 56, goes out on his own every week for several hours. He keeps in touch with staff while he's out and checks in if he needs help.

Ian is thriving in his own home, which he proudly named Magpie's Den in honour of his favourite football team, Newcastle United. He answers his own front door, plans his own barbecues and has been on his first holiday in over 30 years - a week in Skegness that was so successful he's already planning his next trip away.

He has built a strong, loving relationship with his fiancée who he met while in hospital. FitzRoy has worked closely with her provider to support their relationship safely and respectfully.

**Ian has also reconnected with his local community. He holds a season ticket for Notts County, he plays 5-a-side football every week at Mansfield Football Club and loves joining in on the pub quiz afterwards. These ordinary pleasures – sport, relationships and routines – are the building blocks of his happiness.**

Ian still has challenges with his mental health. His self-harming - behaviour that previously led to frequent hospital admissions – has reduced significantly. FitzRoy has worked closely with clinicians and Ian to find safer ways of supporting him.

The team recognised that Ian needs something to continually look forward to, to be excited for and work towards. This is now a core element in his support, and there are always new and exciting things as well as some routine favourite comforts to look forward to.

Ian's journey is a testament to what personalised, properly-funded supported living can achieve. His support team has remained stable with nearly zero staff turnover - a rarity in social care.

The team uses regular reflective practice sessions with input from behavioural specialists to keep learning and adapting. Everyone involved - from clinicians to social workers to support staff - works together to ensure Ian's voice is heard and his needs are met. FitzRoy's specialist PBS team has worked closely with Ian's staff team to best support Ian on his journey to independence. Partnership working within social care is crucial to ensuring people like Ian receive the best support.

Ian is already planning his next holiday and looking ahead to the future with his fiancée. He has things to look forward to, a sense of purpose and the freedom to make choices. As Ian's support manager says: "We're not just helping Ian live safely - we're supporting him to live gloriously ordinary days."

Ian's real story was provided by FitzRoy.

# Jack

**Jack has a degenerative muscular condition and receives vital live-in care. His care budget was recently reduced by £400 per week. Jack has to fill this gap and worries he will never be able to save up for his future.**

I'm 32 years old. I have Spinal Muscular Atrophy, a neuromuscular condition which causes severe muscle weakness. I use an electric wheelchair and require personal care for most aspects of my life.

I live in Didsbury in South Manchester in a flat which I own. I employ a live-in personal carer who provides me with support so that I can live independently. I work full time as an internal auditor for a financial institution, so I spend my weekdays either in the office in central Manchester or working from home. Outside of work, I enjoy watching live sport, socialising with friends in person and virtually on the PlayStation, going to the cinema, all the typical activities that anyone with or without a disability would enjoy. I feel I currently have a good quality of life thanks to the social care I receive, and my aspirations are to continue living my life in the future with the same quality of life.

I receive an individualised budget from my local council to help fund my care. This is to cover 5 hours' worth of care during the day and sleeping overnight. This doesn't fully meet my care requirements, so I need to personally fund the rest of my care. I have a live-in carer meaning that they are available to provide support when I need it rather than in chunks of care. This is important as I require lots of small pieces of care during the day (e.g., getting a drink, switching on a light, scratching my head etc.). Assigning blocks of care during the day isn't practical to me as my needs can be unexpected and having the flexibility of care is fundamental to me being able to live an independent life.

There are many different aspects to the care I receive. There are the items you would expect to keep me safe and well, including support with washing, dressing, taking medication. Even more importantly, I am reliant on care to access the community. Without my carer I cannot leave the house, get driven to social activities, or access the workplace.

Accessing live-in care has brought significant improvements to my life. It has allowed me to participate in great experiences which have shaped my life up to now. This has included living away from home independently at university in St Andrews in Scotland, spending a year in Germany as part of my degree, and going on trips abroad.

I have generally been very lucky with the social care budget I have received, which supports me to live independently and employ care workers with whom I have built strong relationships. I was in receipt of broadly the same budget since I left home to go to university at the age of 18 up until I was 30 with annual assessments in place. However, my most recent care budget assessment, from 2024 resulted in a significant drop in budget, losing approximately £400 per week, which I am having to personally fund myself. This is difficult to understand since my condition has not improved over time (in fact my condition causes me to get weaker over time). It has become a significant financial strain on me to fund a large portion of my care, which other people my age without a disability wouldn't need to consider.

**Social care has delivered immeasurable improvements to my quality of life. It has allowed me to live my life the way I want to live it and allowed me to have a successful career and active social life.**

**The recent reduction to my budget has caused a lot of anxiety. I know that I will not be able to self-fund the difference eventually and I will be left with no choice but to limit my activities to align to my approved budget. This will only reduce my quality of life.**

I think there needs to be more flexibility in assessments for care budgets. They are not tailored to the individual and are not tailored for someone like me who doesn't do the same thing every day, doesn't access care in defined blocks of time. There is an expectation that I can package up my life into defined blocks of care, and anything outside of that cannot be accommodated by my budget, unless other items from my daily life are removed.

There is a misconception that reducing the amount of care increases my independence, but it does the exact opposite. I cannot leave the house without social care, and the reduction isolates me from society.

There is a lack of aspiration for people with disabilities, determining that seeing them survive is enough rather than thriving. For example, where I live a recipient of social care must fund all care if they hold savings of more than £23,000. If I can never have savings, it means I can never get a bungalow to live in, raise a family, prepare for retirement. It really concerns me for my future.

Jack has written his story himself on behalf of SMA UK.

# Janice

## Janice shares her experience of caring and supporting her mum in a care home at the end of life.

My mother passed away in December 2023. She was living in a care home with dementia and terminal cancer. Like many people, I assumed she would be cared for by staff trained to support her through her final months. Sadly, that wasn't the case.

Despite repeated requests, my mother was denied access to specialist palliative care. Even when her hospital team and I asked directly, the GP refused to refer her. To make things worse, her existing pain medication was withdrawn without our knowledge. In her final months, she was left with only paracetamol during the day and a small dose of codeine at night. It was clear she was in mental and physical pain but there was no proper plan to make her comfortable.

The staff in the dementia unit were kind but not equipped to deal with the symptoms of terminal illness. When my mother developed problems with mucus in her chest and throat, she spent long periods coughing and choking, sometimes unable to breathe properly. She was too frail to clear it herself and staff said that they were not trained in the techniques used to manage those symptoms, and this would have required admission to hospital. I often found myself trying to help her breathe because no one else was there to help her, and at times I felt that even basic care and comfort was not provided.

We asked for more intensive nursing but she could only receive a short daily visit from a community nurse. Moving her to the care home's nursing unit wasn't guaranteed, and there was even a risk she might be transferred far away from her family. We felt trapped by the lack of options.

**What hurt the most was not being able to be with her when she died. Staff kept telling us she was 'fine' and 'her usual self' right up until two days before she passed. They promised to call when the time came but the call never came. I will always regret that I lost my last chance to speak to her. Staff trained in palliative care would have recognised the signs of active dying and made sure her family were there with her at the end.**

**I do not think that anyone should have to end their life in that way. My mother was very strong and brave right up to the end. She never complained and was grateful for even the smallest act of kindness.**

The sight and sound of my mother's suffering was heartbreaking and very traumatising and will undoubtedly stay with me forever. Looking back, I believe the staff were doing their best but were under-resourced, and poorly trained for this kind of care.

Considering my experiences, I truly believe that national policy should be changed urgently so that all terminally ill people have a mandatory right to adequate, specialist palliative care or end of life care in whichever setting they feel is right for them. For me, good care would mean staff trained in specialist palliative and end of life care available in every care home, who can manage symptoms of terminal illness, with all families given clear, honest communication so they can be there when it matters most.

**No family should be left helpless, and no one should end their life in pain and without dignity. I have been left feeling eternally frustrated, helpless and very saddened – heartbroken even – that I was not able to help my beautiful, kind and courageous mother when she needed that help the most.**

Janice has written her story herself on behalf of Marie Curie.

# Kate

## Kate's dad didn't receive suitable social care at home before he died. This took a huge toll on him and the family.

My father was diagnosed with prostate cancer when he was very poorly. He made it clear he wanted to die at home. We promised him that, but it was a constant struggle to make it happen.

There was no clear coordination between hospital and community services. I was forever writing letters, chasing nurses and trying to find someone who would help. Too often it felt like the whole responsibility of arranging his care was left to us as a family.

**The practicalities were exhausting. Every time his catheter blocked, we had to take him to A&E because no one could deal with it at home. Each time, he sat for hours in pain. We even started bringing our own pillows so he could rest a little while we waited. It was heartbreaking to watch him suffer so unnecessarily.**

**Every week his trips to A&E became more frequent. Once, we arrived to find my dad so thirsty and completely dehydrated. For the first time ever he said, "I don't want to be here by myself", so I insisted on staying the night with him. Every time his catheter blocked it was like, "Here we go again." The whole trauma.**

We tried to set him up having care at home, we tried to say, "Look, why does he have to spend all this time waiting, distressed and in pain?". We got told that care at home would be sorted, but it never happened.

At home, we had to do everything ourselves - muddling through medication and setting up the room. Eventually, in his last week, we managed to get a hospital bed delivered so he could be downstairs.

I don't think Dad was ever comfortable, but he masked it. It was awful. I was struggling managing work and running to and from the hospital. Between me and my sister, one of us would always be there helping out.

We were fortunate that we had a family friend at the time who was a nurse. She stayed with dad because we didn't have any painkillers - we were just given the prescriptions, so me and my sister would drive huge distances late at night, completely exhausted, trying to find a chemist that could dispense the drugs. Nobody came out to deliver them or administer them or call in to the house or co-ordinate anything.

Dad needed a top up of pain medication as he was passing away. We could tell he was in agony. Luckily again, we had our nurse friend with us who was able to administer his pain relief into his syringe driver as we couldn't do this ourselves. We all stayed around him. We made the room comfortable with lights, candles and things and we just talked to him and played the classical music he liked until he passed away peacefully.

When my dad died, it was at home and not alone - exactly what he wanted. But it took everything out of us as a family to make that happen. We were fortunate, but many aren't.

**Dad's experience has shaped my own fears. I'm now living with stage 4 cancer myself. I know how much difference it makes when care is coordinated – I've seen it at specialist hospitals where the team talk to each other and everything runs smoothly. But I also know what it feels like when you're lost in the system, with no one taking responsibility. My experiences of end-of-life care so far are my biggest fear. I've told my husband: 'Do not let them take me to hospital alone. I need an advocate.'**

I also see the postcode lottery of care. My stepdaughter, who died during Covid, had a very different experience in another borough. She had a full palliative care team, with medication ready weeks before she needed it. For us, everything was a fight; for her, everything was prepared. That contrast says it all. It feels like nobody cares for you properly unless you're lucky enough to be in the right place. That's not how it should be.

My dad was passionate about improving care. Even while he was unwell, he drafted a job description for the kind of role he thought patients needed: someone who would coordinate services, communicate with families and make sure no one fell through the gaps. He believed it should never be left to families to fight for basic end-of-life support.

For me, good care would mean joined-up services, reliable community support, and someone to coordinate everything so families don't have to fight every step of the way.

Kate has written her story herself on behalf of Marie Curie.

# Keith, Paul and Sarah

## Paul and Sarah care for their autistic son, Keith. They have had difficulty getting appropriate, safe, reliable care and worry about what will happen when they can no longer care for Keith.

Keith, 36, is a non-verbal autistic adult with high support needs. Keith loves being outdoors – he will walk for hours in any weather. He likes being in water, swimming, spinning the wheels on toy cars, listening to songs from the eighties on the radio, looking at magazines and he loves eating crisps. Keith communicates through behaviour, actions and sounds. Care workers need to know him well to understand what he is trying to communicate. Routine is absolutely vital to Keith. He needs consistent care in a consistent location. During lockdown Keith was diagnosed with depression because his routine changed so much and he couldn't go outside.

Keith lives at home in Milton Keynes with his parents, Paul and Sarah, and his sister, who is diagnosed with Asperger's[1] and works full-time. Neither Paul nor Sarah work anymore - they are both full-time unpaid carers. Previously, Paul was a trained chef and worked in a computer shop. He stopped working when Keith was diagnosed with epilepsy at age 16. "I had to walk away. It wasn't a choice – my family came first." Sarah was a hairdresser.

As well as being autistic, Keith has epilepsy and IBS which contribute to complex needs that require 2:1 support. Despite this, only Sarah can claim Carer's Allowance. Paul does not receive any Carer's Allowance.

It took years of fighting to get suitable support for Keith. Initially they were given one night of respite a fortnight. When Paul and Sarah fought to get him day care, their respite was stopped. At the time, Paul would hide in his daughter's wardrobe to get a five-minute break.

When they received care through their local authority, Paul constantly felt like the council was trying to find reasons to withdraw Keith's support. He felt that staff weren't trained to support Keith, and said they would ignore suggestions from Paul and Sarah about the best ways to support him, which would lead to meltdowns and dangerous situations that could have been avoided. Paul and Sarah are constantly worried, always waiting for the phone to ring. Past incidents include solitary confinement, Keith running out in front of a car in distress, and Keith being dropped off by a taxi service (employed by the council to transport him) alone in the middle of the street.

[1] People who might previously have received this diagnosis now receive an autism diagnosis. Some people who were originally given this diagnosis still use the phrase and some don't. We have used the language people prefer when writing these pen portraits.

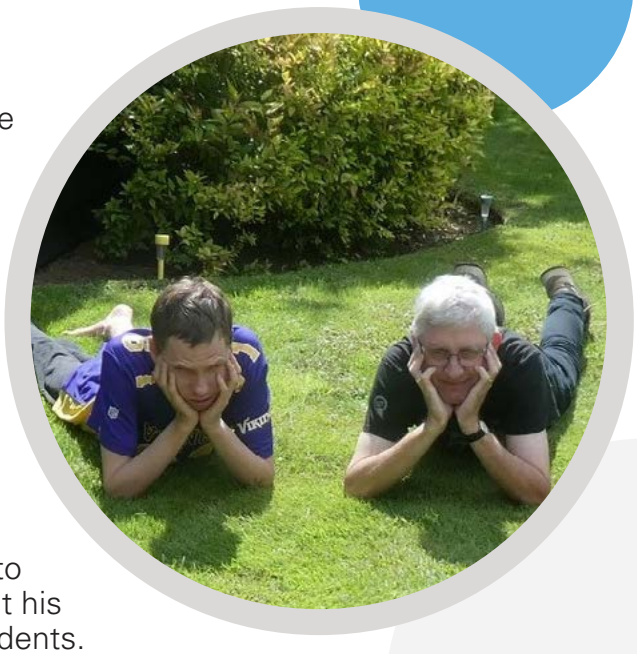
In 2022, the local authority withdrew Keith's day care support. They gave 2 weeks' notice, and did not issue anything in writing. The reason given was that they could not meet his needs. Paul submitted a Subject Access Request and discovered that the council had a meeting where they had decided Keith lacked mental capacity and would be better off in residential care instead of being transported to the day centre. This meeting was not minuted, and Paul and Sarah had not been informed about it. Paul and Sarah were very concerned about the impact this change would have on Keith's safety and happiness.

After services had been stopped in April, Paul and Sarah eventually found a new day centre for Keith to start going to in October. The withdrawal of support had already had a serious impact on Keith's wellbeing. Paul was told the local authority wouldn't provide transport to the day centre. Paul and Sarah hired legal support and said they would go to a judicial review if transport was not provided. At the last minute, the council agreed to provide transport so Keith could attend the new day centre.

The local authority told Paul that Keith could get more care if they moved to NHS Continuing Healthcare (CHC) funding. A few days after Keith started at the new day centre, the local authority moved him to CHC funding, but Keith's respite care decreased from seven nights a month to just five.

Over time, Paul has become ill. He was diagnosed with Type 2 diabetes, and had two heart attacks during two particularly stressful periods – one while challenging an incorrect care bill via the ombudsman, and the other when they were fighting to get respite care. Paul lost a significant amount of weight, to the concern of people around him. He says "There was a day when we were interrogated by council staff – it's all on tape. I looked so unwell they wanted to call me an ambulance, but I said no – I'm not going anywhere until Keith's care is sorted out. It was a nightmare. I wouldn't put my worst enemy through it." He puts Keith's care before everything else – he doesn't have a choice. Paul needs multiple surgeries which he has had to delay because he can't afford to be out of action for the recovery period. When Keith received local authority care, they had an emergency plan in place for if Paul or Sarah became suddenly ill (for example, if Paul had another heart attack), which was reassuring. Now Keith's care is CHC-funded, there is no such plan in place, which worries Paul and Sarah. Paul worries that if he is honest about his health problems in his carer's assessment, it might be used against him as a reason to put Keith into full-time residential care, which Paul believes would be hugely detrimental.

**Paul says "Being a carer is stressful enough, but the hardest thing is having to constantly fight for every little bit of support for your family. Because they're not listening to you." Paul describes hiring lawyers, challenging decisions via the Local Government Ombudsman five separate times, and providing masses of paperwork to prove their need for support. The mental toll on Paul has been considerable. He says "I've felt like a failure. I thought I'd let him down when the services ended. I blamed myself."**



Now, Keith's care is fully funded through CHC. He goes to a day centre five days a week and gets five nights of respite care each month. This care allows Paul and Sarah to rest, take care of themselves, spend time together and with their daughter, who they also support. Paul also spends time campaigning and sharing his experiences on a voluntary basis, trying to get better support for unpaid carers and disabled people who need care.

Currently, Keith enjoys going to the day centre, and the care is mostly good. Keith runs out of the house to get on the bus that transports him to the centre, he fits in, the staff are trained to meet his needs, and they notify Paul and Sarah of any incidents. Paul describes it as 'needs-led'. There was a bad accident at the centre where Keith was badly scalded in the shower and staff did not call 999 (which they should have given the severity). Several members of staff lost their jobs. Because Keith was enjoying being there and there weren't any other suitable care facilities in the area that could meet his needs, Paul and Sarah felt they had no choice but to continue sending Keith to the centre. There haven't been any similar incidents since.

**Paul says in an ideal world, the many barriers to getting care and support and related benefits would be removed. There would be better training and understanding for people with complex needs. Paul would like Keith to get the full support he needs from staff who are trained to meet all his needs. Paul would also like his daughter to get the right support "especially when we're no longer here. I know Keith will be in full-time residential care, and my daughter will need assisted living."**

**If they were properly supported now, Paul and Sarah's first priority would be getting themselves well, including having postponed surgeries, and then they might even be able to start working again. Paul is turning sixty this year. He hopes that one day he and Sarah might be able to go on holiday, and get a good night's sleep. "I'd like to be able to do the things that sixty-year-olds do: go out, and spend some time with my wife."**

Paul says unpaid caring should be recognised as a job. He also thinks Carer's Allowance should have different rates that reflect the level of care you provide. "I just want to make a difference. And I don't think that will happen until the people making the decisions are involving people with lived experience. That's the key. And not just as a box-ticking exercise. Too often people – who might be going through even worse than I am – just aren't heard."

Keith, Paul and Sarah's real story was provided by the National Autistic Society. Paul is happy to be contacted to discuss their experiences further. Contact csa@nas.org.uk for Paul's details.

# Martin

**Martin is registered blind, and has a learning disability and anxiety. He has flourished following his move to a Sense supported living bungalow. He no longer displays challenging behaviour and is able to leave the house and participate in the community after years of isolation.**

Martin is 55 years old. He is registered blind and has a learning disability and anxiety.

Martin lived in a residential care home for 16 years before moving to a Sense supported living bungalow. His previous home was not meeting his needs: Martin showed behaviours that challenged and was fearful of the world outside. He would lash out at staff because he could not process his environment, which was not explained to him. Everyday tasks, such as eating, became stressful experiences. He was on multiple medications and spent much of his time alone, monitored by staff.

When Sense staff first visited Martin, he was pacing up and down by himself. The staff monitoring him changed every hour, but no one was actively engaging with him. Martin had not been outdoors for 16 years.

Moving to the Sense bungalow required careful planning. Over six months, Martin gradually built trusting relationships with his support staff. He has now been living in his bungalow for 10 years. He receives 24 hour sleep-in care with 2:1 support during the day to access community activities (this has been reduced from 6 hours per day to 4.5 hours).

**Martin thrives on routine and understanding what is happening around him, which allows him to process experiences positively. During his first months in the bungalow, he experienced many "firsts," such as going into the garden and answering his front door. He was initially nervous about going outside, so staff supported him gradually.**

As Martin enjoys cups of tea, staff used this as a motivating activity to help him engage with his environment. The fridge was moved next to the back door so he could make a cup of tea while observing the garden. Then an armchair was placed near the door, allowing him to enjoy his tea while looking outside. Finally, a table and chairs were added to the garden, and Martin gradually began enjoying his tea outdoors.

Martin's next milestone was venturing into the community. It took two and a half years for him to walk down the road to his local shop to buy a drink and a packet of crisps.

Music is a key interest for Martin. When he first received his mobility vehicle, he would sit on the driveway listening to music to get used to it. He now confidently uses the car to attend a day centre in Rotherham.

**A typical day for Martin now includes visits to his local leisure centre for the sauna, gym, and swimming pool or attending the day centre to play drums. He enjoys shopping and eating fish and chips on Fridays. Martin also maintains regular contact with friends, his mum, and sister. His next milestone is to go away for an overnight trip.**

**Martin is supported by a longstanding, stable staff team who know him well. He no longer displays behaviours that challenge and is a happy, sociable man.**

The main challenge is outdated social care records. Martin's files still describe him as demonstrating behaviours that challenge, leading some professionals to assume he requires medication, sedation, or restraint. These records do not reflect his progress over time.

Medication reviews are slow because there is only one learning disability liaison nurse covering the area. Martin does not have a dedicated social worker and therefore lacks a professional in statutory services with whom he has a built relationship.

Local authority reviews tend to focus on reducing support rather than celebrating progress. For example, Martin's daytime support has been reduced from six hours to 4.5 hours, despite his increased independence.

What's Working Well

- A stable, longstanding staff team provides consistent, person-centred care.
- Gradual, structured exposure to new experiences has allowed Martin to grow in confidence and independence.
- Opportunities for social engagement, hobbies, and meaningful community participation have significantly enhanced his quality of life.

Martin's story demonstrates the transformative effect of high-quality social care. From a person isolated and fearful of the world, he has grown into a confident, happy, and sociable individual, engaging fully with his home, community, and personal interests.

Martin's real story was provided by Sense and edited by the CSA for clarity and conciseness. More about Martin's story can be found here: Giving Martin the keys to open up his world.

# Mary

## Mary uses a wheelchair and lives in an assisted living home. Services have been reduced from when she first moved in, to the extent she has to employ two carers privately. She doesn't receive any financial help and has to cut back on other things.

Mary is 87 and lives alone in Bournemouth in what is formally described as an "extra care facility," although she feels it no longer lives up to that name. A lifelong disabled woman, Mary was born with only one kidney, which became diseased in her twenties. She now uses a wheelchair and rarely leaves her flat.

Seven years ago, when Mary moved into the facility, it was well-managed and appropriately staffed, with an on-site warden, two care workers during the day, and one at night. However, since a change in ownership, support has significantly declined. There is no longer a warden, and just one care who performs a single morning "wellness check" which Mary describes as little more than a daily check to see if residents are still alive. As a result, she privately employs two care workers, Jolanta and Ula, whom she deeply values. They assist with every aspect of her daily life from bathing and cooking to cleaning and laundry. Friends also support her by bringing food and preparing meals.

Mary's two adult sons live abroad, so much of her social connection comes through regular FaceTime chats, letters, and visits from friends. A keen cryptic crossword enthusiast, she also enjoys writing to her circle and playing games on her iPad - particularly Angry Birds 2.

Despite her independence of spirit, Mary is finding it increasingly difficult to manage the financial and bureaucratic burdens of later life. "I struggle with the cost of everything going up and up," she says. "I can't do without my care workers, so I will need to cut back in other places."

Mary has not applied for government benefits before but mounting financial pressures and rising living costs have prompted her to explore what support she may be entitled to. Unfortunately, her attempts to access help have been met with limited assistance and overwhelming bureaucracy including a 24-page form sent to her by post.

She explains that Bournemouth Council told her they are "really busy," while social services said her queries about benefits fall outside their remit. At 87, Mary finds it extremely difficult to manage complex forms and processes without dedicated support.

These challenges have taken a significant emotional toll. Mary feels overlooked and abandoned by the very systems meant to provide safety and dignity in later life. Having worked hard, paid taxes, and remained self-reliant throughout her life, she now feels let down and discarded.

"I want to live my final years comfortably," she says, "without the stress of organising care and constantly worrying about how I will pay for things." Mary believes successive governments have failed older people when it comes to social care. "There is so much suffering," she adds. "And honestly, I welcome death as a solution to my problems."

This is Mary's real story, provided by Age UK and edited by the CSA for clarity and conciseness. Mary's name has been changed for privacy.

# Matt

**Just a few months ago, 25-year-old Matt described himself as being 'in a rut with no way out', his confidence gone and his future uncertain. Today, he feels hopeful and motivated thanks to the support of a disability charity.**

Matt, who is autistic, is determined to build a career and initially chose accountancy because of his love for maths. "Maths was always my strongest subject in school," he said, "and accountancy just felt like the natural path because it was a job that used that strength." He began with a Level 3 apprenticeship and gained experience with three different companies.

These early roles started off positively as Matt began his adult working life, but he soon encountered the challenges of workplaces with little awareness of autism. "In one place they just weren't supportive at all," he recalls. "It had a terrible impact on my mental health. Being autistic made it harder to adapt, but no one seemed to understand that or offer help."

By contrast, his second job was far more positive. "That workplace was supportive, and I felt like I could actually do my best there." Sadly, when his apprenticeship ended, the job was outsourced, forcing him to move on. His third role was also lost to outsourcing, a trend he noticed across the sector.

After losing his last job, Matt was unemployed for almost a year, spending ten months applying for accountancy positions without success. The experience gradually eroded his confidence. Even when he was offered an interview, Matt said he found the experience particularly challenging. He said: "Interviews are daunting for anyone, I'm sure, but as an autistic person, it's hard to prove with words alone that I can do the job. Actions speak louder than words, but interviews don't give you that chance. I know I'm capable, but saying it is very different from showing it. The most common feedback I got was, 'we really liked you, but we found someone else.' That doesn't help me improve, it just leaves me stuck."

By November 2024, Matt's confidence was 'in the gutter'. At this point, the Job Centre referred him to Hamelin's Ability Works employment programme. Matt emphasises the importance of this referral: "The Job Centre does a good job, but they aren't specialists in autism. What made the difference was that they knew about Ability Works and could refer me to a programme that really understood my needs."

Ability Works, set up by disability charity Hamelin, is a free programme for autistic adults and people with learning disabilities. It provides workshops, one-to-one mentoring, CV writing, interview preparation, and work experience opportunities to help people secure paid employment of their choice. The programme also aims to raise awareness of the barriers some people face and what can be done to support them. Barriers include poor preparation by employers, unfair hiring practices, unclear processes, and outdated attitudes.

The truth is, the autistic talent pool remains hugely underutilised. Government figures show that 75% of autistic people have the ability and desire to work, but just 30% are in

employment. That compares to around half of all 16–64-year-olds registered as disabled and around eight in 10 of the non-disabled population. Ability Works was established to address this imbalance.

The Ability Works team worked with Matt to look beyond accountancy and think more broadly about his skills and the job market. The programme analysed which industries were shrinking and which were growing, helping him see where his abilities could be best applied. "That's how I found cyber security," he said. "It's a growing field and it plays to my strengths in problem solving."

With support from the Ability Works team, Matt is now enrolled on a cyber security course at a local college, marking the start of a new career path. "I wouldn't have found this course without Ability Works," he said. "It feels like the start of an exciting new chapter in my life."

Matt said Ability Works has had a profound impact on both his employment prospects and his personal life.

**"When I joined, I was in a terrible place. I couldn't see a way forward. Now I've had the chance to practise interviews, work on team projects, and actually feel useful again. Being around other neurodivergent people also makes me feel less alone. They understand what I'm going through."**

He particularly values the balance of practical sessions and workshops. "The team activities gave me confidence to work with others, and the workshops reinforced things I'd learned before but had forgotten. Without this, I think those skills would have just faded."

Living independently, Matt is proud of managing his own home, though he currently relies on Universal Credit and help from his parents. He is determined to change this and said: "I don't want to depend on benefits or my family. I want to earn my own money and live life like other people. Finding a steady job where I am respected and understood would be a big step forward for me. I remember the stress of working in environments where autism was not recognised, I never want to go through that again."

He is quick to emphasise that many employers are not deliberately unkind but simply unaware. "Most people aren't malicious, they're just ignorant. If they understood the challenges, they would adapt."

Now, with a new course ahead, Matt feels determined and said: "I've proved in the past that I can do a good job. Ability Works has given me back that self-belief. I know I can succeed." He hopes for a stable role in cyber security, the chance to regain independence, and the opportunity to thrive in a career that excites him. He has found a new direction in cyber security, identified with the support of Ability Works, and is about to begin a course that excites him.

He said: "Ability Works has turned things around for me. It's given me back my confidence and shown me there's a future for me. It really does feel like a new chapter in my life. There should be more programmes like Ability Works across the country. I know I'm not the only one who has struggled, and if this kind of support was available everywhere, it would help so many people like me."

# Nathan

## Nathan has a learning disability and lives at home with a parent who currently provides all support. In the future he will need to live in supported housing.

Nathan, 30, has a learning disability and lives at home with a parent. Nathan works at a charity as a Lived Experience Advisor three days a week. He has worked there for five years and has been in work for almost 10 years in total. Nathan's long-term goal is to work in a communications or parliamentary role. Nathan loves watching TV and films (especially when he gets the chance to go to the cinema), and he is also a big fan of playing video games.

At the moment, Nathan doesn't get any formal social care. However, his parent and wider family support him with a range of different things. Nathan lives a very independent life, although his parent supports him by reminding him about various tasks that he needs to do, like managing admin and money. Nathan is learning how to cook, and his parent is supporting him to build skills so that he can be even more independent in the future.

Nathan got employment support to find his first job. After two years of trying to get additional support at work through the Access to Work scheme, he finally found a job coach who is the right fit for him. Nathan's job coach helps him to understand complex information, plan his busy diary, and write up notes. This means that Nathan has more time to focus on the most important parts of his work. The amount of admin required each month for the Access to Work forms makes the process much harder than it should be. It needs to be signed by three people, and Nathan has to fill out the form in paper format, which makes it much less accessible for him.

Nathan's current support plan gives him the freedom and independence to do well at work and pursue his hobbies in his free time. Support from his family works well and he has everything that he needs to live a happy life and to maximise his wellbeing. For Nathan, good care and support is having someone there to remind him about tasks and help him plan his time. This support means that Nathan can manage the different parts of his work and personal life successfully. A little bit of help goes a long way towards maintaining his independence.

Although Nathan's support needs are currently being met, he has spoken to his family about plans for the future. His plan is to move into supported living. It will be essential that the right support is in place to help him with this transition. Nathan will likely need support to find somewhere to live, settle into his new home, build new relationships, learn new money management skills, and continue to work and pursue his hobbies.

It is essential that good social care support is in place throughout this process so that he can successfully adjust to this change in his life and maintain his wellbeing going forwards.

Nathan's story was provided by Mencap and edited by the CSA for clarity and conciseness.

# Norman

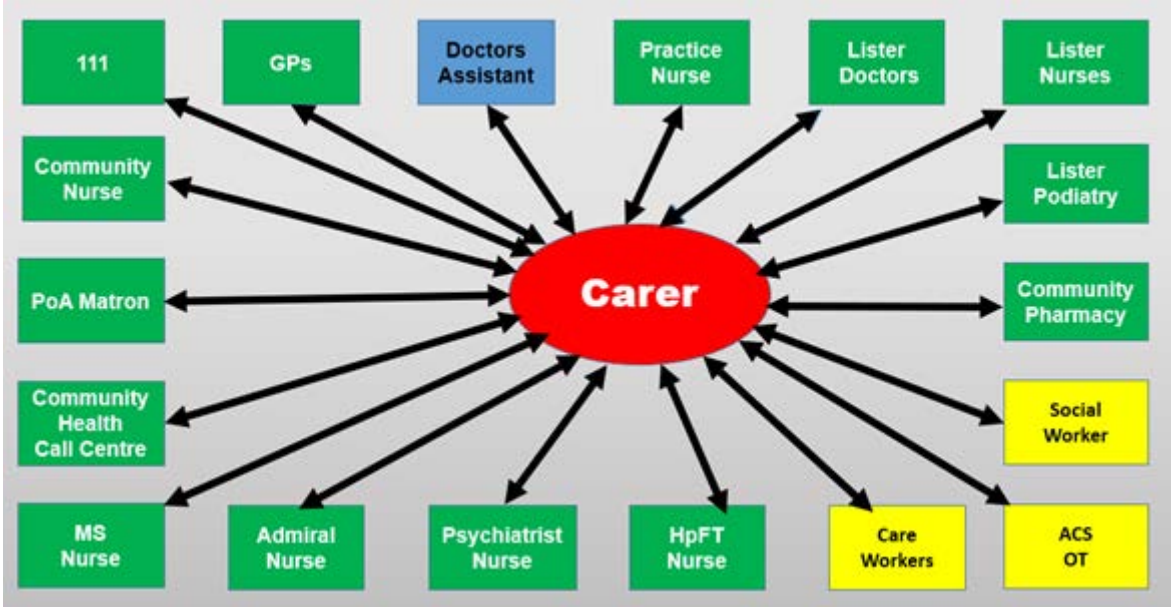
## Norman cared for his wife, Roz, for many years. Norman describes caring as "like having to climb a series of mountains."

Norman was a full-time carer for his wife, Roz, until she died in July 2025. Roz first became unwell at 29, when she was diagnosed with Ulcerative Colitis. Later she was diagnosed with Immune Thrombocytopenic Purpura (ITP) and Secondary Progressive Multiple Sclerosis (MS). In 2019, MS-related neurological damage led to a diagnosis of non-specific dementia.

Despite these progressive conditions, Roz and Norman managed at home for many years. This changed when Roz, then 60, was admitted to hospital with a urinary tract infection. Initially discharged as "fit," she was later found to have sepsis. The infection triggered an MS flare-up and left permanent damage to her legs, meaning Roz never walked again. Norman faced a critical choice: place Roz in a nursing home or retire early to provide care. He chose the latter, giving up his career as an IT Programme Manager.

From that point, Norman described caring as "like having to climb a series of mountains to get the help and support Roz needed." The greatest challenge was the sheer number of professionals involved and the lack of coordination between them. Roz's care often required input from GPs, hospital consultants, social services, district nurses, palliative care, occupational therapy, physiotherapy, and dementia specialists. Rather than working together, Norman found these services operated in silos. He was left making endless phone calls, rarely speaking to the same person twice, and constantly repeating Roz's history and needs.

The web of professionals Norman had to interact with (demonstrated in the diagram below, provided by Norman) was especially difficult during end-of-life planning. Initially, the palliative care team were involved but later withdrew support when Roz was deemed ineligible. End-of-life was first raised abruptly in A&E, when Roz was presented with a Do Not Attempt Resuscitation (DNAR) form. Norman described this as being treated like a "blank cheque" for decisions about her care. Despite having a Lasting Power of Attorney and a written care directive, Roz was still asked to sign multiple ReSPECT forms, sometimes when Norman believed she lacked the capacity to understand. He felt these processes reflected NHS pressures and cost considerations rather than Roz's wishes.




Roz was declared "end-of-life" on four separate occasions, each involving different professionals and conflicting decisions. Norman said this inconsistency highlighted how fragmented services were, and how no one appeared to take overall responsibility for her care.

In February 2025, Roz's hospital-at-home support was withdrawn without explanation, further deepening Norman's frustration. Her health declined, and she was admitted to hospital in June. After 12 traumatic days, she was sedated and died peacefully. Norman expressed relief that this happened in hospital, as he believed community end-of-life support was inadequate.

**Reflecting on the experience, Norman is calling for urgent systemic reform. He argues that patients and carers should be "front and centre" in health and social care processes, with the many professional services working not in isolation but across boundaries to provide continuity and dignity in care.**

Norman's story was provided by Carers UK.

# Pat and Miles

**Pat cares for her husband, Miles, who has MND and complex needs. Pat is exhausted and burnt-out but Miles only gets two weeks a year of respite care through a charity, and nothing funded.**

Pat is 66 and lives near Newcastle upon Tyne with her husband Miles, who was diagnosed with MND in 2021. They've been married for 46 years and have two daughters, Natalie and Jennifer, and a grandson called Nicholas. Pat worked in social services for over 25 years, doing various roles across the sector, and Miles was a postman before retiring.

Pat told us: "By the time I retired, my health wasn't very good as I'd slipped a disc in my back from years of doing desk work. I had an operation to fix it, and it went again after I returned to work six months later, so I took early retirement. We thought that when we both retired we'd be able to look after Nicholas, and we did for a little while, but it became difficult with Miles' diagnosis."

"Miles can't move anything below his shoulders, making his needs very complex. Miles' speech is currently unaffected. Miles cannot move, and I can't move him, so the care workers have to make sure he's in the right position when they transfer him, otherwise he'd be stuck being uncomfortable for hours until the next visit. We have a hoist in the bedroom, and we've taken the doors off in the kitchen and living room so that Miles can get around in his wheelchair. The wheelchair service put an assistant control on the back of the wheelchair so that I can control it for him. We're looking into asking about a head-controlled system to give Miles a bit of independence. We've got ramps to get in and out of the house, but Miles hasn't been out for months other than to go to appointments in an ambulance.

Miles' speech therapist is brilliant and she's always checking up on us. Miles has banked his voice, which was one of the first things we were told to do. Miles has a permanent catheter and he gets horrendous painful spasms from it. He's on medication but it hasn't made much of a difference. Miles is coughing more now and he's getting a lot more mucus at the back of his throat - I don't know what that means for him or what will happen next. I do all his personal care, but I really struggle to help him with this. I know there are suction machines but things like that really make me feel quite sick. To me, that is a nurse's job. The care workers wouldn't do it, there would need to be someone specially trained to do suctioning. If and when this is required I may be expected to do this as someone who isn't a nurse. I would feel very uncomfortable and out of my depth doing this procedure. I also don't feel confident that a hospital can handle Miles' situation because they haven't got enough staff. He has a catheter, he needs fluids, he needs constant monitoring, so we've decided that hospital isn't the place for Miles. The only other place Miles has said he will go to for any kind of health issues would be Marie Curie hospice in Newcastle, because they have a team of nurses, hoists and they always have a doctor present.

Miles receives care through NHS Continuing Healthcare (CHC) for care worker visits four times a day. We had to jump through hoops to get the funding. We really had to know

our stuff and prepare for it, and they seemed to do everything to avoid giving it to us. I asked our MND Nurse about CHC and she told us we wouldn't get it. Three months later I told her again that I wanted to apply as I felt he was eligible. It felt like she was trying to put me off applying, but I pushed forwards with it and they arranged for the assessor to visit us at home to do the assessment. Before they came, they sent a form for me to fill in, which had very generic questions and didn't have much space for detailed answers – it felt more like a tickbox exercise. My advice to anyone would be not to fill that form in, and instead use the headings to make notes, and then discuss the notes at the assessment meeting. Doing it this way meant every section of the form had to be discussed by the people around the table, including the social worker, our MND Nurse and a district nurse. I felt as if we were discussing Miles as a person that way. At the end of the meeting, we got the funding. I'm sure that part of our NHS CHC funding is that Miles would be allowed some paid respite but we've never had any. Miles gets respite from Marie Curie which costs nothing as they're a charity. I've asked the NHS for names of nursing homes who do respite and everyone I've been told to contact said they don't take respite as their beds are full.

Miles has visits from care workers five times a day. Four of these visits are funded by NHS CHC, and one is provided by Macmillan."

**"In 2021, I had been pushing Miles around in a wheelchair and I did my back in and ended up in hospital for a week. I had to have care workers at home to help me shower because I couldn't sit down or walk without crutches, so my back is a constant worry for me. Since then, I've had to stop getting involved in Miles' moving and handling. Miles needs around-the-clock care. In between the care worker visits I'm on my own. I try to do my best, but I'm frightened that getting involved might have consequences on me because if I put my back out again, Miles might end up in a nursing home. It's not his wish or mine, but there will be no other option if I injure myself. Carers should never feel they have to risk their own health to care for a loved one which is how I felt – it's dangerous and unfair. I need to look after myself, but how do I tell Miles that I'm struggling and frightened? What will be left for me if I become a wheelchair user due to injuries caused by caring?"**

"Miles has continuing problems with his bowels, which can be upsetting for us both if care workers are not around to assist. Miles and I have been married 46 years. I don't feel like his wife anymore, I don't have time to sit and chat to him and be a normal person, I just feel like his carer. I'm always on duty and everything has to involve me. I feed him, I give him his drinks, I wash his face, I clean his teeth, I do his personal care. It's not just physical - the emotional side of dealing with this is increasingly difficult. There's no improvement with MND, Miles only ever gets worse. I'm expected to be a nurse, a wheelchair engineer, a hairdresser and everything in between. I don't know what I'm doing most of the time, but I'm expected to know everything. I get up at seven in the morning and most days I don't sit down to start my own day until 11.30am. If I don't get up at seven, I don't have time to have a shower, get breakfast, or get myself sorted.

Everything is about Miles' survival and what his needs are, it's not about me anymore. A lot of the time it feels like my feelings don't matter. I have days where I'm tired but I just have to do it, there's no other option.

Miles doesn't have a suitable seat to sit in, so he goes between his wheelchair and his bed. He can't sit in the same position for more than a couple of hours, so he has to be moved from the bed to his wheelchair and back five times a day when the care workers come. There are always two care workers at any one time to do Miles' care as it takes two people to move Miles and to use the hoist. The care workers work to allotted times which does not always work and most definitely not for Miles.

Miles likes going to the Marie Curie hospice in Newcastle, but they only offer two weeks a year of free respite, they don't offer paid-for. They're very good, they have experience in supporting people with MND, and he feels well looked after when he goes there. He knows there are nurses there who can support him if he needs to go to the toilet, whereas there aren't those facilities elsewhere. It's my one comfort that we have Marie Curie noted down as a place that Miles can go if we find ourselves in an emergency.

Miles doesn't want to go into a care home. I really don't know what I'm going to do if that time ever comes. If Miles wants to stay at home, we need more support. I don't even know if that's available. I have contacted the NHS and we are now looking at getting a better care package for Miles to meet his needs as they have changed so much. The care workers' times can be erratic so it's hard to have a proper timetable to work with. They are very good, they have a good relationship with Miles, but they come in to do whatever they have to do and then leave; the rest of it is left to me.

Unpaid carers need to have breaks. I've been to a log cabin with my daughters for a break while Miles went to Marie Curie. I reconnected with my daughters, we had a laugh and I could switch off. In May 2023 it'll be the first week-long break I've had, and Miles is going to Marie Curie hospice. It's not normal for someone to care 24/7. Care workers go home at the end of the day, whereas I never switch off. I don't get out socially because I need someone to take care of Miles. I find myself trapped and, although we have a lovely home, sometimes it feels like a prison. I can't just go out, everything has to be pre-planned and put in place to make sure Miles is safe. A lot of nursing homes near us don't do respite, and finding a care home that can support all of Miles' needs has been difficult as there is a shortage. The care that we've got at home through CHC works now, but if we need any more care in the future, I don't know where we're going to get that from.

I phoned up about a carer's assessment and they were not very helpful. I was sent some information about courses or talks that I could attend but they were focused on carer's training and support in relation to dementia, mental health, autism, and bereavement - nothing about supporting anyone with physical health issues or MND. I had a follow up call asking why I needed a carer's assessment, and when I explained they told me it could take weeks or even months before I got an assessment. I did say that someone with MND may not have that long, so carers need support quicker than that and they just said there was a long waiting list. They also told me I would have to attend an appointment which could take up to two hours and they do not visit at home to do that. It seems to me that all these courses are arranged assuming that carers can leave the person they care for and have no problems attending. They've told me I will be put on a list but I'm not optimistic that there is any support they can offer me."

Pat and Miles' story was provided by Dementia Carers Count and edited by the CSA for clarity and conciseness.

# Richard

## Richard, who is autistic and has a learning disability, has spent 4 years of early adulthood inappropriately detained in a mental health hospital because there wasn't adequate community support available.

Richard, 21, has a learning disability and is autistic and has spent his whole adult life locked away in mental health hospitals, not because he has a mental health condition, but because he has not been able to get the right support in the community, including suitable social care and housing. When Richard turned 17, his needs became more complex.

**Desperate, his parents started asking social services for help. But social services waited until Richard turned 18. Shortly afterwards, he was admitted to a mental health hospital despite not having a mental health condition. His parents were told it would just be for three months while he was assessed. But he never came home. Instead, Richard, was detained under the Mental Health Act and moved to a different mental health hospital hundreds of miles from their family home.**

Over the years, Richard's family have raised concerns about physical and psychological abuse he's experienced in units. Richard is now detained in a mental health unit much closer to home, but he's still sectioned in a hospital setting, which is inappropriate as he does not need inpatient mental health treatment. Although discharge planning is underway, the family won't be confident he will ever leave until he's out.

Richard should be able to get the right support in the community, so he can flourish and live a happy and healthy life. Fundamentally, a mental health hospital is not an appropriate place to detain people with a learning disability like Richard, just because there is nowhere else in the community to support him. A mental health hospital is not a person's home.

People with a learning disability and autistic people are at increased risk of abuse and neglect in these settings, where there they are subject to disproportionately high use of physical restraint and over-medication. Richard's father said doctors at the mental health hospital had told him that Richard was "over medicated" most of the time.

Richard needs person-centred support in the community. He needs the right community support, including social care support from staff with the right skills to support someone with a learning disability who is also autistic and may display behaviour that challenges. He also needs specialised supported housing designed and adapted to meet his sensory and behaviour needs.

Over the years, whilst trapped in a mental health unit, Richard had been repeatedly physically restrained and injected with drugs to sedate him. "The last mental health hospital he was in he was so heavily sedated he couldn't walk couldn't get out of bed and could hardly speak. If he had stayed there he would probably be dead by now." - Richard's parents

Richard has also spent long periods of time in long term segregation within the unit and spent almost two months isolated in a room with nothing but a toilet in the corner. Any communication with his family was through a small hatch in the door.

**"It's the biggest regret of our lives. We wish we'd never asked for help. He was taken from us and locked up."**

The right social care and suitable housing in the community for Richard and people with similar needs is essential to help prevent inappropriate admission or re-admission to mental health hospitals and ensure people can thrive in their communities.

There has been some positive support to get Richard out of segregation and come off medication in the unit – with an external specialist practitioner brought in to support him (through HOPE(S) – a programme to help end use of long term segregation for people with a learning disability or autistic people in mental health units, which focuses on compassion and dignity and avoids using restraint).

Recently, after his family exposed their situation to the national media, discharge planning has begun, and commissioners have agreed to develop (and fund) the right care package and suitable housing for Richard. This has been a long, hard, and emotional fight for Richard and his family and it shouldn't have taken the media spotlight on their situation to drive change.

**Richard asks his parents daily when he can come out, but they can't give him an answer. Until there is proper community support in place, Richard continues to be locked up.**

There is an NHSE/LGA/ ADASS Building the Right Support (BTRS) service model setting out the support and services that should be available in local areas to support people with a learning disability and/or autistic people who may display behaviour that challenges, and to help prevent inappropriate detention in mental health hospitals. The right support and services were meant to be in place by 2019 under the NHSE-led 3-year Building the Right Support programme.

There is wide variation in progress between local areas in reducing their learning disability and autism inpatient rates and in developing the right community support.

The perverse financial incentives in the health and social care system remain a key challenge and there needs to be much better working between health and social care as well as a commitment to fund and develop appropriate packages of support and housing in the community that adequately meet the person's needs.

At the moment, if the local authority doesn't provide a package of care that meets the person's needs and they end up in crisis and are admitted to a mental health hospital under the Mental Health Act, the NHS pick up the bill whilst the person is in the unit. The same perverse incentives contribute to delayed discharge as once the person is back in the community, the local authority is likely to have to fund at least part of the person's community care package.

The right community support, including the right social care and suitable housing, is the key to ending inappropriate detention in mental health hospitals.

Richard missed out on 4 years of his life because he has been let down so badly by the health and social care system. The family also have another child with the same syndrome as Richard and every day they fear the same will happen to him. It has left the family feeling let down and betrayed by a social care system they believed would help their son, to the point they wished they never asked for help in the first place. The family say the experience has left them with long lasting trauma.

"He's gone through absolute hell, I don't think anybody will ever realise unless they've actually seen it. For one person to go through that much trauma in his life; it's so sad."

Richard wants a future outside of hospital. He wants a job, he wants to work with bikes, he wants to go to college to learn to read and write. He wants a life that's not locked away in a hospital.

Richard's real story was provided by Mencap. Richard's name has been changed for privacy.

# Rosie

## Rosie cared for her mum who had Young Onset Alzheimer's Disease. After a rapid decline in her mum's abilities, and exhausting all the ways to keep their mum living independently, they moved her into a care home.

Rosie cared for her mum who was diagnosed with Young Onset Alzheimer's Disease in her fifties. Being a carer is one of the loneliest things she has ever had to do. None of her peers could relate to her experiences. While they were getting married and getting on with their careers, she was suddenly catapulted into a role she had never anticipated for an undefined period of time.

**"As a carer I could never relax. I was hypervigilant all the time and constantly felt low level anxiety. I felt incredibly lonely. I was often tearful and upset. Life felt very unfair."**

Rosie's mum was a trained chef. "It was really hard to see her start to struggle to make her own food and then for cooking to simply be too dangerous for her to do alone, which happened relatively early on after her diagnosis. We did everything we could to help her stay independent for as long as possible, switching her gas cooker for an electric one and setting up sensors that could monitor if the cooker was being used."

"I was lucky that I was able to spend some time working flexibly from home to support mum. There was always something to do. Some kind of appointment to arrange with the doctor, the dentist, the memory clinic, the opticians, social services, or the care workers, and ultimately mum needed round-the-clock care."

Rosie eventually found that she was doing literally everything for her mum and hated the constant focus on all the things her mum could no longer do, as she and her family sought much needed support through Social Services. After a rapid decline in her mum's abilities, and Rosie and her siblings exhausting all the ways to keep their mum living independently, they were left with no other choice but to move her into a care home.

"Dementia Carers Count was a real lifeline. The charity's support has been amazing. I've learnt so much from the information and resources it has, and I've found being connected with other carers really helpful. I met people who became my support network and had a safe place to share my experiences, with people who knew what I was going through.

**After a diagnosis, you're on your own, in a vacuum, and there's no one place to find help. I don't know what I would have done without Dementia Carers Count."**

Rosie's story was provided by Dementia Carers Count and edited by the CSA for clarity and conciseness.

# Sanah

**Sanah is 28. She has a great carer who visits several times a day but in between, her family has to step in. She is currently fighting to get more care to take the pressure off her family and live more independently.**

My name is Sanah, I'm 28 years old, and I have Spinal Muscular Atrophy Type 2 (SMA), a degenerative muscular condition. I'm a full-time electric wheelchair user. I also live with Psoriasis and Endometriosis.

I am an artist, disability advocate, and content creator. I'm also an ambassador for SMA UK and an Accessibility Ambassador for Om & Bass Festival. You can find me on Instagram and TikTok as @freewheelingsanah, where I share my journey, my art, and moments from my life. I also run art workshops, sell prints at stalls, and take commissions.

I'm not currently working, but I have experience in customer services at O2, as well as creative work with an organisation called Pathfinders, where I worked on video projects. I studied Media at college and Film & TV at university. Now, I create content online and focus on building my art career. My dream is to have my work exhibited in galleries, featured on clothing and products, and shared with more people across the world.

A typical day starts at 6:30am, with help from my carer, who assists me with my morning routine: showering, moisturising, dressing, and helping me into my wheelchair. At 8:00am, my mum makes my breakfast. Having a structured morning helps me feel safe, calm, and prepared for whatever the day brings.

How I spend the rest of my day depends on my energy levels. If I'm feeling well, I love going to the park and painting afterwards. If I'm too tired, I rest in bed with my cat and read a book. Living with multiple chronic conditions has taught me the importance of compassion toward myself, especially on the harder days.

I've had care workers since I was 16, initially to help me get ready for school and into bed in the evening. Now, I receive care in the morning, twice during the day (to help use the toilet), and again in the evening for my night routine. I also receive a few community support hours, which I can use to go out or even take a holiday.

**Care matters to me because it takes the pressure off my family. Having the right carer makes a huge difference and it's important to find someone who truly matches your personality. I'm grateful to have found that perfect match with my lovely carer Liz, who is Polish, full of energy, and brings so much joy to my mornings. We bounce off each other so well that my routine feels effortless and fun, rather than draining. Starting my day with Liz has made such a positive shift in my life.**

But when care workers aren't with me, the responsibility falls on my mum, Imtiyaz, and my sister, Hina. Right now, things have been especially tough because my mum has been ill with pneumonia, and Hina, though incredibly supportive, has her own mental health challenges. This has made it clear that my current care package is no longer enough.

I recently requested an increase in my care package—specifically to have a PA with me for around 15 hours, 4 days a week. This would allow me to go swimming, travel, or simply go to the park without relying on my family. Unfortunately, my request was declined at panel. This was disheartening, because the extra support would be life-changing for my independence and well-being. But I'm resilient and won't give up—I'm gathering supporting letters for an appeal, and if it's declined again, I'll take it to the next level. I deserve the support I need to live fully, independently, and with dignity.

Care isn't just about physical support —it's about freedom, structure, and the ability to live a self-directed life. With increased care, I could:

- Take pressure off my mum and sister, relieving them of unsafe and unsustainable caring responsibilities
- Look after my mental and physical health
- Be more spontaneous and independent
- Live life on my own terms, while I still can

**Because with a progressive condition like SMA, time matters. I want to do the things on my bucket list now, while I still have the ability. Waiting could mean missing out forever. I'm 28 years old, and like anyone else, I want the freedom to decide what I do with my day. I want to wake up and say, "I want to go swimming today," and actually be able to do it.**

**Having my voice heard and taken seriously matters to me. I want my needs to be recognised not just as boxes to tick, but as real, human experiences. Care is not a luxury, it's a lifeline.**

Sanah has written her own story on behalf of SMA UK.

# Sanchit

## Sanchit cares for his two adult children with learning disabilities, and now his wife. He worries about what will happen when he can no longer care for them.

Sanchit is an 80-year-old full-time carer based in Newham, East London. A dedicated husband and father, he lives with his wife who has multiple long-term health conditions, including sarcoidosis, and their two adult daughters, aged 45 and 48. Both daughters have learning disabilities caused by a genetic condition and have required constant care since birth. For Sanchit, caring is not just a role, it's a way of life.

Sanchit provides daily care to his wife and daughters. Mornings begin early, coordinating with paid care workers to support his daughters in getting ready for their day. As part of their care package, the daughters attend a local day centre from Monday to Friday. Sanchit and his wife ensure they are always home by 3pm when their daughters return, providing continuous care into the evening and throughout the weekends.

Although the morning care workers and day centre offer brief periods of respite, Sanchit and his wife are the primary caregivers every evening, overnight and on weekends as well as when their daughters exhibit challenging behaviour or refuse external support. Sanchit says he urgently needs more support on weekends and better access to respite care. These gaps in provision are becoming more difficult to manage, particularly as both he and his wife age and face their own health challenges.

**Over the years, Sanchit has seen a marked decline in the consistency and quality of care services in his borough. While one long-standing carer – who has supported the family for nearly 20 years – provides a sense of stability and trust, Sanchit feels that the broader system is letting families like his down. There is a significant shortage of appropriate respite and weekend care, few social workers, and high turnover among agency staff. For adults with learning disabilities, this lack of familiarity is particularly distressing.**

Sanchit highlights that receiving Direct Payments has been crucial, enabling him to choose consistent care workers and avoid disruptive daily changes. However, he also finds the administrative processes around care complex and burdensome. He describes phone-based assessments as inappropriate for individuals with complex needs and feels that many existing services are not designed with learning-disabled adults in mind.

**As Sanchit and his wife grow older, the emotional and physical toll of a lifetime of caring is becoming increasingly difficult to bear. He says: "Sometimes we feel like giving up because the system makes it too hard." His greatest concern is what will happen to their daughters when they are no longer able to provide care. A previous attempt to move one daughter into supported living failed due to poor transition planning and inadequate provision. The fear of an uncertain future weighs heavily on him.**

Despite these challenges, Sanchit remains active in his local community. He leads a learning disabilities support group and continues to advocate for families like his. He calls for more targeted support for older carers, including a dedicated transition fund to help gradually move dependents into supported living arrangements. He also believes that services must become more accessible - especially for carers from ethnic minority backgrounds - by providing clearer information on legal tools like Power of Attorney and simplifying the administrative process.

Sanchit's real story was provided by Age UK and edited by the CSA for clarity and conciseness. Sanchit's name has been changed for privacy.

# Simon

**Simon is registered blind but receives no formal care or support. He would like help with transport so that he can get out and about, pursue his hobbies, and explore work or volunteering.**

Simon is 47 years old and registered blind. Simon values spontaneity and the ability to get out and about, but this is difficult without support.

Simon does not currently receive any formal social care from the local authority. His support comes entirely from family and friends, who help him access the things that matter most to him including riding his horse, Lizzy, open water swimming and attending church once a week. These activities are essential for his physical health, mental well-being, and sense of freedom.

Simon has previously tried to access support through a social care assessment but found the local authority to be unhelpful and focused only on basic domestic tasks. Simon says he has been offered help with things like shopping and cleaning which he can do himself. He needs support with transport so that he can access activities such as horse riding and swimming. Although he has a bus pass, he can't use it to get to his activities as the buses aren't going to the right places at the right times and using taxis would put a big strain on his finances. He is therefore reliant on family and friends to take him. Without their support, Simon says his life "wouldn't be worth living."

Simon says the lack of support has not helped with his employment prospects. He would like to explore employment or volunteering opportunities, but they currently feel out of reach.

Simon feels the current system only provides people with basic survival needs which you have to fight tooth and nail to get. It focuses on limitations, budgets, and cost rather than positive outcomes. A rigid system "offering a one size fits all" approach doesn't meet his needs or aspirations. He says "People need to listen and not make assumptions about the care I might need or want."

Simon believes social care should empower people to live fulfilling lives, not just meet survival needs. He wants support that is tailored to his life and interests. For Simon, good quality social care means care that is personalised and flexible, giving him choice, independence, and the freedom to live with spontaneity. It should support him in doing the things that matter most, enhancing his overall well-being and ensuring he remains included and connected to the life he values.

Simon's real story was provided by Leonard Cheshire and edited by the CSA for clarity and conciseness.

# Trevor and Yvonne

## Trevor cared for his wife, Yvonne, who has early-onset Alzheimer's, for several years until she moved to a local specialist dementia care home. After Yvonne's diagnosis, Trevor was left to fend for himself as her carer and received no carer's assessment.

Trevor, 73, lives in North West London and for many years cared for his wife, Yvonne, now 69. Trevor first noticed Yvonne's memory-loss symptoms in 2009. It took almost 18 months to convince her to see the family GP, who referred her to the local memory clinic. Exasperatingly, the clinic discharged her as having nothing wrong and it took a further 2 years to get her back into the system where she was diagnosed with young onset Alzheimer's disease in December 2013.

At the time of the diagnosis, Yvonne had been working for Sainsbury's as a store picker for customers who place their orders online after having given up a job she loved as a bookkeeper working for a small local charity. Yvonne's manager supported her to continue working for four years after her diagnosis, reducing her responsibilities, her hours and even allowing her time off work to participate in a clinical drug trial.

Trevor had been an international marketing director, but stepped away from his position so he could balance caring for Yvonne with a part-time marketing role instead. He then retired in 2015.

**Trevor considers himself 'lucky' in that he was a supporting carer to his mother when she was caring for his father so had some insights into the responsibilities and stresses of being a dementia carer, but says "it didn't take me long to realise that seeing the role from the outside looking in every few days was incomparable to living it 24 hours a day."**

At the point of diagnosis Yvonne was discharged from the memory clinic and Trevor was left to fend for himself as her carer. He received no carer's assessment from the local authority, and didn't even know such an assessment existed. Trevor threw himself into gathering as much information as he could about Yvonne's likely regression and the coping strategies he would need to support both Yvonne and himself. Unable to find a support group for relatively young husbands looking after their wives with dementia, he established his own.

Determined to continue to lead as fulfilling a life as possible, Trevor and Yvonne immediately disclosed her Alzheimer's to all family and friends and embraced any help that was offered. Trevor started doing all the cooking and household chores and Yvonne helped as best she could. They continued to socialise, travel and enjoy the great outdoors until she became doubly incontinent towards the end of 2018.

At this time Trevor realized he could no longer look after her 24/7 and, after considering all the available professional care options, he chose a local home specialising in dementia care where Yvonne became a self-funding resident in May 2019, just before her 63rd birthday.

Trevor started to volunteer for dementia charities and during Covid, when Yvonne's care home was in lockdown and he couldn't visit for the best part of 14 months, he spoke out about the damage being done to dementia residents devoid of contact with their loved ones. He continues to campaign for carers' rights and is currently Chair of the European Dementia Carers Working Group under the auspices of Alzheimer Europe.

Yvonne's care has been exemplary for the past six years although Alzheimer's has taken its inexorable toll and she is now unable to speak, recognise him or any family members and is totally reliant on the care home staff for all aspects of her daily needs.

Trevor is now anticipating having to approach either the NHS or the local authority to pick up her funding and finding this very stressful.

**"The lack of social care support for dementia greatly exasperates me, and the process of applying for funding is complex, demeaning and intrusive with the outcome always uncertain. I feel totally out of control for the first time in the many years I've cared for my wife. No carer should have to be put through this indignity as a loved one approaches end of life."**

Trevor's real story was provided by Dementia Carers Count and edited by the CSA for clarity and conciseness.

# Vic

**Vic has been an unpaid carer for over twenty years, supporting both his wife and his son, Sean, who lives with epilepsy and other complex health needs.**

Alongside this, he works full-time as a bus driver for Stagecoach. As he explains, "my day doesn't end when my shift does" — he provides care before work, after work, and through the night. He has not had a proper break from caring in seven years.

Sean has a rare condition that few professionals understand. It causes his heart rate to surge and triggers severe seizures. During hospital admissions, Vic feels he must always be present, as staff are often unfamiliar with Sean's condition. He wants his son to wake up feeling safe and supported, not surrounded by strangers.

Because Sean's seizures can strike suddenly and severely, he requires two trained support staff to attend college safely. That support has not been secured, leaving Sean isolated and unable to reach his potential. "His passion is to help people," says Vic. "He needs more than just me to support him. He can get really low at times." Sean now has a social worker who is trying to help, but his care needs remain unmet.

Vic's wife also has complex health needs, including nocturnal seizures, chronic pain, fibromyalgia, OCD, and severe anxiety. Leaving the house is extremely difficult, and she is heavily reliant on Vic. Hospital appointments are particularly challenging, as her unusual conditions require specialist understanding. A social care assessment two years ago was supposed to provide £34 a week in support through a pre-payment card — but the card was sent to the wrong address and took months to resolve. For Vic, this was a telling example of how hard it can be to access even minimal support.

Despite these struggles, Vic has seen the difference good care and technology can make. For years he stayed alert through the night, listening for every sound in case Sean was having a seizure. An epilepsy motion sensor has been, in his words, a "life saver," giving him a little more rest and allowing Sean to join in more community activities. But it took two years to convince the council to provide it. Vic now urges them to make this technology more widely available. He also deeply values the compassion of his GP practice and local pharmacist, who treat his family with respect. "That kind of reliable, person-centred support makes all the difference," he says.

**Unfortunately, most of Vic's experience of social care is defined by gaps and barriers. Reliable, trained care workers are scarce, respite is almost impossible, and his role is too often invisible. He feels unpaid carers like him are treated as a "silent minority." The lack of breaks leaves caring exhausting and isolating. Friends no longer invite him out, knowing he cannot leave his responsibilities. "You don't want to stop caring," he says, "just to have a breather."**

At work, his caring responsibilities are only partly understood. He welcomes the right to five days' unpaid leave, but says it falls far short of what carers need. Now that Sean is 18, Vic often uses his annual leave to provide care rather than rest. He wants stronger workplace rights and greater recognition of the pressures carers face.

What Vic wants most is a safety net. "I don't really think about my health as I don't have time," he admits, but he lives with constant anxiety about what would happen to his wife and son if he became ill. Right now, he has no confidence that the right support would be there.

Asked what he would say to Baroness Casey, Vic is clear: "Recognise what we do. Caring can really drain you. I don't get breaks. I can't do a day away, a weekend away. It's too difficult to get anyone else in to look after them both. Who is going to look after our health?"

**For the future, Vic wants his son to be safe, supported, and able to pursue his dream of helping others. He wants unpaid carers to have real recognition and stronger rights at work. Above all, he wants a care system that provides families like his with a genuine safety net so that care does not rest solely on his shoulders.**

Vic's real story was submitted by Carers UK and edited by the CSA for clarity and conciseness.

# Anonymous

## FitzRoy supports many supported housing residents who previously lived in secure mental health hospitals. Some have long histories of self-harm, mental ill-health and substance use.

FitzRoy supports people who have spent many years in secure hospital wards, who mostly have long histories of severe self-harm and substance use. In successful transitions to our supported living services, we see significant reductions in self-harm and substance use and many more stable days. This is due to the trusting relationship built between them and our team.

When people's mental health does deteriorate and self harm increases we work with the wider team around them to ensure they get the support they need. Sometimes, it becomes clear that being sectioned is the right decision for their safety and health. While in hospital their mental health can initially worsen, as they lose control over their day to day lives and this can show with increasing and more determined self harm. We have seen cases where self harm has increased to such an extent that even being supported by five staff on the ward cannot prevent it. In some circumstances, patients need to be moved from an acute unit to a psychiatric intensive care unit.

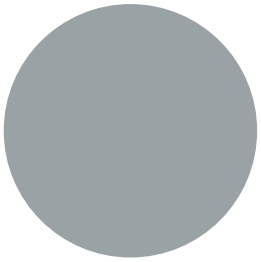
Throughout this period, our staff will stay in close contact – visiting almost every day, phoning and texting. We reassure them that they still have a home and people they trust to come back to. We will work with local mental health teams to plan a smooth, low-stress transition back to supported living. A stable day can mean something as ordinary as walking to Lidl to buy a sandwich. On those days, we have conversations that develop our understanding of them and their needs, as well as their own emotional awareness – exploring triggers and strategies to make stable days more frequent.

Our staff are not mental health clinicians. They are enhanced support workers, but have been trained in suicide prevention, trauma awareness and high-intensity informed support. They support around 15 people locally and often deal with extreme self-harm situations. Their primary aim is simple but vital – to keep people alive and enable them to have as many stable days as possible.

This is what supported living looks like for people with the most complex mental health needs. It is not just about housing – it is about survival, recovery and hope.

This portrait was provided by FitzRoy. It is based on real stories of people who are not currently able to give consent.





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