

## Age Cymru consultation response – Hospital discharge

January 2022



Age Cymru welcomes the Senedd's inquiry into hospital discharge as this an area that disproportionately affects older people and older carers.

Age Cymru provide a person centred, independent advocacy service that amplifies the voice of both older people living with memory concerns or dementia, and for those with capacity that need short term early intervention support to overcome their issues or challenges, or have their voices heard to empower them. We provide non-statutory advocacy and that allows us to work with a broad range of advocacy needs. The projects have been managed and delivered by Age Cymru during 2020-21 have had positive outcomes, despite the challenges of the COVID-19 pandemic and changes necessary for service delivery.

We have gathered information from our Dementia Advocacy project and HOPE (Helping Others Participate and Engage) projects and from local partners to inform this consultation response. Age Cymru projects routinely have referrals from our Information and Advice service when issues older people are facing become too large to cope with alone. Since the projects launched in 2020, we have had a consistent number of clients presenting with advocacy needs relating to hospital discharge management from all areas of Wales. Issues raised relate not only to length of time waiting for discharge, but consistently they concern how discharge is managed. A recurring theme of issues is poor or no communication with next of kin, even in instances where Lasting Powers of Attorney are in place and where family members are known carers for the person. In addition to delays, this can lead to unsafe and completely inappropriate discharge of vulnerable older people to the wrong place at the wrong time.

Too many older people are stuck waiting in hospital beds for much longer than necessary, often during complex discussions between different agencies over who should fund a long-term care package. We regularly hear of cases of older people waiting in hospital for a care package, without knowledge of why they are waiting, or any information as to their options and rights in this process. We hear from our local Age Cymru partners that the majority of older people they speak to do not even know that there is a discharge planning process, let alone that they have a right to be involved in it from the point of admission.

At the other extreme, older people are sometimes discharged without appropriate measures taken to ensure that they will be safe and cared for whilst they recover at home. One person told us: "You can be discharged the day after surgery even if you live alone. There was no discussion about who would look after me, how far my

family lived from me or if my house was suitable for me...how did they know it was safe for me to go home?”. Discharges may also take place at inappropriate times, such as at night, causing unnecessary stress and anxiety for those being discharged. People may be discharged too early, leading to readmission.

Outcomes for people with dementia who are admitted to hospital are markedly poorer than those without the condition. People with dementia stay longer in hospital than others who go in for the same procedure.<sup>1</sup> Furthermore, longer stays are associated with worsening symptoms of dementia and poorer physical health, which means that discharge to a care home becomes more likely and that antipsychotic drugs are more likely to be used. As well as the impact upon the person with dementia and their carer(s), this places further financial pressures upon the NHS.

Currently, specialist mental health beds in hospitals are often not equipped to support those with frailty and physical needs, whilst intermediate care services can be reluctant to admit people with dementia. As a result, discharge from hospital becomes extremely difficult, even when it is clear that hospitals cannot provide the most appropriate support for the person with dementia.

In this consultation response we have used case studies from our projects. These have been anonymised.

## **1. The scale of the current situation with delayed transfer of care from hospital**

Delayed transfer of care was a large issue prior to the pandemic, and the pressures placed on the NHS through the pandemic have exacerbated an already inconsistent process. It is our perception that the changes and additional strain on the NHS have reduced meaningful communication with the patient, their carers, family and including those with lasting powers of attorney. This has resulted in highly unsafe discharge practices.

Though Department of Health Guidance clearly demonstrates that the discharge process should begin at the point of entry, the cases that have come to us indicate a very rushed process that does not follow safe discharge practices. Hospital discharge is a process that should begin when the patient first comes to hospital, or even before in cases of planned care. Though there has been an overall increase in time that older people remain in hospital, it does not appear that that additional time is being used to effectively plan for when the person is medically fit for discharge. Further, delays have resulted in some people facing additional barriers to leaving as their care packages have stopped as they have been in hospital for too long and their care package has ‘expired.’

Since the dementia advocacy service and HOPE project launched in 2020, we have had a consistent number of clients presenting with advocacy needs relating to hospital discharge management, which cover health board areas across all of Wales. The changes that have happened through social distancing measures in hospital

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<sup>1</sup> [https://www.alzheimers.org.uk/sites/default/files/2018-05/Counting\\_the\\_cost\\_report.pdf](https://www.alzheimers.org.uk/sites/default/files/2018-05/Counting_the_cost_report.pdf)

settings have contributed to an already apparent issue with poor communication leading to inappropriate and unsafe discharge practices.

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

Older people are disproportionately impacted by delays with hospital discharge as they are the age group that are more likely to need these services. Older people are more likely than other age groups to provide care for their loved ones, whilst also needing care and support themselves – sometimes from the person that is awaiting discharge. As such the effects of delays in hospital discharge have a knock-on effect on others in addition to the person being discharged.

We have heard from many older people about the stress that this places on them and their loved ones, and the pressures they face due to poor discharge practices. Such poor practice results in distress, disruption and additional financial burdens on older people and their families. These issues could be significantly reduced with improved communications; better professional knowledge on funding arrangements; and better knowledge and understanding of who is involved in the care and support of the person due for discharge. As stated earlier, many older people are not aware that there are discharge procedures or that they have a right to be involved in decisions on their care. Improved resources should be developed that are routinely made available to patients, their unpaid carers and families to help them understand their rights, the discharge processes and how they should be involved, with similar resources available to health and social care staff. Such resources may exist, but they are not routinely used in a meaningful way.

While hospital staff want to discharge people as quickly as possible when medically fit to free up space for other patients, this should never be at the expense of the patient's wider well-being.

*'Mrs A' was discharged from hospital to a care home 100 miles away from her family. Her family were only informed of this after the discharge had taken place. The family had very limited access to transport to visit Mrs A, so together with lockdowns this limited access to visiting.*

*'Mr W' has pulmonary fibrosis, which causes him to have breathing difficulties and to collapse. He had a breathing episode at home and his wife took him to hospital as she has done numerous times before. Mr W was in really poor health and so the decision was made to keep him in the hospital. After an 8 week stay, (during which time Mrs W was initially refused access to information relating to her husband's health and care), she received a distressed phone call from her husband, saying the hospital planned to discharge him the following day to a care home. No discharge meeting had taken place and the decision appeared to have come out the blue. Mrs W and her daughter went to the hospital to speak with the staff to understand the position. They were informed*

*that Mr W was indeed being transferred to a nearby care home who would be better suited to care for his needs and they weren't to worry about paying care home fees as Mr W would definitely qualify for Continuing Healthcare funding.*

*Mrs W expressed her concerns to the district nursing team that she hadn't been told of any discharge plans, that she didn't think the care home selected would be able to care for his high-level needs as there was no nursing care and she was concerned about whether she could afford the care home fees. Despite her concerns, Mr W was transferred to the care home. In the first week of Mr W arriving at the home, Mrs W was informed that her husband would not qualify for Continuing Healthcare funding and that care home fees would need to be paid after the initial 4 week stay. No Continuing Healthcare assessment was done so it is unclear how this decision was arrived at.*

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

An examination of latest published data for delayed transfer of care prior to the pandemic for people aged 75 and over shows that there are huge differences across Wales. These range from 6.5 through to 63.4 per 10,000 population in February 2020.<sup>2</sup> Such differences are unlikely to be explained by differences in age breakdown or health inequalities in different areas of Wales. An examination of differences in practice may throw light on why there are so many inconsistencies and what needs to happen to improve the situation.

Discharge planning should ensure that the right support is available for the person at the right time and in the right place. Information from our services suggests that poor practices are evident in health authorities across all of Wales that can result in the wrong support at the wrong time, and in the wrong place. Due to the nature of our services, it is unlikely that we hear of cases where things have been done well.

The common thread through poor practice is poor communication. Such poor practice results in distress, disruption and additional, unexpected financial burdens to older people and their families that could easily be avoided with improvements in communication. Poor communication also results in additional financial burdens on social care that could be avoided if the right people with the right knowledge are involved in discharge planning.

Through our work with people living with dementia there is a consistent theme of family members and people with Lasting Power of Attorney for health and welfare not being consulted with, nor informed of significant changes in health or medication, or being involved in significant assessments, including capacity assessments and best interest decision making processes. This has led to vital information being missed in relation to safe discharges.

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<sup>2</sup> <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Performance/Delayed-Transfers-of-Care/rateofdelayper10000populationaged75-by-localauthority>

*Mr B was transferred between multiple hospital sites with no consultation with his LPA for health and welfare at any point. The LPA for health and welfare was also excluded from meetings, and no other advocacy was brought into this process. Due to lack of consultation with relevant parties Mr B was found to need one to one care, despite this not having been needed prior to admission or during his hospital stay. This assessment led to difficulties finding a care home placement and led to a four-week delay to discharge.*

There are multiple instances where discharge destinations were changed late in the discharge management process without any notification to family members, where capacity assessments took place without consultation with family and subsequently supported inappropriate discharge destinations that would have put older people at significant risk.

*'Mrs C's' granddaughter had a Lasting Power of Attorney for health and welfare and excellent insight into her grandmother's care needs. Without input from her LPA, the hospital requested a set of keys to be delivered to ward staff so that she could be returned home by non-emergency hospital transport. Mrs C had a limited understanding of where she lived and a history of wandering from her home. Though Mrs C's granddaughter was best placed to provide input into the process she was not consulted with at any stage of the discharge management process until dementia advocacy became involved.*

*'Mrs G' had her discharge arranged without consultation with her granddaughter, who was the main point of contact and had been coordinating all informal care for Mrs G prior to admission. Mrs G had limited insight into where her home was and believed she would be returning to live with her mother, who died some time ago. She had limited ability to meet her own care needs and had consistent falls when living alone. It was a fall that led to her hospital admission, which should have rung alarm bells with discharge professionals. Mrs G's granddaughter had been consistent in reiterating these facts to the hospital, but her concerns were not heard.*

Part 10 of the Social Services and Well-Being Act states that professionals should be skilled enough to identify when a person requires the support of advocacy services. As dementia conditions advance, this can result in reduced ability to make decisions. All the older people living with dementia referred to our project in relation to hospital discharge management were from family members and unpaid carers. No referrals have been received from professionals. As such professionals are not meeting people living with dementia's rights and this is an area that needs further attention. It would be highly beneficial to have independent advocacy support integrated into all hospital stays, with such support offered to the patient when they enter the hospital setting. Having this input early could intelligently inform discharge planning, and make sure that discharge planning is meaningful.

#### **4. The main pressure points and barriers to discharge hospital patients with care and support needs, including social care service capacity**

The crisis in domiciliary care is well documented, with many Health Boards in recent months having released statements relating to capacity issues increasing delays in hospital discharge. It appears from our advocacy work that discharge assessments for care and support are rushed and, in many cases, ineffective, which may be related to insufficient social care assessors being available.

Our advocates have seen cases where older people have been discharged from hospital without an assessment being undertaken of their care and support needs and without necessary adaptations being in place. The burden of arranging care and assessment post discharge has been passed on to informal carers in a number of cases, which leads to distress and family tensions at what is undeniably an already difficult and stressful time.

*Mr S is registered blind with mobility problems as he is waiting for knee replacement. He cannot get upstairs and has no access to a shower, he cannot get to his bed and so sleeps on a sofa.*

*He was accused of `bed blocking` by one of the ward staff because he would not accept discharge to a hospital that is an hour away from his home and where his community networks are. He finally decided to accept the offer of a discharge to a community hospital or some temporary accommodation. However, the hospital did not notify his advocate or his volunteers and family of the discharge date, which meant that secure temporary accommodation could not be secured in time for discharge. He was put in the ambulance with no one being notified, he was then taken to his home address, he was provided with a commode and some crutches and left.*

*Mr L's discharge was delayed for five weeks due to best interests meeting not being coordinated and no OT assessment being undertaken of the proposed discharge destination.*

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

Ensuring that people have a strong voice so that they can effectively participate in, and guide decisions made about their health and social care is key to the achievement of meaningful outcomes and the delivery of high quality services. The 2018 report from the Older People's Commissioner drew attention to the overall reduction in advocacy support dedicated to older people. Since that report, additional advocacy services specifically for people living with dementia have been commissioned. However, the volume of queries to our information and advice services suggests that there is a level of unmet need for wider advocacy for older people and that there is further work to do to ensure that people understand their rights and entitlements.

Separately to advocacy services, the volume of funding dedicated to older people's social care services has reduced by 13% in real terms.<sup>3</sup> This reduction will have an effect on the quality of discharge processes.

The availability of advocacy should be examined across Wales to ensure that people are not disadvantaged by geography and steps should be taken to address inequalities. Advocacy services by their nature are well placed to see where the pinch points in health and social care are. This knowledge can help decision makers see where services need to improve.

All the older people living with dementia referred to our project in relation to hospital discharge management were from family members and unpaid carers; we have received no referrals from professionals in relation to cases of this nature. This suggests either that professionals involved in hospital discharge are unaware that discharge practices have any faults or are causing ongoing issues for the person being discharged or their loved ones, or that professionals feel that their own knowledge is sufficient to secure a safe discharge, which is clearly not the case as seen through our case studies. When advocacy is in place, this can significantly improve the safety and quality of discharge arrangements.

Through all of our work with people living with dementia there is a consistent theme of family members and people with Lasting Power of Attorney for health and welfare not being consulted with, informed of significant changes in health or medication or being involved in significant assessments, including capacity assessments and best interest decision making processes.

This has led to vital information being missed in relation to safe discharges.

*'Mr P' was discharged to his own home with no assessment of any kind. Mr P had a history of falls in his own home and at the point of discharge there were no adequate sleeping arrangements. Mr P's next of kin were given no information at the point of discharge around coordinating a care package, what reablement support was needed or how they should support Mr P to undergo an OT assessment. These issues were only addressed when advocacy support was involved roughly three weeks after Mr P had been discharged to home.*

## **6. What has worked in Wales, and other parts of the UK, in supporting hospital discharge and improved patient flow, and identifying common features**

As stated earlier, a common theme of issues with hospital discharge relates to poor communication by health and social care staff. Where our advocacy services have

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<sup>3</sup> S Milsom and C Breeze August 2020 Rebalancing Social Care: A report on Adult Services <https://www.adss.cymru/en/blog/post/delivering-transformation-grant-programme-2019-20-rebalancing-social-care-a-report-on-adult-services>

become involved, this has played a significant part in securing positive outcomes for older people.

We suggest that the following will improve the safety of hospital discharge and in some cases will reduce older people's need for care and support. These alone will not solve all issues as additional resourcing is needed across health and social care.

1. Clear and timely information should be provided in relation to the discharge process to those with LPAs for health and welfare, families and other unpaid carers of the person. A flowchart outlining potential scenarios would be helpful. Information should be provided to the person and their loved ones and carers on where they can go to for information, advice and support with the discharge process.
2. Professionals with responsibility for hospital discharge should have a better understanding of lasting powers of attorney and communicate with them regularly and appropriately. Communications are not a one way street and professionals need to understand that families, carers and those with LPA have a detailed, longstanding understanding of the person and so can provide valuable insight on how the person's needs can be best met;
3. Patient records should clearly state who is involved in the care of the person so that they are routinely part of discharge discussions and arrangements.
4. Families and carers have told us of ongoing issues getting through to speak to health and social care professionals. It would be helpful to increase the volume of patient liaison services to help address this issue.
5. We have detailed here a range of case studies where things have gone wrong and other services and agencies will be aware of similar issues. Such cases could be used in induction and training to professionals in order to assist professionals in understanding the wider needs of the person over and above their medical needs. Where things have gone wrong, lessons learned need to be incorporated into service improvement.

## **7. 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**

Many of the points in relation to this question have been covered above. The current crisis in both social care and health services, despite additional investment from Welsh Government and the commitment to pay all social care staff the Real Living Wage will take time for improvements to be realised.

We have detailed above issues with communications with patients and their families. There are further issues in communications between health and social care staff that require addressing. The long standing issue of health and social care case management systems not being joined up needs to be addressed. Whilst there are differences in what is recorded and how information is used cannot all be addressed at once, it is vitally important that areas such as hospital discharge are an areas that



is given early attention as this is one area where joined up systems can make real improvements through better sharing of information.

Hospital discharge services should be funded on a sustainable basis in order for improvements to be realised. The level of funding should be sufficient to meet the level of demand and funding should be provided on a minimum of 3 year contracts. Current funding arrangements are often year on year, which do not allow sufficient time to recruit and train staff, or allow the service to become embedded in discharge practices. As discharge services become more embedded in working practices this helps contribute to improved discharge actions and decisions.

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