

January 2022

Subject: Hospital discharge and its impact on patient flow through hospitals consultation

Dear Health and Social Care Committee,

Thank you for the opportunity to respond to this important consultation.

Before the COVID-19 pandemic it was estimated that there were at least 487,000¹ unpaid carers in Wales, providing care on an unpaid basis to people who need care and support due to age, illness, disability or due to mental health. At the height of the pandemic in the summer of 2020, it was estimated that this number may have risen to as many as 683,000². As people live longer with ill health, it is predicted that the number of unpaid carers in Wales will continue to grow into the future. The care unpaid carers provide is diverse; from undertaking medical interventions, personal care such as washing to making meals, transporting loved ones to doctor's appointments, as well as organising access to formal care services.

Before the pandemic it was estimated that unpaid carers saved the Welsh NHS and other statutory services in Wales £8.1 billion³ a year, and Welsh Government data suggests 96%⁴ of all care in Wales is delivered by unpaid carers. As more people have taken on caring responsibilities and services have been reduced or closed entirely, it was estimated that unpaid carers saved Wales £33m⁵ every day at the height of the pandemic in summer 2020. Unpaid carers are the critical third pillar of health and care services in Wales.

Carers Wales is the national membership charity for unpaid carers in Wales. As part of Carers UK, we provide a range of information resources for carers, support carers to balance caring with employment and provide carer-focused wellbeing initiatives. We also conduct research into the experiences of carers in Wales and use our findings to respond to policy developments and campaign for better support for carers.

This consultation response has been informed by our existing insights and research into the experiences of unpaid carers in Wales and has been supplemented by a dedicated survey based on this consultation

¹ Carers Week (2020): Carers Week 2020 Research Report

² ibid

³ Welsh Government (2018): Minister confirms £15m investment to support carers and adults with care needs

⁴ Social Care Institute for Excellence (2017): Preventative support for adult carers in Wales: rapid review

⁵ Carers UK (2020): Unseen and undervalued: The value of unpaid care provided to date during the COVID-19 pandemic

that was completed by 14 carers in Wales. We have addressed each of the consultation's core themes in turn.

- *the impact of delays in hospital discharge, both on the individual and the patient flow through hospitals and service pressures.*

Delays in hospital discharge can have a profound effect on an individual, including leading to a loss of skills and independence. This in turn is likely to have a significant impact on the carer who looks after them who may find themselves having to provide more care, and more complex care, following discharge. This can in turn seriously limit the ability of an unpaid carer to maintain employment or have breaks from caring, risking their finances as well as their own physical and mental health. Delayed discharge can also increase the risk of hospital-acquired infections, including but not limited to COVID-19, placing still further pressure on their carer after discharge.

Our research has found that where the cared for person is in hospital for an extended period, and the carer is not frequently informed of developments and consulted by health staff, the carer may live with uncertainty for weeks or months, bracing themselves for an unexpected hospital discharge which severely impedes their ability to plan for and maintain education or employment, or find time for hobbies and social interaction. Carers feel they must put their life on hold until they know more about what will happen to their loved on.

In many cases, the person in hospital facing delayed discharge may be a carer themselves, such as for their partner or child. Our research over several years has found persistent worries among carers regarding the lack of contingency planning for emergencies within care plans should a situation arise where they are no longer able to provide care. In 2019-20, 56%⁶ of carers who had undergone a carers needs assessment said they were not asked about emergency planning during the assessment, while only around a quarter (27%) of carers who responded to our State of Caring in Wales survey⁷ in Autumn 2021 and who had undergone an assessment said that it fully considered the support that would have to be put in place for the person they care for should an emergency occur. The expected continued community prevalence of COVID-19 into the medium term further underscores the importance of contingency planning should carers fall ill. Delayed discharge can lead to an uncertain and extended period where someone in need of care is separated from their carer and, should there be inadequate communication with the family, family and friends may struggle to cover the carer's absence. The Welsh Government must issue guidance to local authorities requiring them to improve monitoring of the assessments they deliver, or fund others to deliver, to ensure all carers needs assessments include contingency planning.

⁶ Carers Wales (2020): Track the Act Briefing 5: Monitoring the 4th year of implementation of the Social Services and Well-being (Wales) Act 2014

⁷ Carers Wales (2021): State of Caring 2021: Wales Briefing A snapshot of unpaid care in Wales

- *the variations in hospital discharge practices throughout Wales and cross-border, and how they are meeting the care and support needs of individuals.*

While we cannot speak to variations in practice between hospitals, 77% of respondents to our survey on this consultation, from 11 local authorities, said the person being discharged did not have their needs assessed, which could suggest that hospitals are under pressure to discharge patients quickly in a way where their care needs can be overlooked. At a time of immense pressure on so many hospitals, it would be unsurprising if this is occurring in other areas of Wales.

- *the main pressure points and barriers to discharging hospital patients with care and support needs, including social care services capacity.*

Insufficient capacity in social care services is a significant barrier to enabling the discharge of patients from hospital. Over a year and a half on from the start of the pandemic, and over 6 months since Wales emerged from the last lockdown in early 2021, carers who completed our State of Caring survey⁸ in Autumn 2021 reported that there was still widespread disruption to the services they rely on to provide care, with only 8% of carers saying day centres had fully re-opened and only 40% said support form paid care workers had fully re-opened. From summer to winter 2021, 6 out of 7 health boards in Wales (all except Powys), and their associated local authorities, announced that they would no longer be able to honour all previously agreed care packages and would be asking families and carers to step in and provide more care. With the expectation that alert level two restrictions will be eased in the near future, the Welsh Government must commit to work with local authorities to fully re-instate disrupted carer services across Wales in the short term as doing so would make it easier to discharge patients from hospital.

While the lack of social care in the community, and services to support the health and wellbeing of carers to manage their caring role, clearly impedes the ability for patients to be safely discharged, we are concerned that many hospitals and health staff may pay insufficient attention to these factors as they seek to free up hospital beds.

Research shows carers in Wales are under overwhelming pressure. 73%⁹ have been unable to take any breaks from caring at all since the start of the pandemic, 80%¹⁰ say they are having to provide more care compared to before the pandemic, while 60%¹¹ say their physical health has deteriorated and 71%¹² say their mental health has worsened during this period. Insufficient investment in services for carers impedes hospital discharge as so many carers are close to breaking point.

⁸ Carers Wales (2021): State of Caring 2021: Wales Briefing A snapshot of unpaid care in Wales

⁹ Carers Week (2021): Breaks or breakdown Carers Week 2021 report

¹⁰ Carers UK (2020): Caring Behind Closed Doors: 6 months on

¹¹ Carers Wales (2021): State of Caring 2021: Wales Briefing A snapshot of unpaid care in Wales

¹² Carers Wales (2021): State of Caring 2021: Wales Briefing A snapshot of unpaid care in Wales

- *the support, help and advice that is in place for family and unpaid carers during the process.*

Unpaid carers must be involved and consulted meaningfully at every stage of the hospital discharge process. As they are experts by experience in the care of the person they look after, insufficient involvement of carers, as so often happens, risks the needs of the person in hospital being misunderstood or not fully understood. Considering that carers will have to care for the patient after discharge, sustained and meaningful consultation with carers is the only way to accurately understand the level and types of care they will be able to give to the patient. The Social Services and Well-being (Wales) Act 2014 says carers should only care if they are “willing and able” to do so. Fulfilling this legal obligation requires consistent, meaningful consultation with carers throughout the hospital discharge process. A carer who responded to our consultation survey said there should be *“An honest assessment of their needs and the unpaid carers needs. Too much emphasis to get patients back home regardless due to Covid pressures. The discharge coordinator should be in direct contact with the carer.”*

To receive support, help or advice carers must be identified as carers by staff involved in the discharge process. Where this doesn't happen, carers can miss out on the help and advice they need. As one carer who responded to our consultation survey explained *“I had to ask several times before someone would discuss the discharge and his needs. The staff couldn't understand why I needed to know”*, while another said, *“The hospital's need to acknowledge the carer, as they have valuable input. I had difficulty speaking to hospital staff even as a wife, carer and power of attorney, which was logged at the hospital”*. Guidance to staff involved in the process must emphasise the importance of identifying carers and involving them in the process. To support this, steps must be taken by health boards to ensure relevant staff undertake mandatory training on the experiences and roles of unpaid carers to enable them to identify carers expeditiously. Health boards should also review the information that is provided to carers before discharge to ensure it covers condition specific information, general information on caring and information about carers services provided locally or nationally, such as our own Carers Wales information and advice resources.

Advocacy services support people to understand and engage with processes and express their wishes to professionals. The importance of Advocacy services is highlighted by the Social Services and Well-being Act and health boards should consider how they can help carers through the discharge process by promoting access to advocates for patients and their carers.

The restrictions on hospital visits introduced in response to COVID-19 has reduced the access of carers and other family members to both the patient and the healthcare staff looking after them, increasing the likelihood that carers are out of the loop regarding the discharge of their loved one. One carer who responded to our consultation survey said they were *“Not able to visit due to covid, [with] no contact from hospital at all”*.

Hospitals across Wales have gone to great lengths to enable communication between families, patients and staff, but we would encourage health boards to consider how they can further facilitate regular

communication with carers at a time of reduced physical visiting. In a situation where a carer is not frequently informed of developments and consulted by health staff, a carer can live with uncertainty for weeks or months, bracing themselves for an unexpected hospital discharge they may receive little notice of.

- *what is needed to enable people to return home at the right time, with the right care and support in place, including access to reablement services and consideration of housing needs.*

Under the Social Services and Well-being (Wales) Act 2014, unpaid carers have a legal right to have their needs assessed through undertaking a Carer's Needs Assessment whenever they request one, or when their caring role changes. Accordingly, every carer must be offered an opportunity to have their needs assessed before a discharge takes place. This ensures the needs of the carer and the support they may need to care for the patient have been assessed. Therefore, no patient should be discharged from hospital before a care package is in place if it is required, as discharging a patient without support in place could result in eventual re-admission to hospital for the patient and potentially admission of an additional person in the form of a carer who has seen their health deteriorate through struggling to care. Guidance must be issued to relevant staff to ensure these principles are consistently adhered to. Many carers feel they are set adrift and left to cope by themselves after discharge has taken place, with little to no contact from health or social care services. We would ask for regular follow up calls and appointments to ensure the carer is supported and has the information and knowledge to care effectively.

"We need to know what to expect, hubby discharged with a catheter neither of us had been told how to deal with it. A fellow carer had her husband sent home without notifying her, she was elderly, home alone, no extra care in place and she could not cope, he could not eat, and it was a very unsafe discharge. I hear this all too often."-carer respondent to consultation survey.

For exceptional cases where it is not possible to put a support package in place before discharge, processes must ensure quick and efficient communication and joined-up working between health, social care and local authority staff to ensure key personnel, such as social workers, are put in place as soon as possible.

Additionally, we welcome good practice in healthcare settings that helps patients to regain their independence before being discharged, such as the trial ward in St David's Hospital in Cardiff. Setups like these, and similar initiatives such as step-down facilities, could ease pressure on carers after discharge.

Turning to housing needs, patients must be discharged into homes that are conducive to their recovery and which enable them to live as independently as possible. Doing so is likely to reduce the extent that unpaid care or formal care packages will be needed to help the patient recuperate. It appears that many

older people are needing increasingly complex adaptations as COVID-19 restrictions and shielding has meant issues in their main have gone unaddressed.

“my mother is 9 months home and still her bathroom has not been adapted for her”-carer respondent to consultation survey.

Staff involved in discharge should consider whether the home they propose to discharge the patient to facilitates their recovery, and organisations or services which carry out home adaptations should be publicised to carers and patients and adequately funded.

Yours faithfully,

Jake Smith

Carers Wales