British Red Cross

CARE STORY

Refusing to ignore people in crisis

What is care story?

People are at the heart of the health and social care system. Whether they are informal carers looking after loved ones, volunteers and professionals working across the sector, or people receiving care and support – everyone has a story to tell.

We have been asking people to share their care stories – the good, bad and mixed – to help us better understand what is working through the eyes of those on the ground.

Thirty-five stories have been analysed so far. They have been touching, tragic, funny, inspirational – and above all human. Each has offered an honest and unique perspective on what it is to give and receive care in the UK today.

Below are a few insights we have already started to gather from reading through people's experiences. They are broken down into the following themes:

- Pressure on frontline services
- The need for person-centred care
- The need for lower-level, preventative care
- The need for integrated care

The stories submitted so far have undoubtedly reinforced our call for everyone to get the support they need to live independently at home.

Pressure on frontline services

- **Health-care professionals and volunteers working across the sector have written about a lack of resources in the community and the contribution this makes to hospital bed shortages and delayed transfers of care.**

Typical consequences that people have highlighted include the cancellation of operations, pressure on emergency services, and people remaining in hospital because they have not yet received a suitable care package.

"My role includes identifying the functional needs of patients and determining whether they are safe to go home, or are in need of rehabilitation or a package of care. Currently we are at the centre of the social care crisis. All too often, we recommend that someone will need a package of care to return home safely and then watch them remain in hospital, despite being medically fit for discharge. We continue to work with people to maintain and improve their mobility and activities of daily living. However, without the resources in the community, people have to stay in hospital. They are at increased risk of picking up an infection and generally deconditioning."

(Occupational Therapist working in an acute hospital)

"I am a retired nurse and I experienced on many occasions 'bed blocking' due to the lack of care packages available for people to return to their own home safely. I worked on a busy surgical ward and found that the lack of social care available in the community was a major contributing factor to the delay in discharging people from hospital. I found this delay frustrating as it had a knock on effect to other people and usually meant a delay or cancellation in operations due to a lack of beds."

(Former nurse who has experienced slow patient flow)

The inefficient provision of medicine and how it slows down discharge was also touched on. Suggestions as to how to improve patient flow included investing in in-patient pharmacies and discharging patients who live locally as soon as possible after breakfast or ward rounds and courier their medicines to them.

The need for person-centred care

- **The need to look beyond people's conditions and illnesses and recognise what is important to them as a person, has been emphasised in several stories.**

"Our aim is to help them focus on what is important to their recovery, build up their emotional and physical strength and re-engage with friends and activities… Through discussion, we learned that the person had served in the Forces; we referred to the Linburn Centre for The War Blinded after which an Outreach Worker carried out an assessment of their home, providing them with aids."

(*Someone writing about a pilot initiative in Scotland for cancer patients* - Transforming Care After Treatment [TCAT])

- **For many, the top priority is to regain or maintain independence, wanting to remain in the family home and the community in which they are familiar.**

"They were desperate to remain independent"

"The aim is to enable people to live as independent a life as possible in their local community"

"…we asked if she could go home to be told that there was no support in the community at such short notice as she was going downhill quickly. All we knew was she did not want to stay in hospital"

"Mum was not discharged home immediately but spent three more weeks in an EMI Unit where she thrived but was desperate to return to her own home where she was born 93 years previously"

"As well as freeing up beds, discharge in the morning would also be better for patients - it is not fun having to wait until the evening before you can go home."

"I looked after my Mom for years who had dementia along with a lot of other medical problems. She was a very private person who preferred to be in her own home."

> **An overstretched system results in carers and other health workers having less time to focus on the needs of the individual. Two stories mentioned that when a care plan was in place, it was often overlooked.**

"My wife's needs increased as palsy progressed. I only saw one carer read the plan… They were always pushed for time, would skimp on the plan and sometimes left my wife in a hurry and in tears. The only time I left my wife was when the carers came, twice a day for 20-30 mins. I did most of the care, hoisting, toileting myself."

(Someone who provided round the clock care for their spouse)

"The Agency regularly sent new carers (they had a very high turnover) who rarely read the Care Plan and my father who didn't want strangers dealing with his private hygiene was irritated and resentful."

(Primary carer for a parent with dementia)

> **Everyday needs are not always being met. Some people struggle to find the time to provide full time care for their loved ones.**

Family members are often expected to take on the responsibility of meeting these needs themselves. However, in reality this can be a struggle.

"I also have to help with the hygiene, in terms of getting a shower, but it is also difficult because we leave the house very early, and arrive very late due to work and University, therefore, sometimes we cannot help with the hygiene, and taking a shower on her own, puts her life at risk because she might fall, hurt herself or even worse, and there is no one to help her. Also, we had to cancel a few medical appointments because we just do not have time, we cannot afford to get out of our jobs and University."

(A university student whose family is struggling to care for a relative)

> **Sometimes the pressure facing families can be made worse by a lack of information, difficulty navigating a complicated system and particularly frustratingly, administrative errors.**

"…It turned out later that his original assessment had been filed incomplete. That only came to light because I spoke to someone in the Voluntary Sector who flagged up that I hadn't had a Carer's assessment. We were flailing around then because the financial situation was so difficult. My father had been assessed and granted Pension Credit which meant his Council Tax was waived…My live-in presence at my father's home meant he lost an increment on his assessment" so he lost his Pension Credit and Council Tax relief AND was told he had to pay back about 8 months of benefits."

(Someone who was the primary carer for their father)

"One family member caring for their spouse mentioned that their needs were also not taken into consideration, increasing feelings of distress."

The need for lower-level, preventative care

> **Even the smallest of interventions can have a big impact on someone's life and reduce the risk of readmission or the need to move into a care facility.**

"I was very grateful when the British Red Cross came and fitted two wall rails in the bathroom and one in the downstairs loo. British Red Cross also loaned me a special stool to sit on whilst having a wash at the kitchen sink in the early days after my operation."

(An elderly person who benefited from a simple intervention provided by the British Red Cross)

"A Border Care Alarm was also arranged in case they fell or took ill… in addition they were given a vibrating pillow."

(Someone writing about the support received by a cancer patient)

> **A person's physical and emotional wellbeing are both important to recovery and prevention.**

Being able to take part in everyday activities can help people work towards achieving their goals; giving people the opportunity to adapt and live with a condition or illness and not be defined by it.

"Working has made my body and legs stronger. Working on the till, lifting bags of donations, hanging and rotating clothes helps my hands. It's like going to the gym."

(A volunteer who's main concern was to return to work – they have cerebral palsy, asthma and suffer from depression)

> **By engaging with the local community in which the individual needing care resides, it is possible to reduce feelings of loneliness and isolation.**

'As a Red Cross volunteer I have just finished visiting an elderly lady in my local area as she felt very isolated and had several medical issues including vascular dementia. She was no longer able to drive and felt very lonely and depressed as her only relative lived in London. Although she was known within the local health care system and had visits from health professionals I was able to contact three local clubs run by individuals at Age Concern and arrange for her to attend luncheon and social clubs (including transport)… I feel this interaction has really helped the service user to feel part of her community and to give her some interaction with others on a regular basis.'

(Red Cross volunteer)

> **Cuts to services mean that people are are not able to to access the lower-level support needed to continue to live in their own home.**

“Some services used to provide help to vulnerable people who needed transportation to a medical appointment; helping with domestic tasks, such as cooking, maintaining the house clean, and help with hygiene, such as taking a shower. Unfortunately, I am aware that those services are less available now, and some of them you have to pay, therefore, there are more vulnerable people who do not get any support and some who have go into care homes because they don’t have anyone to support them at home, which it is quite sad because living at home is different than living in a care home. People often feel like they have more dignity and more independence if they lived at home.”

(A university student whose family is struggling to care for a relative who wants to stay at home)

The need for integrated care

- **Several stories highlight the need for improved communication and co-ordination of services.**

Some stories have been positive about the effectiveness of multidisciplinary teams in areas where integration has started to take place.

“… I then phoned our local medical practice, and our G.P. assessed him over the phone. He decided that he did not require hospital admission, but alerted the integrated emergency response team based in South Cumbria. From that point on the care and attention he has received from the G.P., the response team, the medical practice, the occupational therapist and, most importantly, the locally based bank of district nurses has been outstanding. I cannot praise too highly the support and help he has received and continues to receive. As a result of all the combined efforts he is now well on the road to a full recovery.”

(The son of an elderly man who needed support in the home after having a fall)

- **Collaborating with other services beyond health and social care can further ensure safety and wellbeing. This includes the emergency services and other departments such as housing.**

“The local fire safetyofficer visited to discuss fire safety and to check their smoke alarms”

(Support given to a cancer patient)

Our agent arranged a joint visit with the housing officer who inspected property and agreed that our client was actively trying to clear her home

(Help given to a lady to remain in her home after the council started an eviction process due to hoarding)

This is just a taster of what we have been told so far. Other issues such as the post-code lottery dictating the quality of social care received; hospital treatment; and ambulance response times as well as concerns that those unable to self-fund might not be receiving the same level of care have been highlighted. A more detailed report will be published later this year.

Recommendations

Care needs to be adequately funded, person-centred, preventative and integrated.

- **Social care should be given the funding priority it deserves.**
    - An independent analysis of current and predicted levels of unmet need in the short, medium and long term, including costings, should be carried out as a priority.
- **Our care system needs to look beyond a person’s condition or illness.**
    - We must make sure people are at the centre of their own care and move away from a one-size-fits all approach to treatment and support.
    - This involves taking the time to learn about the person as a whole by listening to what they want to be able to achieve.
- **Non-clinical interventions, such as emotional and practical support at home, mobility aids and services that help reduce loneliness and social isolation, should also be better recognised**
    - The upcoming Green Paper must look at ways non-clinical interventions could play more of an integral role in our health and care system.
- **More people should be able to access preventative services so that fewer people reach the point of health and social care crisis:**
    - The upcoming Green Paper must look again at what resources are needed to make the prevention vision, including the Care Act’s prevention duty and responsibilities, a reality.
    - All health and social care planning documents, national and local, should fully incorporate and prioritise prevention.
- **Care should be better integrated.**
    - More needs to be done to both explore what is meant by integration as well as what is needed to make it work in practice.

Authored by Matthew Eaton, with support from Olivia Field.. For any further inquiries please email:
advocacy@redcross.org.uk   www.redcross.org.uk/carestory   #CareStory