

## Response from Carers Wales, June 2020

### Health and Social Care Committee:

#### Inquiry into Hospital discharge processes



Carers Wales is part of Carers UK. Established in 1965, we have led the carers' movement for over 50 years. We are a responsive, expert charity, led by carers, for carers and with carers. As the UK's only national membership charity for unpaid carers, we are highly respected in our field. Since our inception, we have been campaigning with carers, transforming understanding and winning critical developments in carers rights.

Carers are not a homogenous group and will have different needs depending on their caring situation and caring responsibilities. In Wales according to You Gov polling in 2019 suggested that there were almost 400,000 carers in Wales<sup>i</sup> (at the last census in 2011 there were 369,186 carers). Of these carers 87,173 were aged 65+ and 131,120 aged between 50-64. Since the Covid19 pandemic, new research by Carers UK<sup>ii</sup> suggests that an additional 196,000 people are caring for an older, disabled or seriously ill relative or friends bring the total number of carers in Wales to over 683,000.

We welcome the Committee's inquiry into hospital discharge processes. Many carers have told us that they have not been consulted or involved in the discharge process for those they care for prior to the person being discharged, despite there being clear policy that carers should be consulted prior to discharge and that carers have a right to have their needs assessed under the Social Services and Well-being (Wales) Act 2014.

#### Context

The Wales Audit Office has published reports on delayed transfer of care, one in 2019 and another in 2016. The reports highlight that delayed transfers of care are a consequence of a whole system problem which is not being responded to effectively. The Parliamentary Review of Health and Social Care in Wales (January 2018) suggested principles for seamless care and a seamless system where health, social care, and others integrate and work together to deliver clear outcomes. This seamless care should also include the feelings and wishes of the patient, as well as the carers who will ultimately be looking after the person on return home.

The Social Services and Well-being (Wales) Act 2014 give carers a right to an assessment of what support they need and, where relevant, that the assessment take place prior to a person taking on a caring responsibility. Anecdotal evidence shared with us suggests that carers are not being considered prior to discharge, not receiving carers assessments and it is being assumed that carers can and will take on aspects of care.

A Healthier Wales expects that in the future, care will be provided closer to home with a seamless whole system service. The ambition within the plan for care being provided closer to home will inevitably mean that carers will be expected to take on more caring responsibility. Page 7 of A Healthier Wales states "as part of working together to achieve our future vision, we need people to take more responsibility, not only for their own health and well-being, but also for their family and the people they care for, perhaps even for their friends and neighbours. As highlighted by a carer responding to Carer Wales Track the Act 2018 stated "this policy explicitly proposes increasing the responsibilities of carers". It is therefore vital that carers are identified at the very earliest opportunity within health settings, are given the information and advice they need, are told their rights and are treated as with dignity and respect as equal partners in care. This could include carers receiving

proper practical guidance, and where necessary, training on aspects of care such as administering medication, manual handling.

We wholeheartedly support your Committee's recommendations in your Caring for our Future report on the inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers. Recommendation 21 states: *Carers should also be identified by health service staff, given information about their rights to a carers' needs assessment and be considered as equal partners in care in discharge processes within health settings.*

### **The experiences of patient's families and carers of discharge processes**

In response to the inquiry, we particularly want to share the experiences of unpaid carers of discharge processes.

We have received feedback from carers that they have refused to accept a patient home, deeming it to be an unsafe discharge because necessary support and services have not been put in place. We also have anecdotal evidence of instances where patients have been discharged and have been re-admitted, or have been close to being re-admitted due to a failure in discharge processes and carers not receiving adequate services.

**In order to support this response to the Committee, we asked carers for their direct experience through an online survey. We had 11 responses which were mainly experiences pre-Covid19.**

Even though this is a small response, from a range of different health board areas across Wales, it is worrying to see how carers are still not routinely being told about their rights, identified and treated as partners in care.

**We asked: Was there a delay in your loved one being discharged from hospital, if yes, why do you think this was?**

*"it took a long time from being told about discharge to actually getting it signed off. The biggest issue seemed to be with the pharmacy and a lack of clarity as to what was happening at shift change. There was also an issue that the patient was told about discharge and details were not given to me. I had to wait to speak to a doctor"*

**When asked whether they thought the discharge was safe**

"Eventually. I was on the cusp of refusing to take them home as I didn't think they were ready and the necessary arrangements hadn't been put in place... it appeared to be a case of making space for beds"

"No wheelchair to bring him home"

"No, they couldn't wait to get <them> out of there"

"No, not at all"

"Lack of support"

"First discharge failed"

"He was discharged without my consent at short notice in what I would call a sly way as when I went to visit one evening he was packed with his medication to come home and his bed given to someone else. This ended up as a failed discharge as my husband went back in the next day and was in for a month. Very poor discharge and nothing set in place for follow up care".

"Not at all. My husband was seen by our GP the next morning and found it hard to believe he was sent home so ill. Drove him back immediately to be re-admitted to hospital and the staff in A&E could not believe he had been discharged the day before"

"No, they wanted her out. Four days after a pacemaker was fitted they said she was ready to discharge, I couldn't have her come home to me as I was staying with my sister, who was ill at home, so that I could care for her and her terminally ill husband who was confined to bed. They kept her in for another week".

"No, she was still not well enough. She was not eating, having blackouts, doubly incontinent and confined to bed".

"A long time waiting for mediation"

"It was unsafe"

"Repair work <needed> on his home"

We also asked carers a number of other questions:

**1. When your loved one was in hospital, were you identified as a carer?**

- 6 said no
- 2 said yes
- 1 was unsure
- 1 was the carer in hospital

**2. If you were identified as a carer, were you given information and/or advice?**

- 8 responded no
- 1 was an in-patient
- 1 was only given information about the procedure for her son

**3. Were you involved in the discharge process?**

- 8 responded No
- 3 responded Yes (but one already had a care plan in place)

**4. We asked whether they were consulted in what aspects of care they were willing and able to do.**

- 7 responded no (with one commenting that they just assumed that they would do it)
- 1 responded yes
- 1 responded saying that they had been assertive and told them what they were able and willing to do

**5. We asked whether they had been offered or told about their right to have their own needs assessed through a Carers Needs Assessment or What matters conversation.**

- 10 said no
- 1 said yes (but that they were already in the system)

**6. We asked if their loved one was identified as needing further help did they get 6 weeks free care after discharge from hospital?**

- 7 responded no
- 3 deemed it not applicable
- 1 answered yes (but it was not offered and it had to be brought to their attention)

In addition to the above, carers have also recently told us the following:

“From my personal experience, I found that the discharges of my father from hospital were often protracted as numerous professionals in health and social care needed to be involved. I was the carer for my parents for many years. My father was physically frail and was living with my mother who had Alzheimer’s disease. For some years, they lived in their own home with both of them receiving a package of care with 4 visits a day. My father needed numerous admissions to hospital with either pneumonia or as a result of falling. The discharge planning did not start until my father was found by health staff to be medically ready for discharge and then it required social services staff to make an appointment to assess him and then plan, commission and plan a package of care. During his admissions to hospital, my father’s ability to stand and walk decreased significantly and he ultimately needed to be in a wheelchair”.

Stay in hospital from 18<sup>th</sup> February 20 – 10<sup>th</sup> March 20 - I fell downstairs during the evening of February 17<sup>th</sup>. The following morning, my GP advised me to call 999 which resulted in me going by ambulance to the Royal Gwent Hospital I had fractured my pelvis. The staff and other patients on the first ward, where I was for the first few days, were all lovely. However, I was transferred about 3 or 4 times after and ended up on a dementia ward. We were all given leaflets about the Hospital Discharge Procedure. A lady came to see me on the morning of the 10<sup>th</sup> and said she would come back later to discuss my discharge. She never came back. To my surprise, I was told at lunchtime that my transport was waiting. I asked repeatedly about my medication, but none was forthcoming. I was taken home by ambulance and arrived at 2 pm. I was given a Zimmer frame with no tray. I still couldn't walk, but no thought had been given to how I was to prepare food and drink. My medication was delivered by taxi some time during the evening. I live alone and feel that this was an unsafe discharge as no consideration had been given to my circumstances.

### **Evidence on the barriers and enablers to effective communication and joint working between health, social care and the third sector.**

As a carers organisation we believe that unpaid carers clearly have a role in helping to enable effective communication between all the sectors regarding the care of the person they look after. Unpaid carers should be equal partners in care, their contribution valued and recognised so that they are considered in all aspects of health and social care planning and delivery. Only by professionals truly valuing carers will there be any change in the way carers are treated by statutory services.

Over the years there have been many examples of good practice, various toolkits and training rolled out. One main barrier is whether people actually read them and do the training. It should be a mandatory requirement across all health and social care to undertake ‘carer awareness’ training. This needs to be a top down approach.

Discharge pathways should include the wishes and feelings of unpaid carers and be part of the discharge approach in all health settings in Wales. Carers should be identified as early as possible in this process and signposted to appropriate information, advice and support.

Delays in discharge can lead to poorer outcomes through the loss of independence, confidence and mobility, as well as risks of hospital acquired infections, re-admission to hospital or the need for long-term support, this also has implications for family carers if they find their caring role and responsibilities are intensified due to poorer outcomes for the patient. This in turn may also mean that carers need more support from statutory services which could have cost implications for statutory services. Moreover, the cost to carers could also be higher. We know from research that for those carers who provide more than 50 hours of care a week are twice as likely to be in bad

health than other carers. Consequently, not getting discharge right has potentially wider cost implications for health and social care, if a carer becomes ill and needs services in their own right.

Despite guidance to support good discharge planning <sup>iii</sup> specific areas for improvement could include:

- Ensuring that carers are identified and recognised by professionals
- Ensure that carers are given information, advice and support as early as possible
- Ensure that carers are told about their rights
- Ensure carers are consulted and listened to during the discharge process
- Ensure carers are offered a carers needs assessment/what matters conversation to help understand and support their needs
- Ensure more integrated working with social care
- Ensure that there are enough rehabilitation beds/community hospitals to discharge patients to in the event that they are not well enough to go home rather than expect a carer to look after them
- Ensure that discharge planning begins as early as possible to ensure services are in place ready for discharge
- Ensure greater clarity and transparency around how the discharge process works and ensure that carers are aware of the process
- Ensure that staff are adequately trained in discharge planning and discharge policies – this should be mandatory and regular refresher training undertaken
- Ensure that effective monitoring is in place to drive improvement
- Collaborative working with social services and the third sector to ensure that there is adequate support available in the community post discharge
- Ensure post discharge that rehabilitation and other services meet the needs of the carer as well as the patient.

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<sup>i</sup> Carers UK – Getting Carers Connected – Carers Week 2019 research

<sup>ii</sup> Carers UK – The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak

<sup>iii</sup> Welsh Health Circular (2005), Hospital Discharge Planning Guidance, 2005/035 2 National Leadership and Innovation Agency for Healthcare (2008), Passing the Baton 3 National Institute of Clinical Excellence (2015), Transition between inpatient hospital settings and community or care home settings for adults with social care needs 4 Defined discharge pathways set out the sequence of steps and timing of interventions by healthcare professionals for defined groups of patients, particularly those with complex needs to ensure patients experience a safe and timely discharge.