

sia spinal
injuries
association
FOR LIFE AFTER SPINAL CORD INJURY

Aspire

Supporting people with spinal injury

back up

transforming lives after spinal cord injury

More than a number

NHS Continuing Healthcare - a **manifesto for change**

“To think that’s what they can
put you through is horrendous.”

We believe...

1. Care and support packages must meet people's needs and aspirations

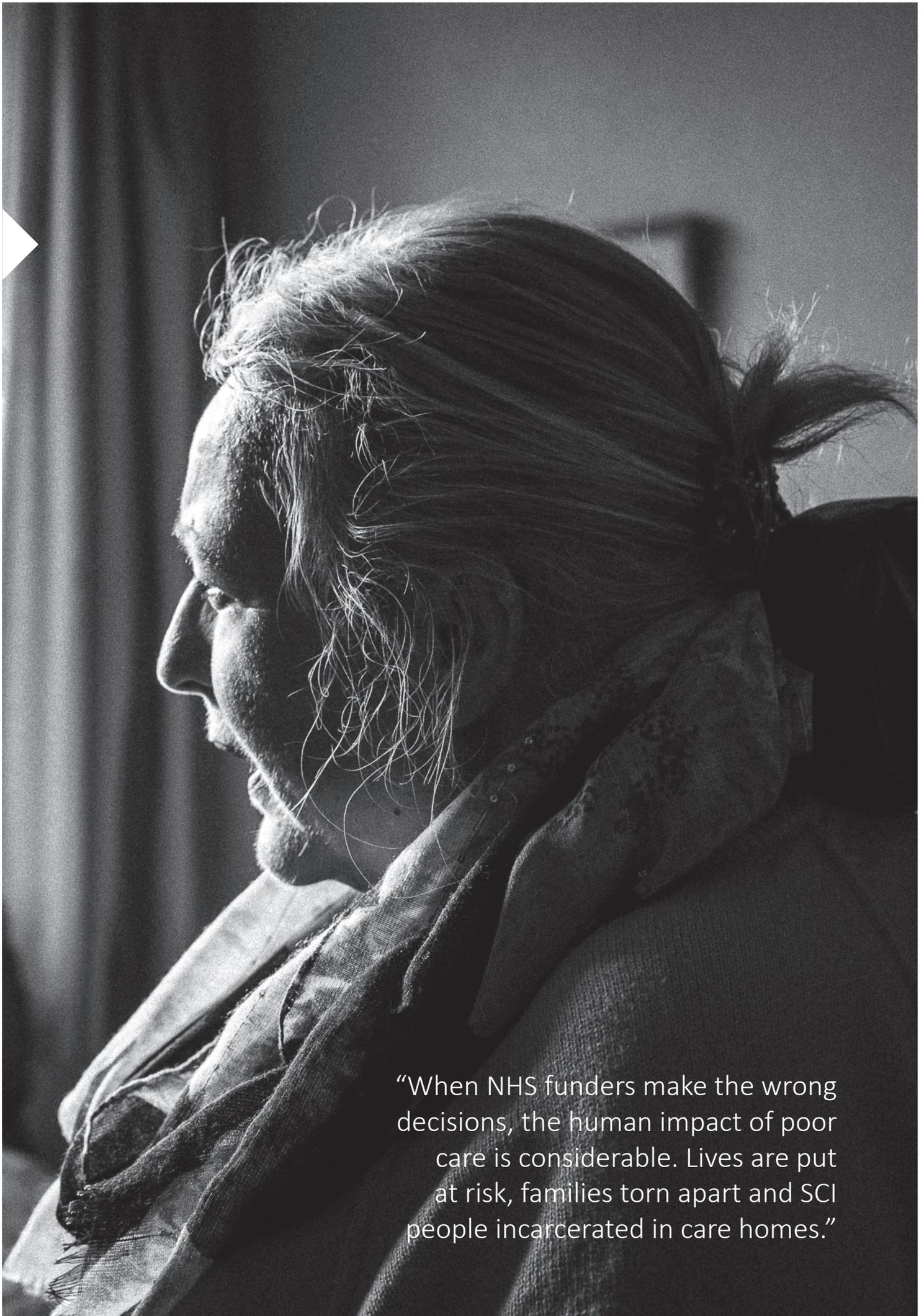
Commissioning by Clinical Commissioning Groups (CCGs) of NHS Continuing Healthcare (CHC) care and support packages must meet all of that person's assessed health and associated care needs and be in their preferred setting.

2. Eligibility decisions must be legal and comply with the Care Act

Decisions on eligibility for NHS Continuing Healthcare by Clinical Commissioning Groups must be consistent with primary legislation, case law and statutory guidance.

3. Clinical Commissioning Groups must be held to account

Oversight of the delivery of CHC must be independent and effective and include meaningful sanctions for those organisations found to be failing.



“When NHS funders make the wrong decisions, the human impact of poor care is considerable. Lives are put at risk, families torn apart and SCI people incarcerated in care homes.”

Introduction by Baroness Masham

When I founded the Spinal Injuries Association (SIA) in 1974, it was so that spinal cord injured people could access specialist spinal cord injury health services, an essential part of the path to a fulfilled life after injury or diagnosis.

NHS Continuing Healthcare is critical to so many spinal cord injured people. As a Government funded package of care that is not means tested, it supports people with the highest healthcare needs to live independent, healthy and fulfilled lives once they are outside of the hospital environment.

Yet many spinal cord injured (SCI) people are still not getting this essential care. The NHS Continuing Healthcare assessment process is open to local interpretation, often framed with the aim of cutting expenditure. Regional variations in eligibility are common, lengthy delays in assessments all too frequent and the appeals process burdensome. This all leads to wrong and unsafe decisions on eligibility.

Those that manage to get over this hurdle may then find themselves faced with unsafe care packages that do not meet their needs, or draconian policies forcing them to receive their care in nursing homes rather than living in their own homes with their families.



Across our networks, SCI people consistently share harrowing accounts of the impact these shameful and inhumane policies have on their health and well-being. These NHS organisations have further marginalized severely disabled people and denied them choice in their care. This is entirely wrong, especially when with the right support, they would be able to live at home with the families who love them leading fulfilled, productive lives.

Despite all of these issues, neither the Care Quality Commission nor any other agency currently has any independent oversight of NHS Continuing Healthcare, leading to bad and even unsafe practices continued.

This report documents the conclusions of the three leading charities for spinal cord injured people – Spinal Injuries Association, Back Up and Aspire. We have included recommendations for NHS Continuing Healthcare, alongside some of the personal experiences SCI people have had with NHS Continuing Healthcare. It is based on years of successfully advocating on hundreds of individual cases, as well as our active and sustained engagement with a wide range of NHS Continuing Healthcare experts, NHS England and the Department of Health and Social Care.

“Overall, our ambition since 1974 is little changed - that every single spinal cord injured person has the lifelong healthcare support they need to lead a fulfilled life.”

More than a number

NHS Continuing Healthcare - a manifesto for change

NHS Continuing Healthcare is a vital lifeline of support for severely disabled people whose health needs go above and beyond their social care needs.

It offers essential support for people with long term and serious health conditions, including those with a spinal cord injury (SCI) by providing long-term planned and funded care. CHC support enables people with a SCI, typically paralysed from the shoulders down, to live independently, confident that their health needs will be met. This may be in their own home or another location of their choice. It also ensures SCI people can be part of their family again. In many cases SCI people will resume work, engaging fully in society and ultimately leading productive and fulfilled lives.

NHS Continuing Healthcare is not means tested and CCGs are legally obliged to provide this care once a person has had their needs assessed and confirmed as eligible.

To receive NHS CHC funding, claimants must be assessed by Clinical Commissioning Groups (CCGs) according to a legally prescribed decision making process to determine whether the person has a 'primary health need'. Eligibility for NHS Continuing Healthcare is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided.

Yet we consistently hear a depressing and worrying tale of widespread variation in access and eligibility, delays in assessment and arbitrary caps on what is funded – all of which leads to unsafe care provision.

The human impact for the person and their families is simply devastating - stress and anxiety inevitably follow, families are torn apart, people are often unnecessarily put into care homes and serious health complications can develop.

There is also the financial impact; the victims of poor care decisions will often reappear with health complications in other, more expensive parts of the health system at a great cost to the NHS. This situation is indefensible, and simply cannot be allowed to continue.

It's quite clear that the right decisions, at the right time, offering the right care package in the right location will avoid the disastrous scenarios described in this manifesto and ensure a better quality of care is provided to those who need it most. This will not only ensure spinal cord injured people lead a fulfilled and productive life after the devastating impact of a SCI, but that the wider system itself will work more effectively and efficiently and at a reduced cost to the NHS.

NHS Continuing Healthcare

Our Concerns

In 2018 the House of Commons Public Accounts Committee (PAC) published a report ¹ on NHS Continuing Healthcare. The report followed an investigation by the National Audit Office and highlighted the Committee's serious concerns about how CHC is managed by both NHS England and the CCGs. It found:

- Some patients are not receiving the care they are entitled to because they are not made aware of the funding available, or because the system is too difficult for them to navigate. Written evidence to the Committee indicated that 78% of health professionals believe the system is difficult for patients and their families to navigate.
- Those people that are assessed spend too long waiting to find out if they are eligible for funding, and to receive the essential care that they need. About one-third of assessments in 2015–16 took longer than 28 days. About 10% of Clinical Commissioning Groups (CCGs) reported that assessments took longer than 100 days on average between November 2015 and October 2016. In some cases people have died whilst waiting for a decision.
- There is unacceptable variation between areas in the number of people assessed as eligible to receive CHC funding, ranging from 28 to 356 people per 50,000 population in 2015–16, caused partly by Clinical Commissioning Groups (CCGs) interpreting the assessment criteria inconsistently.
- The Department of Health and NHS England recognise that the system is not working as well as it should, but are not doing enough to ensure CCGs are meeting their responsibilities, or to address the variation between areas in accessing essential funding.
- NHS England wants CCGs to make £855 million of efficiency savings in CHC and NHS-funded nursing care spending by 2020–21, but it is not clear how they can do this without either increasing the threshold of those assessed as eligible, or by limiting the care packages available. Both options will ultimately put patient safety at risk.

The report accurately reflects the experiences of severely disabled SCI people who rely on CHC to meet their essential needs. Spinal Injuries Association's Advocacy team were successful in almost every one of the approximately 100 cases it fought on behalf of its members in 2018/9 which further demonstrates the serious shortcomings in the implementation of CHC policy and procedures and the impact it has on already vulnerable people. Spinal Injuries Association, Back Up and Aspire all frequently hear depressing and alarming accounts of cuts to the size of CHC funding that is reducing care provision to unacceptable and unsafe standards. There are instances of overnight care being removed and examples of people who have been threatened with a move out of their own home and into residential care due to CHC budgetary constraints.

- The patient experience of the complex application process is frequently stressful, confusing and combative.
- Care packages can be insufficient to meet an SCI person's assessed needs and in some instances are unsafe.
- Some CCGs try to save money by forcing SCI people to live in a care home even when they are medically able to live at home.
- Even when eligibility is agreed and care packages in place, claimants are in constant fear that their care will be withdrawn at a moment's notice.

¹ <https://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/inquiries/parliament-2017/investigation-nhs-healthcare-funding-17-19/>

NHS Continuing Healthcare

Making Continuing Healthcare work for SCI people

Well organised care that is safe and appropriate to an SCI person's needs transforms lives. Such care is life saving and life changing.

SCI people often share accounts of how good care can help rebuild their lives after injury, allowing them to be productive and contribute to society. Getting back into work, raising a family and living independently are all possible with the right support.

Yet as the case studies in this report also show, the same system can devastate lives. The human impact of poor care is considerable - lives are put at risk, families torn apart and SCI people incarcerated in care homes when NHS funders make the wrong decisions.

The financial implications are clear too. As our case studies show, the victims of poor care decisions merely show up in other, often more expensive, parts of the health system at a greater cost to the NHS.

We know that such devastating outcomes are unnecessary, avoidable and costly.

We urge the Government to take immediate action on three key aspects of CHC.

1. Care and support packages must meet people's needs and aspirations

Commissioning by Clinical Commissioning Groups (CCGs) of NHS Continuing Healthcare (CHC) care and support packages must meet all of that person's assessed health and associated care needs and be in their preferred setting.

2. Eligibility decisions must be legal and comply with the Care Act

Decisions on eligibility for NHS Continuing Healthcare by Clinical Commissioning Groups must be consistent with primary legislation, case law and statutory guidance.

3. Clinical Commissioning Groups must be held to account

Oversight of the delivery of CHC must be independent and effective and include meaningful sanctions for those organisations found to be failing.

Action is needed urgently in these three key areas. Without these measures, CHC will continue to fail SCI people with inevitable and life threatening consequences.



We believe...

1. Care and support packages must meet people's needs and aspirations

CCGs must prepare, plan and deliver care in ways that enable SCI people to live at home, or in a setting of their choice.

Over the last 50 years, SCI people have consistently shown that with the right rehabilitation, care and support, they can live independent and fulfilling lives in the community, actively participating in family life, learning and work.

Spinal Injuries Association, Back Up and Aspire want CCGs to follow the letter and spirit of the Care Planning and Delivery Guidance in the 'National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care 2018 (Revised)'. They should commission care packages that:

- Are based on needs-led care planning and sufficient to meet all of the person's assessed health and associated social care needs.
- Place the wishes and choices of SCI people at the very centre of decision making and care planning. The NHS must maximise personalisation and control and place the SCI person's preferences for the nature and setting of care and support at the centre of the care planning and delivery process.
- Have no arbitrary financial or hourly limits on "care at home" packages.
- Give due regard to the person's Human Rights, in particular the right to respect their private and family life and the right to live independently and to be included in the community¹.

¹ UN Convention on the Rights of Persons with Disabilities (Article 19)



We believe...

**2. Eligibility
decisions must
be legal and
comply with the
Care Act 2014**

The 1999 Coughlan judgement established the clear legal boundary between local authority responsibilities and the NHS. However, all too frequently those with the same or greater needs than Ms Coughlan are found ineligible for CHC.

We are calling on the NHS to work with us to develop an accurate and comprehensive health and care needs profile of Ms Coughlan at the time of the Court judgement.

This needs profile must be used when considering the eligibility of SCI people for NHS CHC. Where there is clear evidence that the person being assessed has levels of health care need that are equivalent to or greater than those of Ms Coughlan, then they must be found eligible for full NHS Continuing Healthcare.

Eligibility for CHC is a matter of law and not a matter of policy:

- The statutory guidance for CHC directs CCGs to consider the primary legislation and Coughlan judgement when deciding whether an individual is eligible for CHC.
- Primary legislation (The Care Act 2014) sets a limit on the amount of “health” care that a Local Authority can lawfully provide. Once the person’s “health” care needs exceed this threshold, it is unlawful for the Local Authority to provide them with any care and support and instead becomes the responsibility of the NHS.

- The Court considered this lawful limit of Local Authority provision in the case of R v. North and East Devon health authority ex p Coughlan (1999). Miss Coughlan is spinal cord injured and the judgement was that her “health” care needs were “of a wholly different order” to those that a Local Authority can lawfully provide.

This Coughlan case is significant because complete SCI is almost unique amongst long-term conditions:

- It is possible to predict an SCI person’s long-term health care needs with a high degree of accuracy, once the initial period of rehabilitation has been completed.
- It is possible to make accurate and direct comparisons between people with the same neurological level of injury, as defined by the corresponding vertebra or vertebrae.
- It is a non-improving condition where, after the initial period of rehabilitation has been completed, it is highly unusual for the person’s health and care needs to be permanently reduced or removed.



We believe...

3. Clinical Commissioning Groups must be held to account

The CCGs' understanding of CHC, including their statutory responsibilities, is deeply flawed. There are significant regional variations in eligibility decisions, and far too many decisions by CCGs are being overturned on appeal. Independent oversight of the whole CHC process is now desperately needed, as this will hold CCGs to account for their decisions and also help improve the quality of CHC delivery across the country.

We demand truly independent oversight of the entire NHS CHC process – assessment, commissioning and delivery. There is urgent need to ensure independent oversight of CHC eligibility decisions and the commissioning of care packages. The process of challenging individual decisions is not fit for purpose and causes considerable and lengthy stress to claimants at a time when they desperately need help and support:

- The process is wholly imbalanced, pitting a well-resourced CCG against an under-resourced individual, who is usually going through a traumatic life event.
- The delays in the appeals process (typically it takes three years to progress through the system) demonstrate a denial of justice for the affected person.
- There is a complete absence of an independent complaints process. If the claimant is unhappy with the outcome of a challenge to a decision, there is no meaningful independent complaints process, short of resorting to the potentially costly legal route.

There is no meaningful sanction imposed on CCGs even when they are clearly shown to have failed to follow Department of Health and Social Care statutory guidance. This independent oversight must include:

- A simple, independent and rapid complaints procedure for people being assessed for or receiving CHC funding.
- Meaningful sanctions on NHS bodies (both CCGs and NHS England) who act unlawfully in making eligibility decisions or who commission inadequate or inappropriate packages of care for those who are found eligible.

CCGs are failing to follow the statutory guidance published in the National Framework for NHS Continuing Healthcare. This is ever more common, and the effects on SCI people are significant. Examples of these serious shortcomings include:

- Assessors failing in their statutory responsibility to make a recommendation on a SCI person's eligibility for CHC to CCGs
- CCGs using lawfully questionable "ratification panels" (or other similarly termed bureaucratic structures) to overturn recommendations of eligibility without giving the required substantive justification.
- CCGs either failing to implement NHS England Independent Review Panel (IRP) decisions that they disagree with, or unjustifiably delaying the implementation of the IRP decision.



The following case studies were developed in partnership with SIA's Advocacy Team and highlight the appalling human impact that poor CHC decision making has on spinal cord injured people.

Case Study

Maria Adamson

In 2013, Maria Adamson, from Lancashire fell down the stairs. She became a tetraplegic with almost no movement below the neck. She spent two years in hospital but just weeks before she was due to go home, her husband was tragically killed in a motorcycle accident.

NHS funded 24 hour Continuing Healthcare (CHC) made a huge difference. Supported by carers who could manage her complex needs, she was able to live at home and spend time with her family.

During this time she had two reviews. Each concluded she was eligible for CHC funding as her health had not improved. At her next 'routine' review, her local NHS funders immediately withdrew her 24/7 care, even though previous assessments had confirmed her eligibility for the essential care that enabled her to lead a safe and independent life.

The family were forced to ask the local social services department for help. Yet all they could provide was six hours of care a day. Maria said. "I can't do anything without support, I can just about pick up gadgets so I really depend on other people. How can I manage on six hours a day with my needs?"

Maria had no choice but to move out of the family home and into a care home. She added. "I've been here eight months. It's not like at home. They don't really meet your needs and don't really look after you. At home and with 24 hour care I could do anything I wanted. They were always there and if I wanted to go out, to a meeting or to see friends, I could go, even travelling to meet my sister. The care staff were familiar with things like Autonomic Dysreflexia – a life threatening condition that I have and all of the other issues associated with my needs. I'm terrified that I will be here for the rest of my life. It's unbelievable how they've done this to me. I just feel I am a number, not a person. I wouldn't wish it on anybody to be in a situation like this."

At the time of the publication of this report, and following SIA's involvement in her care, the local CCG have verbally agreed to reinstate her care package. Meanwhile, Maria's health has declined and she has been admitted to hospital with pneumonia.

"I'm terrified that I will be here for the rest of my life. It's unbelievable how they've done this to me. I just feel I am a number, not a person. I wouldn't wish it on anybody to be in a situation like this."



Case Study

Val Thompson

In 2013, Val fell down the stairs at home and broke her neck. In that moment, her life changed forever. Val spent the following year in hospital and with an NHS Continuing Healthcare package in place, was finally able to return home to live with her husband again. They were now able to start rebuilding their lives together.

However, in 2017, after what should have been a routine reassessment, Val's care was withdrawn with just five days' notice. A letter from her local NHS funder said, "Following discussion of all supporting evidence, NHS Midlands and Lancashire Commissioning Support Unit concluded that you are no longer eligible for fully-funded Continuing Healthcare. Although you have a number of care needs, they are routine, predictable and non-complex in nature." Val was now expected to rely on her husband to act as a carer and pay for most of her care herself.

Val was distraught. She told us, "There is simply no way I could manage without carers. I had a routine review but the assessment was no more than a brutal box ticking exercise. I got a call on the Friday to tell me that my care would cease on the Wednesday. I just broke down. I just could not see how we could manage. I just burst into tears. I need the carers so I can live at home.

With the help of SIA, I appealed. Once I was told I had got my package back, I was over the moon. It was such a huge relief. To think that's what they can put you through is horrendous. It's not something I would wish on anybody.

"I got a call on the Friday to tell me that my care would cease on the Wednesday. I just broke down. I just could not see how we could manage. I just burst into tears."



Case Study

Mr Q

Mr Q is a 49 year old man who has a C5/6 injury, and is paralysed from the shoulders down. He has been spinal cord injured for 31 years. Though he did not want to be photographed, as he was on bed rest as part of treatment for Pressure Ulcers, he was keen to share his experience with us:

Initially when I had 24 hour care my health was fairly good. I used to volunteer in the disabled community and was the chair of my local disabled group. I ran a pilot scheme for hiring out mobility scooters. I was awarded 'community volunteer of the year' back in 2009. My name was in two different newspapers.

My carers lived locally, so sometimes, if I didn't need them I might send them away for a couple of hours as I knew they were just a phone call away. When my local CCG found out that I was doing this, they cut my care to seven hours a day as well as a night visit.

The result was catastrophic. I rapidly developed a long list of problems including spasms in my bladder and blockages which required an immediate washout. With 24 hour care this was never an issue but became a serious problem when my hours were reduced.

From September 2015 to September 2016 I was admitted to the local district general hospital five times, staying for a total of two months. They were not familiar with spinal cord injuries and my care

went haywire. I had very low self esteem, and was frustrated, angry and sad. I also had five cases of septicaemia and two massive seizures. I had panic attacks, frequently passed out and was in dangerous life threatening situations. It was as if my life didn't matter, just the pennies.

The CCG eventually realized that they were spending more money on hospital admissions than if they returned me to 24 hour care at home, so that catheter issues, blockages etc could be dealt with immediately, at home, without the pain and cost of going to hospital. My care was reinstated, but only after they had ended up spending more money, causing more damage to my health and giving me further long term health issues. Now, I have had no hospital admissions. I am in a better place and there is less uncertainty in my life.

People need to understand that a person's health may be settled, but it doesn't mean it will stay that way if care is reduced. I feel it's cheaper in every way to pay for 24 hour care than for repeated hospital admissions.

"With 24 hour care this (life threatening health complications) was never an issue but became a serious problem when my hours were reduced."



Case Study

Peter Hamilton

I was living in New York and working for an investment bank as a software developer. But in the weekend I was a skydiver. I loved doing it, and every weekend I could I was travelling out of the city to jump out of a plane. On the fateful day, I had an unlucky landing, I had a tumble. There wasn't a scratch on me, but I had broken my neck and became a C5/6 tetralegic.

I was in hospital for 17 months, first in New York and then in the UK. Now I had to battle for my care. It was soul destroying. We went through a huge amount of effort. There was loads of waiting and we were initially rejected. We felt like giving up at that point – there was so much stress and heartbreak battling against these people who seemed to be out to reject you at all costs.

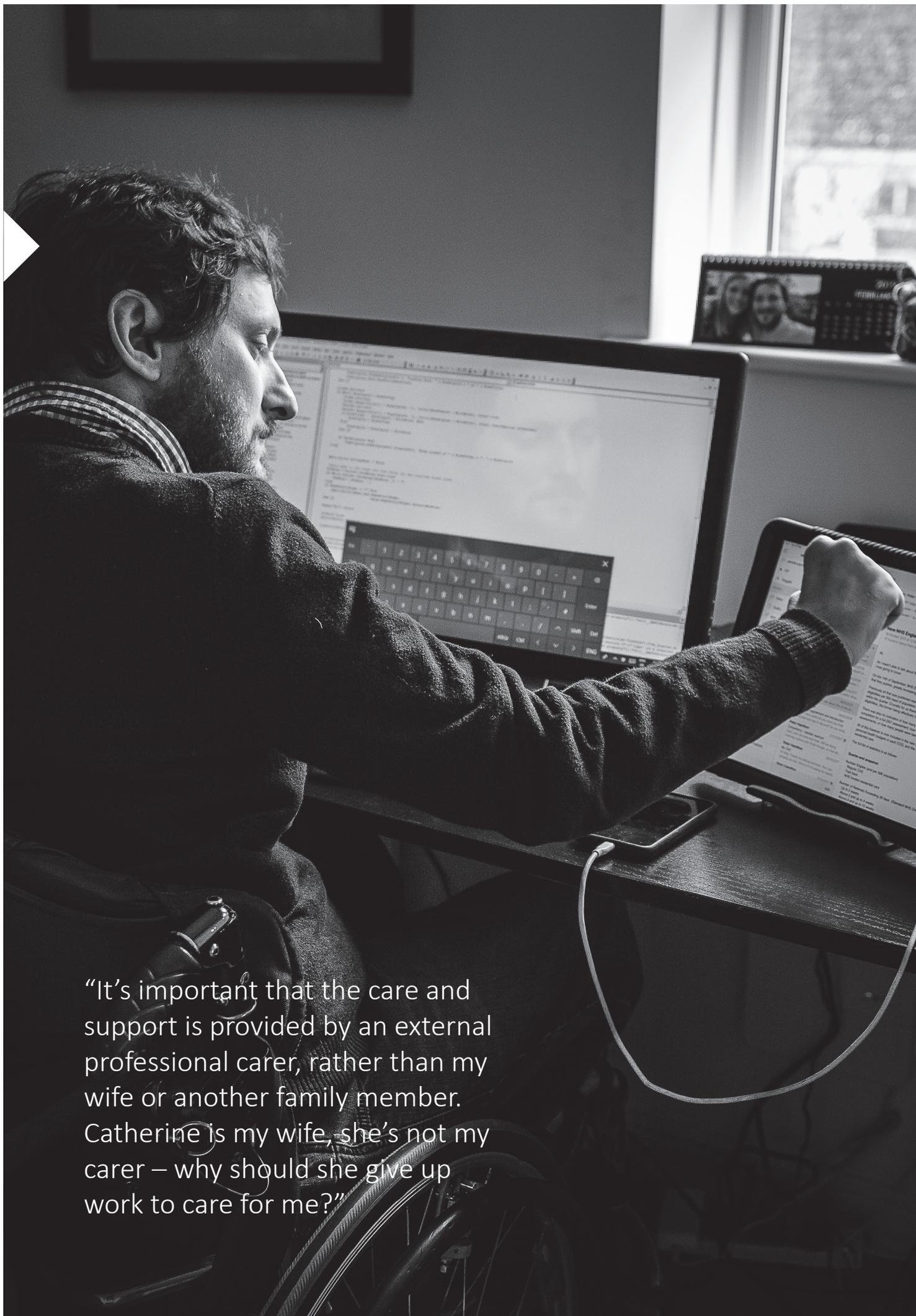
They consistently underscored my condition and that was completely unjust. They assessed life threatening conditions such as Autonomic Dysreflexia (a severe and unexpected increase in blood pressure) and Pokliothermia (an inability to regulate body temperature) far too low essentially disregarding their importance. The Nurse Assessor even asked if I had any income so it felt there was some unofficial means testing which is completely against the assessment process. From the beginning it seemed she was out to marginalise my needs and find any reason she could to reject my application.

After much distress, a care package was agreed and is now running well. I need people who are well trained and understand the complexities of my condition. I've had no challenges, the care reviews have gone well. I think I'm definitely one of the lucky ones in that regard.

It's important that the care and support is provided by an external professional carer, rather than my wife or another family member. Catherine is my wife, she's not my carer – why should she give up work to care for me?

My carers come in the morning, stay all day and then leave. The care package allows me to work, have a life. Since my accident I've been able to get back to work, start my own business, live independently. Whilst I do all of that I have a PA to support me. We've just had a baby, we can go out and do shopping, I can be a husband to my wife, not a burden. I honestly couldn't be happier now and that's all down to a good care package.

I can't imagine if these people ever put themselves in our situation and think about how it feels. The cruelty going on in the system right now due to funding pressures is destroying people's lives.



“It’s important that the care and support is provided by an external professional carer, rather than my wife or another family member. Catherine is my wife, she’s not my carer – why should she give up work to care for me?”

Conclusion

“I was terrified,” explained Val Thompson, one of SIA’s members whose care was abruptly removed after an ill informed review.

After months of stress battling NHS decision makers, common sense finally prevailed and her care package was restored. Yet Val’s experience and those of other SCI people in this report are by no means unusual. Indeed, we often hear of people scared to go on the record fearful that their situation will be made worse if they speak out.

How is it possible that a package of care, designed with the intention of helping severely disabled people has gone so wrong? A smooth experience of care should be the norm, not the exception. It is our view that current provision is frequently inhumane and sometimes unlawful. The basic aspirations of safe care and a fair, accessible system are being lost. A lack of understanding of the NHS’s own rules, severe cost cutting pressures and shortages of trained staff are all to blame.

Everybody should have the right to lead a fulfilled life. It is outrageous that in the 21st century and in one of the world’s most developed nations vulnerable people are forced to accept unsafe care due to poor NHS decision making. It is nothing less than a national disgrace.

Yet, there is hope. We are working to highlight these injustices. We have identified practical changes that will improve people’s experience of CHC and even save the NHS money. When someone’s care needs are not properly met, they do not disappear. They simply re-emerge in another invariably more costly part of the NHS. We’re working hard to share these measures more widely and are committed to working in partnership with like-minded organisations to make them a reality. In this respect we remain true to the principles of Baroness Masham who in 1974 set to ensure that every spinal cord injured person should get the care they need to lead a fulfilled life.

With thanks to our case studies who so kindly shared their experiences – Val Thompson, Mr Q, Maria Adamson and Peter Hamilton.

“It is outrageous that in the 21st century and in one of the world’s most developed nations vulnerable people are forced to accept unsafe care due to poor NHS decision making.”





Spinal Injuries Association (SIA) represents the interests of the 50,000 people living with a spinal cord injury in the UK, as well as the many hundreds of thousands of people who are their families, friends and health professionals. We provide spinal cord injured people with the hope, confidence and practical skills to rebuild their lives in the aftermath of injury, during their rehabilitation and at any time afterwards. SIA supports spinal cord injured people and their families with practical and emotional support, advice and information, empowering them to lead full and independent lives. We campaign for change, ensuring that each person can lead a full and active life.

For more information visit
www.spinal.co.uk



Back Up is a national charity that inspires people affected by spinal cord injury to get the most out of life. Each year, we reach over 1,000 people with our award-winning services that are designed and delivered by people affected by spinal cord injury. With a team of over 400 volunteers, we offer wheelchair skills training, an accredited mentoring service, telephone support, life skills and activity courses, and support returning to work or education. Back Up also offer support to family members, and we're the only UK charity with dedicated services for children and young people with a spinal cord injury.

For more information visit
www.backuptrust.org.uk



Aspire is a leading national charity that provides practical support to people who have been paralysed by Spinal Cord Injury, helping them move from injury to independence. Aspire exists because there is currently no cure. Our services include Accessible Housing, Independent Living, Housing Advice, Welfare Benefits Advice and Assistive Technology.

For more information visit
www.aspire.org.uk

Leigh Day

Leigh Day is proud to support 'More than a Number'. As a claimant-only law firm specializing in spinal cord injury claims we see on a daily basis both the devastating effects of spinal cord injury and how good care can transform lives. But we also see huge strain placed on severely disabled people as they struggle to navigate a system that too often works against their needs at a time when they need support the most. For this reason we are delighted to support this report and challenge cuts to NHS Continuing Healthcare.

'More than a Number' is a really important contribution to ensuring that every severely disabled person can get the care and support they need to lead a fulfilled life. It deserves to be read by anyone with an interest in the long term care of severely disabled people and we remain committed in our support of a full, active and independent life for every SCI person.

Get involved

To support our campaigning work or to comment on this report, please contact:

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